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Dementia and people with intellectual disabilities

Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia

RC PSYCH
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Division of Clinical Psychology
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Foreword

People with intellectual disabilities are living longer than in previous decades and greater longevity is associated with higher rates of physical and mental disorders of ageing. The prevalence of dementia in people with intellectual disabilities is increasing, and that requires better methods of detection and support. The evidence base on how dementia affects people with intellectual disabilities, and how that can be managed, has expanded over recent decades through the excellent efforts of researchers and clinicians working with people with dementia and their carers. The joint guidance is therefore timely in bringing together the evidence on current practices in dementia care.

The key to care is the early detection of dementia in people with intellectual disabilities who have a range of cognitive abilities for which reason diagnosis can prove especially challenging. The guidance highlights good practice in dementia care through the development of care pathways to support the care of people from the time of diagnosis to end-of-life and the multidisciplinary approaches required. Accurate diagnosis relies on good data using baseline assessments of cognitive function when people are young and functioning well. Such comparative information is invaluable to clinicians tasked with assessing for signs of dementia.

Promoting greater awareness among families and carers of the presentation and lived experience of dementia should help to reduce the stigma associated with it and offer hope that people with dementia can continue to live good lives. Good practice innovations such as ‘brain health checks’ could raise awareness on preventative strategies that could delay the onset of dementia. The guidance offers balanced, holistic perspectives on the care that people require emphasising the importance of psychological and social interventions to ensure people with dementia live good quality lives.

The guidance is an invaluable resource on the diagnosis, treatment, and care and support for people with intellectual disability who have a diagnosis of dementia. It is easily accessible for the reader who may have little clinical knowledge by providing clear explanations of the assessment processes and the delivery of support to people. Commissioners of services will find indicators of what makes a good service and tools to assess their quality.

The excellent range and quality of the content of the guidance leads the reader to appreciate the need for further research in assessment, effective interventions, and care and support. More work is required if we are to support effectively the growing numbers of people with intellectual disabilities with a dementia diagnosis. The guidance signals how we can currently improve the quality of care people receive and what more needs to be done in the future to ensure that services provide high-quality, evidence-based care to people with intellectual disabilities living with dementia.

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Purpose of the guidance

This report is a revision to the second edition of the joint British Psychological Society and the Royal College of Psychiatrists (2015) guidance on dementia and people with intellectual disabilities. It has been written by a joint working group of the DCP Intellectual Disabilities Faculties of the British Psychological Society and the Royal College of Psychiatrists.

The main purpose of the guidance is to enable those working in clinical and social care services to improve the quality of life of people with intellectual disabilities who develop dementia, by providing guidance to inform assessment, diagnosis, interventions and support. The guidance is aimed at clinicians in intellectual disabilities and older peoples' mental health services and services for younger people with dementia. It should inform local decisions, to be taken by commissioners and providers about which services provide which part of the care pathway, ensuring that all elements of this guidance are considered and in place for people with intellectual disabilities and dementia.

Since the original guidance was published there has been a far greater awareness about dementia in the general population and a proliferation of strategies and standards documents. However, dementia and people with intellectual disabilities still receives minimal focus at national level. The current guidance has been updated using both the current research literature and the experience of senior clinicians working in the field. Some areas of the guidance have only needed minor changes, whilst others have had a more extensive rewrite.

As before, our main focus has been to highlight the key factors that we consider are the elements of an excellent service, and to help those working in services evaluate how they might help the increasing numbers of people with intellectual disabilities who are developing dementia given improvements in life-expectancy. It is important to note that the majority of people with intellectual disabilities who are diagnosed with dementia in services are people who have Down's syndrome, who have a genetic form of dementia that presents at a younger age (typically in their forties and above) compared to those with intellectual disabilities not due to Down's syndrome. Almost all dementia diagnoses in people who have Down's syndrome are due to Alzheimer's disease. In contrast, the dementia profile in the rest of the population with intellectual disabilities is similar to that of the general population, including Alzheimer's disease, vascular dementia, Lewy body dementia, and frontotemporal dementias.

It is with these principles in mind that this report has been produced and has the following aims:

- To bring together available and relevant evidence-based practice with a consensus of clinical opinion and experience.
- To provide a framework for good practice and for the development of multi-agency care pathways.
- To promote effective and timely assessment, diagnosis, and interventions for people with intellectual disabilities suspected or confirmed as having dementia and to ensure quality support to them and their staff and other carers.
- To provide guidance for service providers, developers and commissioners.
- To provide a set of standards of good practice against which service provision can be benchmarked and audited.
- To provide a quality outcome measure to use to evaluate what the person with intellectual disabilities and dementia is experiencing in their care.
- To promote the development of comprehensive and effective local services and to reduce the number of individuals who are failed by current service provision.

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Section 1 – Context

1.1 DEMENTIA STRATEGIES

The initial 'Dementia Challenge' for England was launched in 2012 (DH, 2012a). This set targets for improvements by 2015 in three broad areas: 1) health and care, 2) the establishment of dementia friendly communities, and 3) improving dementia research. An additional ten year plan was announced in 2022 to address prevention of dementia, the backlog in dementia diagnosis, and how medicines and emerging science and technology can be harnessed to improve outcomes for people with dementia (DHSC, 2022).

In Northern Ireland, BPS dementia papers were launched at Stormont in November 2015 and subsequent to this, the *Dementia Learning and Development Framework* was published in 2016 to support health and social care staff to deliver better care for people living with dementia, their families and carers.

In May 2023 the Scottish Government published the new *Dementia Strategy for Scotland: Everyone's Story*, which set out a shared vision for dementia in Scotland over the next 10 years, with rolling two year delivery plans (Scottish Government, 2023). The strategy was developed in collaboration with people with lived experience.

In 2018 the Welsh Government launched the Dementia Action Plan for Wales 2018–2022 (Welsh Government, 2018), which set out a clear strategy for Wales to become a dementia friendly nation that recognises the rights of people with dementia to feel valued and live as independently as possible in their communities. The All Wales Dementia Care Standards (2021–2023) have been developed by Improvement Cymru (2021) outlining a delivery framework for the Action Plan and includes 20 standards which have been co-developed with people with lived experience of dementia.

Although this document primarily references the context of dementia in the UK, this document also aligns with targets (to include awareness, prevention and diagnosis, research care and treatment of dementia) as set by the World Health Organization's Global Action Plan on the public health response to dementia, 2017–2025 (WHO, 2017). An International Summit on Intellectual Disability and Dementia, held in Glasgow, Scotland in 2016 of individuals and representatives of numerous international and national organisations and universities including from the UK with a stake in issues affecting adults with intellectual disability (ID) affected by dementia produced and published a number of consensus documents (Watchman & Janicki, 2017).

This document has been revised with these challenges in mind, paying particular attention to how they apply to people with intellectual disabilities. It sets out standards of clinical practice in the areas of assessment, diagnosis and interventions for people with intellectual disabilities who develop dementia with an emphasis on how people with intellectual disabilities who develop dementia can be best supported in a manner that maintains their dignity and quality of life.

1.2 DEMENTIA PUBLICATIONS

Interest in the field of dementia in the general population has further increased since the publication of the first edition of this guidance in 2009. At that time the National Dementia Strategy for England had just been published (*Living well with dementia: A National dementia strategy*; DH, 2009). The strategy has three key steps: improved awareness and understanding of dementia and removal of the stigma that surrounds it; early diagnosis and intervention; and

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improving the quality of care for people with dementia by developing a range of services for people with dementia and their carers which fully meets their changing needs over time. The strategy had 17 objectives to be met in a five-year plan; the objectives included improving awareness and diagnosis, better access to care and advice, the needs of carers, the commissioning of health and social care services, better end of life care, workforce planning, and research. As noted above, similar strategies have been published in Scotland (*New Dementia Strategy for Scotland: Everyone's Story*; Scottish Government, 2023), Wales (*Dementia Action Plan for Wales 2018–2022*; All Wales Dementia Care Standards (Welsh Government, 2018, 2021) and in Northern Ireland the Regional Dementia Care Pathway (Health & Social Care Board & Northern Ireland Executive, 2018) was developed from the outworkings of a number of recommendations from Improving Dementia Services in Northern Ireland (DHSSPSNI, 2011).

The National Institute for Health and Care Excellence (NICE) and the Social Care Institute for Excellence (SCIE) initially published a joint clinical guideline on the management of dementia in 2006 and updated it in 2018 (NICE, 2006, NICE, 2018a). A further review was carried out in September 2023 with a decision not to further update the guidance at this time. This guideline includes recommendations on: involving people living with dementia in decisions about their care; assessment and diagnosis; interventions to promote cognition, independence and wellbeing; pharmacological interventions; managing non-cognitive symptoms; supporting carers; and staff training and education.

These are all relevant to people with intellectual disabilities, given the risk of dementia at a younger age in people with intellectual disabilities (recognised in the NICE guidance), particularly affecting people who have Down's syndrome, with the added complexity of the potential difficulty recognising the possibility of dementia and arriving at an accurate diagnosis given their pre-existing cognitive impairments.

In England, *The Dementia Care Pathway: full implementation guidance* was published by the National Collaborating Centre for Mental Health (NCCMH) in July 2018. Commissioned by NHS England (2018), the full implementation guidance sets out key commissioning and service development touch points to support improvements in the delivery and quality of care and support for people living with dementia and their families and carers.

In November 2023 Healthcare Improvement Scotland (HIS) within NHS Scotland published the Scottish Intercollegiate Guidance Network (SIGN) guideline on assessment, diagnosis and support for people with dementia (SIGN 168 Assessment, Diagnosis, Care and Support for People with Dementia and their Carers), however this document did not include specific guidance about people with a learning disability.

The Dementia Action Plan for Wales 2018–2022 and the All Wales Dementia Care Standards (2021–2023) apply to all people living in Wales, including those with learning disabilities. There is a specific standard relating to individuals with learning disabilities (Standard 4) which outlines that 'Learning Disability (LD) services will define a process to capture the total population of people living with a learning disability and specifically Down Syndrome to offer a cognitive wellbeing check. This will include people known to all services including health, social and primary care services that include the GP and Memory Assessment Service'.

The International Consensus summit in 2016 focused on three key areas: 1) human rights and personal resources (applications of the Convention for Rights of People with Disabilities and human rights to societal inclusion, and perspectives of persons with ID); 2) individualised services and clinical supports (advancing and advanced dementia, post-diagnostic supports, community supports and services, dementia-capable care practice, and end-of-life care practices), and

3) advocacy, public impact, family caregiver issues (nomenclature/terminology, inclusion of persons with ID in national plans, and family caregiver issues) producing a range of publications to outline recommendations and best practice (Watchman et al., 2017; Janicki et al., 2017; McCallion et al., 2017; Dodd et al., 2018; Santos et al., 2018; McCarron et al., 2018; Watchman et al., 2019).

1.3 ASSUMPTIONS MADE WITHIN THE GUIDANCE DOCUMENT

Within this document, a number of assumptions are made throughout. These include the need for effective partnership working between all agencies involved in the care of people with intellectual disabilities and dementia as highlighted in reports cited in the previous section. The working party recognises that each area will be configured to meet local need, but effective care can only be provided when there is good partnership working within health services – between intellectual disabilities and older people's services, and across statutory, private and voluntary agencies.

Regardless of how each service is configured, the working party has assumed that certain principles and ways of working are already integral to the delivery of services for people with intellectual disabilities, and that these will also be available to people with intellectual disabilities who develop dementia. It has been assumed that services already deliver care in line with Valuing People (DH, 2001) ensuring that everyone who wants one has a Person Centred Plan and a Health Action Plan, as well as an individualised care plan. In Scotland, Keys to Life (SG, 2013) highlights the need for co-produced support plans with the right support provided at the right time in the right place. In Wales, the Learning Disability Strategic Action Plan (2022–2026) outlines that all individuals with a learning disability should have increased access to health checks and Health Action Plans. It has also been assumed that services will be delivered in line with both their relevant mental capacity legislation, the Human Rights Act and relevant National Standards for dementia care (e.g. NICE, 2006, 2013, 2018a, SG 2011).

Section 2 – Epidemiology

2.1 OLDER POPULATION WITH INTELLECTUAL DISABILITIES

There have been significant improvements in the mean life expectancy of people with intellectual disabilities from an estimated 18.5 years in the 1930s to 66 years in the 1990s (Braddock, 1999) and this has continued to improve. There are over 1 million people with intellectual disabilities in the UK, and as noted by Emerson et al. (2012), the population of older people with intellectual disabilities is set to increase four times faster than the overall adult intellectual disability population (Vseteckova et al., 2022). The life expectancy of people with mild intellectual disabilities now approaches that in the general population of a similar socio-economic status, but the life expectancy of people with more severe levels of intellectual disabilities remains reduced compared with the general population (Walker et al., 2015). As highlighted by Tilley and colleagues (Tilley et al., 2022), in England for example, an estimated 53% of the total population of people with intellectual disabilities were aged 45+ in 2020 (with almost 5% aged 85+), predicted to rise to 56% by 2040 (and 7.5% aged 85+); similar trends are predicted in Wales and Scotland.

People who have Down's syndrome have also experienced enormous gains in longevity due to improved health care. In the UK, the prevalence is approximately 6 per 10,000, corresponding to an estimated 41,511 individuals living with DS in 2015 (de Graaf et al., 2021). The birth prevalence of Down's syndrome in England and Wales has remained relatively stable despite antenatal screening (which has been offset by an increase in Down's syndrome resulting from younger maternal age), while mean life expectancy has increased to 58 years (Wu & Morris, 2013). This has resulted in a growing population of older adults who have Down's syndrome. It is because of these factors that consideration needs to be given to age-related illnesses that most commonly occur in later life, such as dementia.

2.2 PREVALENCE AND INCIDENCE RATES OF DEMENTIA AMONG OLDER PEOPLE WITH INTELLECTUAL DISABILITIES (EXCLUDING PEOPLE WHO HAVE DOWN'S SYNDROME)

Estimating prevalence rates of dementia can be problematic because of a number of methodological issues. These include diagnostic difficulties associated with dementia in a population which has pre-existing cognitive and functional impairments and the complexity of establishing accurate population samples of people with intellectual disabilities. However, there is evidence from several studies that people with intellectual disabilities have an increased risk of developing dementia compared to that observed in the general population.

There is very limited research investigating the specific risk of dementia and other age-related disorders in those with other specific syndromes, some of which are associated with a reduced life-expectancy, or with autism.

Several studies have investigated rates of clinical dementia among people with intellectual disabilities living within the community and used established or modified criteria based on systems for the diagnosis of dementia. Moss and Patel (1995) reported that 12 per cent of a group of people with intellectual disabilities over age 50 years had dementia. Cooper (1997) found that the rate of dementia increased as expected in a population-based study with just over 20 per cent of those over the age of 65 years meeting criteria for dementia.

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Strydom et al., (2007) reported findings from a population-based survey of adults with intellectual disabilities (without Down's syndrome) across several London boroughs. They found that prevalence rates varied depending on the diagnostic criteria used, with DSM–IV criteria resulting in the highest rate and ICD-10 the lowest. Rates for dementia, of whatever cause, using DSM–IV criteria were 13.1 per cent in those 60 years and over and 18.3 per cent in those 65 years or over. This compares to prevalence rates in the general population of 1 percent for 60–65-year-olds to 13 percent for 80–85-year-olds and 32 percent for 90–95-year-olds (Hofman et al., 1991). See Figure 1 below for a comparison of dementia rates between individuals who have Down's syndrome, intellectual disabilities and the general population.

Alzheimer's disease was found to be the most common type of dementia, and had a prevalence of 8.6 per cent in those aged 60 and older, three times greater than comparable general older adult population rates, but cases of Lewy body dementia, vascular dementia, and fronto-temporal dementia were also identified based on clinical observations while rates varied according to diagnostic criteria used – DSM-IV criteria were more inclusive than ICD-10 (Strydom et al., 2007). Prevalence rates increased with age though shifted towards younger ages compared to the general population but did not differ significantly between mild, moderate and severe intellectual disabilities groups (Strydom et al., 2009). Overall, the incidence rate for dementia in those aged 60 and older was estimated to be 54.6/1000 person years with the highest incidence rate in the age group 70–74 (Strydom et al., 2013).

2.3 PREVALENCE AND INCIDENCE RATES OF DEMENTIA AMONG PEOPLE WHO HAVE DOWN'S SYNDROME

The association between Down's syndrome and the risk of 'precipitated senility' was first reported by Fraser and Mitchell in 1876, with Struwe (1929) describing the significant Alzheimer-like neuropathological changes in the brains of people who have Down's syndrome, and almost all older adults who have Down's syndrome were found to have the neuropathological hallmarks of Alzheimer's disease at post-mortem (Mann, 1988) which has since also been demonstrated in vivo with amyloid PET imaging studies (Landt et al., 2011; Hartley et al., 2014).

Studies have reported rates of dementia meeting the necessary criteria that start at a few per cent from 30 to 39 years of age, increasing to 10–25 per cent in the 40 to 49-year-old group and to 20 per cent and 50 per cent in the 50 to 59-year-old group and between 30 per cent and 75 per cent aged 60 years or older (Hewitt et al., 1985; Wisniewski et al., 1985; Lai & Williams, 1989; Holland et al., 1998). Between 50 and 60 years of age the prevalence of dementia doubles with each five-year interval (Coppus et al., 2006). Studies have varied in their findings beyond the age of 60: some studies have found that prevalence rates continue to increase, with most individuals eventually diagnosed with dementia (Visser et al., 1997; Tyrrell et al., 2001) whilst others described a decrease in prevalence in the older age group due to the increased mortality associated with dementia (Coppus et al., 2006). Incidence increased steadily with increasing age and did not decline after age 60, from 2.5 per 100 person years in those aged <50 to 13.31 per 100 person years in those aged 60 and older (Coppus et al., 2006).

A recent study (Baksh et al., 2023), used large-scale primary care data from GP surgeries in the UK, including a total of 10,204 people with Down's syndrome, 39,814 age and sex matched general population controls, and 69,150 people with intellectual disabilities. Compared with controls, people who have Down's syndrome had a much increased risk of incidence of dementia; approximately 95 times higher than in age and sex matched controls from the general population (Incidence Rate Ratio of 94·7; 95% CI 69·9-128·4), and compared to other people with intellectual disabilities, risk of dementia was approximately 17 times higher in people who

have Down's syndrome (IRR 16·60, 14·23-19·37). The age group with the highest incidence of dementia in people who have Down's syndrome was in those aged 55–64, with an incidence of 54.10 per 1000 person years (95% CI 47.84 – 60.96) compared to an incidence rate of 0.42 per 1000 person years (95% CI 0.24 – 0.67) in the same age group in the general population. In other people with intellectual disabilities, the incidence was highest in those aged 65–74 (7.15 per 1000 person years; 95%CI 6.09 – 8.34), compared to 1.63 per 1000 person years in people from the general population in the same age group (95% CI 1.03 – 2.44).

Case reports, cross-sectional and longitudinal studies have all confirmed an increase in the prevalence rates of clinically diagnosed dementia with increasing age that starts when people who have Down's syndrome are in their 30s and steadily increases in prevalence into the 60s. However, not all people who have Down's syndrome present with the pattern of memory loss and functional decline characteristic of dementia at the same age, with variability in age of onset. Recent analysis (Sinai et al., 2018) using data from assessment clinics across England (N = 254 cases with Down's syndrome and dementia) established that the majority of individuals who have Down's syndrome who are diagnosed with dementia presented in their 50's (interquartile range 50.9–59.3 years), with a mean age at diagnosis of 55.8 years (SD 6.29). A quarter was diagnosed before the age of 50, and a quarter after age 60.

Ultimately, the lifetime risk for dementia in Down's syndrome has been estimated to be >97% (McCarron et al., 2017), and median survival of seven years after a diagnosis (McCarron et al., 2014) though in earlier studies it has been estimated that approximately 70 per cent of adults who have Down's syndrome are likely to develop symptoms should they live to age 70 (Zigman et al., 2002).

FIGURE 1: COMPARISON OF DEMENTIA PREVALENCE RATES BY AGE

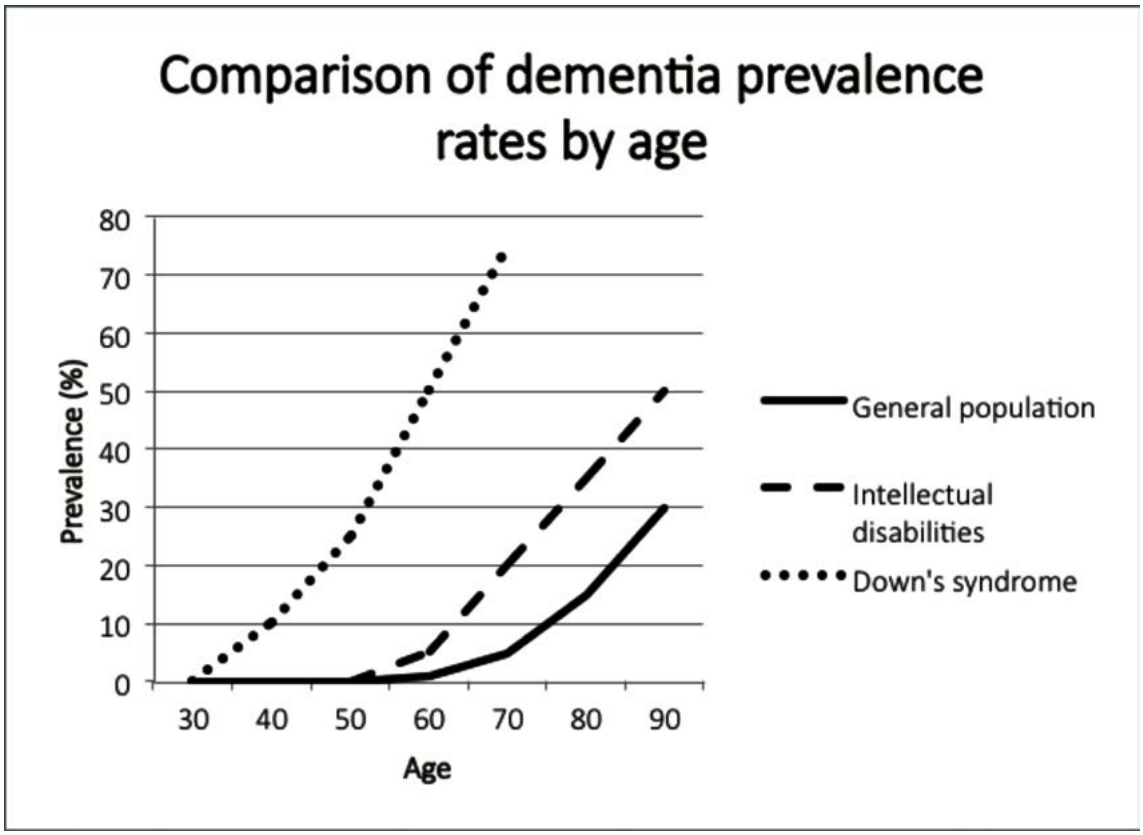

Figure 1 summarises the age-related prevalence rates of dementia in people who have Down's syndrome, those with intellectual disabilities without Down's syndrome, and in the general

population from the papers previously cited. The exact rates have to be considered with caution but the trend represented in this figure is now increasingly accepted. The early presentation and course of dementia is now well established for people who have Down's syndrome. For those with intellectual disabilities but without Down's syndrome, age-related prevalence rates are brought forward to a small degree compared to the general population but not to the same extent as for people who have Down's syndrome. This latter group would appear to have a uniquely early risk for developing dementia, almost invariably of the Alzheimer's type due to a genetic predisposition for Alzheimer's disease. For the former group the full range of causes of dementia is observed.

Neuritic plaques, characteristic of Alzheimer's disease, are composed of the insoluble form of the amyloid-beta (or 'amyloid') protein. The gene encoding for the Amyloid Precursor Protein (APP) is located on chromosome 21, where there is an extra copy of the gene in trisomy-21. The triplicated APP gene results in an increase in the APP protein levels, which is broken down producing an excess of amyloid-beta; this biochemical pathway is likely to account for the increase in risk of Alzheimer's disease in people who have Down's syndrome. Children who have Down's syndrome have been found at postmortem to have evidence of diffuse cerebral amyloid deposition, whereas in adult life neuritic plaques and neurofibrillary tangles characteristic of Alzheimer's disease are found. The assumption therefore is that this slow deposition of amyloid in the brain leads to a cascade of adverse neural events over time and ultimately to the full pathology of Alzheimer's disease. Further evidence implicating the extra copy of the APP gene in Alzheimer's disease in Down's syndrome was from reports in rare cases of partial trisomy 21 in people who have Down's syndrome without triplication of the APP gene, but who bore normal two copies of the APP gene. Neuropathological changes associated with Alzheimer's disease did not occur in these people and neither did clinical dementia develop despite the advanced age of the individual (Prasher et al., 1998; Doran et al., 2017).

However, whilst the brain pathology characteristic of Alzheimer's disease would seem to be near universal in later life, it is clear that the older people who have Down's syndrome with full trisomy 21 who develop the clinical features of dementia will do so at different times but mostly after the age of 40 years. The reason for the varying age of presentation remains unclear but is likely related to differences in adaptation, resilience or protective factors.

KEY POINTS

People with intellectual disabilities have a higher risk of developing dementia compared to the general population, with a significantly increased risk for people with Down's syndrome and at a much earlier age.

Life expectancy of people with Down's syndrome has increased significantly and the number of older people with Down's syndrome has been increasing.

The incidence and prevalence of Down's syndrome is relatively stable.

Section 3 – Baseline assessment, prevention of dementia and brain health

3.1 BASELINE ASSESSMENT WITH PEOPLE WHO HAVE DOWN'S SYNDROME

A core feature of dementia is a decline from a pre-morbid baseline level of the person's functioning. Establishing pre-morbid level of skills, abilities and personality characteristics can be challenging in the intellectual disability population due to variance in cognitive functioning and abilities, frequent poor record keeping from childhood and the possible lack of consistent involvement of family or staff throughout the person's lifespan who would have knowledge of people they have supported.

Signs of early dementia can be subtle and can overlap with other conditions and so require careful observation to identify concerns in a timely way. Families and staff carers can often be so close to the person that they become less able to recognise minor changes in functioning through adapting to the person's increase in needs. Similarly, for some people there is an absence of people who can comprehensively describe and evidence the person's baseline of functioning, the role of baseline cognitive assessment becomes apparent.

Good practice guidance from the Foundation for People with Learning Disabilities (Turk et al., 2001) recommended that every service for people with intellectual disabilities should set up a register of adults who have Down's syndrome and conduct a baseline assessment of cognitive and adaptive functioning by the age of 30 years (being mindful of likely continued brain development throughout the second decade of life). Despite this, the availability of assessment and treatment across the UK remains inequitable. Most areas now offer reactive assessment for those with signs of deterioration, and many services now offer baseline assessments and some also offer prospective screening to adults who have Down's syndrome such as that described by Hobson et al., 2012; Cairns et al., 2010; Jervis & Prinsloo, 2007; McBrien et al., 2005.

A recent survey of psychologists in the UK regarding baseline assessments (Dodd, 2025) indicated that 64 per cent (47 out of 73 returns) offered baseline assessments for people who have Down's syndrome – although seven services have limits to what they offer e.g. only offering assessments to people referred for other reasons to their service; limitations due to current resources. Almost all services offer baseline assessments at age 30, with a couple of services starting at 40, and one at age 18. Of the 47 services that offer baseline assessments, 34 (72%) include direct cognitive assessment with the person, although all include a range of informant assessments/interviews. The main assessment tools currently used for direct assessment were the NAID (now the NAID-R) and the CAMDEX DS (now CAMDEX DS II). For informant assessment a much more varied range of tools were used.

3.2 THE IMPORTANCE OF BASELINE ASSESSMENT

There is currently no definitive 'test' for dementia. Its presence is a matter of eliciting a clinical history suggesting dementia and establishing evidence of change in function from a known baseline and excluding other diagnoses that may mimic dementia. In the mainstream population, it is more straightforward to gauge pre-morbid functioning from self-report or employment history

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than it is in the population of people with intellectual disabilities where self-report is limited and few paid carers are in possession of a full history.

Unless a baseline is established when the person is healthy, it is difficult to know whether there has been a deterioration later in life. By the time an individual is referred with concerns, considerable deterioration may have already occurred, and an accurate account of pre-morbid functioning may be difficult to construct (Trinity College Ireland, 2017). Longitudinal data is then needed to establish decline from a baseline as it is not possible to compare results of an assessment with an 'average' result for the person who has Down's syndrome, intellectual disabilities or general population.

Whilst it may be possible to establish a diagnosis of dementia from a one-off assessment when there is good historic data from which to compare, or the clinical picture is extremely clear, there is a risk of false negative or positive diagnoses. In such scenarios a repeat assessment in six months or one year may clarify the nature of the presentation.

Prompt diagnosis ensures that attention can be paid in a timely way to necessary changes to a care package, medication, preparing family carers and support staff for the inevitable changes and challenges that dementia will bring.

3.3 WHEN SHOULD BASELINE ASSESSMENT OCCUR?

It has been suggested that an assessment around the age of 30 years would be helpful (Turk et al., 2001; McBrien, 2009), and this has been endorsed by both Public Health England (2018), NHS Northern England Clinical Network (2018) and Improvement Cymru (2021). Ongoing neurodevelopment in late adolescence and early adulthood should be considered so as not to set baselines at too early an age when the brain is still developing. Carr (2000) demonstrated stability in intellectual ability and daily living skills for a cohort of people who have Down's syndrome during the age period 21–30 years, whilst others have shown that subtle cognitive decline may start around/after age 35 (Startin et al., 2018). This suggests that a baseline conducted around the age of 30 would helpfully capture people prior to any cognitive decline, and is supported by the results of the survey of services.

A baseline assessment at around age 30 years will capture a person's functioning once the brain is thought to be relatively fully developed, and the person has had sufficient opportunities to have acquired adaptive skills, and before the potential for the onset of dementia. A copy of the baseline assessment should be given to the person and their carers to keep in the person's health action plan/person-centred care plan for future reference.

3.4 TERMINOLOGY AND GAINING CONSENT

It is important that professionals undertaking baseline assessment for people who have Down's syndrome consider the terminology that they use in describing this assessment. Conducting a baseline assessment at around age 30 has the primary aim of having a record of the person's ability at the peak of their abilities. At this stage it is not a dementia assessment and should not be labelled as such.

It is important for services to consider how it explains a baseline assessment to the person who has Down's syndrome, and how it assesses the person's capacity to agree to the baseline assessment. Many services have developed Easy Read information sheets and consent forms to explain why a baseline assessment is needed. Consideration needs to be given to how much detail

about possible dementia is shared with the person at this stage. Family carers and staff need to be involved in discussions about the importance of having a baseline assessment for future care.

3.5 IDENTIFYING PEOPLE WHO HAVE DOWN'S SYNDROME

A key issue in delivering baseline assessments for people who have Down's syndrome is identification of those eligible before the age of 30. Many people who have Down's syndrome may not be known to adult community learning disabilities services in early adulthood. GP quality outcome framework (QOF) registers in England should now identify whether a person has Down's syndrome, and local commissioning boards should be able to access the number of people who have Down's syndrome in 10 year age bands. In Wales, work is underway to update GP registers to ensure they accurately identify individuals with a learning disability (and those who have Down's syndrome), and a key objective of the Wales Learning Disability Action Plan 2022 to 2026 (Welsh Government, 2022) is to increase access to health checks. This will, as a minimum, identify the number of people who will require access to baseline assessment and thus the funding required to deliver this service.

Gaining access to adults who have Down's syndrome may be more complicated due to issues with information sharing. In some areas paediatricians will refer children who have Down's Syndrome into their local Down's syndrome health screening clinic so that local community learning disability teams are aware of these individuals. Another solution is to ask GPs or other professionals completing the Annual Health Check to gain consent and refer the adult who has Down's syndrome for a baseline assessment or to consent to be added to a database to be called back around aged 30 for a future assessment. The digital flag for reasonable adjustments has potential to improve identification of people who have Down's syndrome, and this needs further investigation.

Functional limitations of electronic health record systems may require the development of additional databases to capture relevant clinical information about people who have Down's syndrome, or people on dementia care pathways. It is important to be aware of relevant data protection issues and organisational protocols (such as registering your database with the Trust or Health Board's information governance department) and be mindful of the potential need to gain consent/assent from service users and/or their carers to have personal information recorded in such a way.

Some services seek simultaneous consent for inclusion on dementia databases alongside permissions to contact people regarding possible research projects that may be of interest in the future.

3.6 PREVENTION OF DEMENTIA AND BRAIN HEALTH

Within the general population, 12 modifiable risk factors for dementia have been identified: low levels of education, hearing loss, traumatic brain injury, hypertension, alcohol, obesity, smoking, depression, social isolation, physical inactivity, air pollution, and diabetes (Livingston et al., 2020). Modifying these risk factors may prevent or delay up to 40% of dementia cases (Yamasaki, 2023). NICE guideline NG16 (NICE, 2015b) covers mid-life approaches to delay or prevent the onset of dementia, disability and frailty in later life. The guideline aims to increase the amount of time that people can be independent, healthy and active in later life. People with intellectual disabilities in general and people who have Down's syndrome may also be at risk of some or all of these factors, as well as other issues such as thyroid problems and high rates of psychotropic medication prescribing that could impact on cognitive functioning.

Annual health checks are an opportunity for a discussion with the person with intellectual disabilities and their staff or family carers about identifying possible personal risk factors and developing a plan to address them.

McCarron (2021) in Ireland's National Intellectual Disability Memory Service recommended that everyone who has Down's syndrome should have a Brain Health Check from age 30–35, with the development of a Personal Prevention Plan. This gives an opportunity for early intervention. Services should consider developing a Personalised Brain Health plan for people who have Down's syndrome as a consequence of a baseline assessment for example using the format in the National Intellectual Disability Memory Service publication 'Keeping your brain healthy' (NIDMS, 2020). This focuses on five key areas: Keep moving; Keep your heart healthy; Spend time with family and friends; Try something new; Get enough sleep.

3.7 AFTER A BASELINE ASSESSMENT

After completing the baseline assessment, professionals should support staff and family carers to understand how to identify early signs of dementia. This may include leaving appropriate leaflets and/or offering basic awareness training to staff and families so that they know what to look out for. An example of an Early Signs of Dementia checklist can be found in Appendix 1.

KEY POINTS

- It is recommended to assess every adult who has Down's syndrome by or around the age of 30 to establish a baseline against which to compare future suspected changes in functioning.
- This assessment must include direct cognitive assessment with the person.
- Baseline assessments should not be labelled as a dementia assessment.
- At local level, it is important for local services to work with ICB's, GP's, local authorities, and care providers to identify all adults who have Down's syndrome in your local area.
- In England, consideration should be given for the use of the digital flag for reasonable adjustments to identify people who have Down's syndrome to enable baseline screening and brain health plans.
- An individualised brain health plan post baseline assessment should be implemented for each person who has Down's syndrome.
- It is important to help staff and family carers be aware of early signs of dementia through the provision of leaflets and training.

Section 4 – Prospective monitoring, reactive assessment and ongoing monitoring

Services need to consider what type of assessment and monitoring service they offer to people with intellectual disabilities who may develop dementia. As people who have Down's syndrome are at greater risk due to a genetic predisposition, monitoring and assessments is considered to be more relevant for this group at a younger age than in others who have intellectual disabilities not due to the syndrome.

4.1 PROSPECTIVE MONITORING

Prospective monitoring entails checking for early signs of dementia by repeating the baseline assessment at regular intervals. This necessitates, as do baseline assessments, having a register of all adults who have Down's syndrome and additionally a method of recalling people for a re-assessment. Jethwa and Cassidy (2010) and O'Caoimh et al., (2013) suggest an accurate and extensive record of baseline skills levels in people with intellectual disabilities is crucial and regular comparison with baseline is key to early diagnosis. Prospective screening is however resource intensive and many services are not commissioned or resourced to undertake prospective screening.

The frequency of prospective monitoring for dementia should be matched to the rising risk with age. For example, following the baseline assessment at 30 years; services might consider then reassessing every two years for those in their 40s; and annually for those aged 50 and over. Assessment is non-invasive and is usually enjoyable for the participant (see Section 7); issues with prospective monitoring following age 30 more often relate to service capacity and funding.

4.1.1 ADDITIONAL BENEFITS OF REGULAR ASSESSMENT

One argument in favour of prospective screening concerns the known health risks for all people who have Down's syndrome. Many treatable illnesses can produce symptoms of cognitive decline independent of dementia. The evidence is that all too often, such disorders remain undetected in intellectual disabilities populations (Watchman, 2014). This applies particularly to people who have Down's syndrome who are prone to certain health problems (Coppus, 2014). Many carers and indeed some GPs are not aware, for example, of the need for routine thyroid function tests for adults who have Down's syndrome. There are useful factsheets, available free of charge on the internet from the Down's Syndrome Association, that can be used to raise awareness of this issue.

A review of six months of routine prospective screens carried out in one intellectual disability service (Major & McBrien, 2011) showed that of 33 prospective assessments of apparently healthy adults who have Down's syndrome, 12 (36%) revealed concerns that had not previously been identified by carers. These included dementia-like symptoms (memory and behavioural change), physical or mental health concerns that could be immediately treated, and action required by social services, including one requiring the instigation of the safeguarding protocol. Improved access to regular health screening (e.g. annual health checks) will help to minimise the prevalence of undetected physical and mental health concerns.

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4.1.2 PROSPECTIVE ASSESSMENTS – SHOULD WE OR SHOULDN'T WE?

The evidence does not currently indicate a need for baseline assessment or prospective screening for people with intellectual disabilities without Down's syndrome. Screening for people who have Down's syndrome needs to be justified in terms of likely gain, the demands placed on the service, and there needs to be consideration of the issue of informed consent. Some services may decide against it for reasons of intrusion, commissioning intentions and/or resource limitations. Baseline assessments should always be more of a priority than a prospective screening.

The person's annual health check should check for early signs of dementia. The early signs of dementia checklist should be shared with families and staff and used by GPs at annual health checklist – see Appendix 1. Apparent changes in scores on cognitive assessments do not in themselves indicate dementia but do require further investigation.

4.2 REACTIVE ASSESSMENT

Reactive assessment is the most common service provided by intellectual disabilities services. However, the reliability and efficiency of reactive assessment can be greatly enhanced if a baseline assessment is available, as data can be compared in a timely way.

Reactive assessment means conducting a thorough assessment of the medical, cognitive and social functioning after concerns about deterioration have been raised. This relies on carers noticing relevant signs of change and making a referral to the GP or intellectual disability service. This does not always occur in a timely manner. Due to a high turnover of staff in many intellectual disabilities residential settings, staff may not be aware of changes in a person's presentation and diagnostic overshadowing can occur. To enhance this, brief dementia checklists can be used by residential staff or at annual reviews (e.g. Whitwham et al., 2011), and staff awareness training can be provided for services supporting people with intellectual disabilities.

4.2.1 TERMINOLOGY

A first assessment when there are concerns regarding possible deterioration is not the same as a baseline assessment when the person is healthy and should not be labelled as such, but clearly labelled as a 'first concerns assessment'. This is an important distinction and needs to be understood both by clinical teams undertaking assessments and by health and social care staff who are referring the person with learning disabilities for assessment. Information relating to dementia care pathways and the roles of the multidisciplinary team can be found in Section 7.

For people who have Down's syndrome, professionals will be able to repeat the assessments used at the baseline assessment and compare the person's quantitative and qualitative findings to see if there is any change in performance. The professional will need to ascertain firstly whether there has been a change in functioning, and then consideration of what may have caused the change.

4.2.2 ONGOING MONITORING

Regardless of whether a service offers prospective monitoring, it is important that a programme of regular ongoing monitoring is established once the person is suspected/diagnosed of having dementia. This will enable the progression of the disease to be described, suitable medical, psychosocial and environmental interventions to be put in place, and the quality outcome for the person to be measured. See Sections 7, 13 and 19.

KEY POINTS

A first assessment after concerns have been raised is not the same as a baseline assessment.

It is worth considering screening all adults who have Down's syndrome over the age of 40 regularly because of the increased risk of dementia and the presence of undetected but treatable illnesses. This should link to the person's health action plan.

Once the person has suspected/diagnosed with having dementia, a programme of regular monitoring and reassessment needs to be established.

Section 5 – Possible reasons for apparent decline in functioning in adults with intellectual disability

Changes in functional ability with or without behaviour change are often the initial presentation of dementia in adults with intellectual disabilities. It is important to remember, however, that some changes may be part of the normal ageing process. There are a number of other reasons an individual with intellectual disabilities may show a cognitive decline. The list below, whilst not exhaustive, describes the most common reasons for change in ability. It is important to recognise that two or more conditions can co-exist (Tsou et al., 2020).

1. **Dementia:** The typical presentation of dementia is one of gradual loss of skills along with change in personality and cognitive decline. Dementia is a diagnosis of exclusion therefore, it is important to consider other conditions that may cause loss of skills and cognitive decline, especially as many of these are treatable.

2. **Physical problems** include such conditions as hypothyroidism, anaemia, uncontrolled epilepsy and chronic infections. Electrolyte abnormalities, hypo- or hyper-glycaemia, nutritional deficiencies particularly vitamin B12 or folate could also cause functional decline in adults with intellectual disabilities. A medical history and a thorough physical examination with relevant clinical tests are required at the time of initial assessment. These may need to be repeated from time to time as necessary.

3. **Sensory impairments:** People with intellectual disabilities in general and those who have Down's syndrome in their middle/old age specifically are likely to develop hearing and visual impairments. Visual impairment could be due to development of cataract or conditions such as keratoconus in individuals who have Down's syndrome. Some 60–80 per cent of people who have Down's syndrome will have hearing problems at some point in their lives. Conductive hearing deficit caused by earwax and the narrow acoustic canal is frequently seen in people who have Down's syndrome.

4. **Mental health problems:** The most common differential diagnosis is depressive illness (McBrien, 2003) but other conditions such as the exacerbation of an existing psychotic disorder can mimic the presentation of dementia. Severe anxiety can also cause an apparent decline in functioning.

5. **Sleep problems:** Sleep problems are very common and easily overlooked (Giménez et al., 2021). Obstructive sleep apnoea or other sleep disorders can cause day time drowsiness, mental slowing as well as confusion, and are particularly common in people who have Down's syndrome. Day time drowsiness and slowing could be interpreted as dementia if the sleep problem is not identified. International guidance recommends that people with Down's syndrome should be screened for sleep apnoea during childhood and may also be required in adulthood (Bull et al., 2002). Effective treatments are available for obstructive sleep apnoea and should be actively pursued given the considerable health benefits.

6. **Iatrogenic (medication related) causes:** Medications with anticholinergic side effects can cause cognitive impairments in elderly people and people with intellectual disabilities. Use of high dose psychotropic/anti-epileptic medications and multiple medications can contribute to cognitive impairment as well. The ACB Calculator can be used to assess

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this (King & Rabino, 2024). There is also an online and phone app that could assist in identifying side effects for combinations of medication, such as dizziness, drowsiness, and anticholinergic effects – available here https://medichec.com/. Some of the common medications that could cause a dementia-like presentation are listed in Table 1.

TABLE 1: SOME COMMON MEDICATIONS THAT COULD CAUSE COGNITIVE IMPAIRMENT (DIAGNOSIS AND TREATMENT GUIDELINE, MAYO FOUNDATION FOR MEDICAL EDUCATION AND RESEARCH, MORAN ET AL., 2013)

MEDICATION CLASS	EXAMPLES	SIDE EFFECTS THAT CONTRIBUTE TO COGNITIVE DECLINE
Antipsychotic medications	Chlorpromazine, Olanzapine Clozapine	Sedation, mental slowing, effect of anti-cholinergic properties affecting cognition
Anti-epileptic medications	Phenobarbitone, Phenytoin, Sodium Valproate Carbamazepine	Sedation and mental slowing
Antidepressants	Clomipramine	Same as above
Benzodiazepines, particularly long acting preparations	Clonazepam Temazepam Diazepam	Sedation, confusion, mental slowing
Older generation antihistamines	Diphenhydramine Hydroxyzine Promethazine	Sedation
Pain medications (analgesics)	Meperidine Propoxyphene	Confusion, dizziness, tiredness Meperidine can cause seizures

7. **Impact of life events:** People with intellectual disabilities in their middle age can face a number of life events associated with grief and loss e.g. loss of a parent or long-term carer and getting to know new carers moving away from home or loss of day activities. These can lead to many changes in the person's life and can have a significant impact on a person's wellbeing. In some individuals, the impact of life events may lead to a regressive state with apparent loss of skills. Changes in routine such as new structure to day opportunities or changes in support staff can cause profound reactions in an individual with intellectual disabilities leading to functional decline and a dementia-like presentation.

8. **Abuse:** Current or recent physical, emotional or sexual abuse in people with intellectual disabilities may result in loss of skills and regression and the development or exacerbation of behaviour problems that might superficially mimic dementia. Safeguarding procedures such as those practiced in England and Wales help protect vulnerable adults.

9. **Impact of poor environment:** An unsuitable physical and social environment can lead to loss of skills. A physical environment that has not been adapted to meet the person's changing needs may mean that areas of their home or day service may not be accessible. This may lead to a lack of stimulation, isolation and lack of social opportunities for positive interaction. In the event that this is also associated with changes in support structure, where people do not know the individual well, these changes may be attributed to dementia.

10. **Regression disorder ('Down's syndrome regression disorder'):** This has very similar features to dementia, but the main differences are that it presents at a much younger age (in adolescents and early adulthood; unlikely after around 30 years), it has a more acute onset (weeks) and there are often catatonic features (Walpert et al., 2021).

11. **Acute organic brain syndrome (or 'delirium' or 'acute confusional state'):** This may co-exist with dementia or be part of the differential diagnosis. Someone with uncontrolled epilepsy, for example, could present with confusional state that may mimic dementia. People with dementia may deteriorate rapidly and develop an acute confusional state when they have an acute physical health problem such as a urinary tract or respiratory infection. For any behavioural presentation, then physical health causes must be excluded first.

KEY POINTS

There are a number of reasons why an individual with intellectual disabilities may show a cognitive decline.

Do not forget about the following causes of apparent functional decline as these are often missed:

- iatrogenic causes of cognitive impairment particularly when the individual is taking multiple medications;
- impact of the environment particularly in relation to occupational deprivation and under stimulation;
- impact of abuse on individuals with ID;
- impact of grief and loss on individuals with an ID;
  depression needs to be excluded as a possible cause of the observed.

Section 6 – Clinical presentation of dementia

6.1 CRITERIA FOR DEMENTIA

Within the general population, diagnostic criteria have been developed in order to improve the accuracy of the clinical diagnosis of dementia. These include the ICD-11 and DSM-5 criteria where dementia is included within 'neurocognitive disorders' and conceptualised as mild/minor neurocognitive disorder (similar to mild cognitive impairment) or major (i.e. dementia). These are summarised below.

ICD-11 (WHO, 2024) SUMMARY OF CRITERIA FOR DEMENTIA

Dementia is under the categories of 'neurocognitive disorders' in the ICD-11. Note also that compared to ICD-10, the ICD-11 is closer to DSM-5 in that there is less emphasis on the requirement for memory impairment (most evident in the learning of new information) as some dementia types and some due to Alzheimer's type manifest as a non-amnestic presentation.

Below are criteria quoted from the ICD-11 (WHO, 2024) for dementia:

1. 'Marked impairment in two or more cognitive domains relative to the level expected given the individual's age and general premorbid level of neurocognitive functioning, which represents a decline from the individual's previous level of functioning, is required for diagnosis.

   Memory impairment is present in most forms of dementia, but neurocognitive impairment is not restricted to memory and may be present in other cognitive domains such as executive functioning, attention, language, social cognition and judgement, psychomotor speed, and visuoperceptual or visuospatial functioning.

2. Evidence of neurocognitive impairment is based on:

   - information obtained from the individual, an informant or clinical observation;
   - substantial impairment in neurocognitive performance as demonstrated by standardized neuropsychological/cognitive testing or, in its absence, another quantified clinical assessment.

3. Behavioural changes (e.g. changes in personality, disinhibition, agitation, irritability) may also be present and, in some forms of dementia, may be the presenting symptom.

4. Symptom course may provide information about the aetiology of dementia. Most dementias are progressive (e.g. dementia due to Alzheimer disease, dementia due to Lewy body disease, frontotemporal dementia), whereas other forms are reversible (e.g. dementia related to nutritional or metabolic abnormalities), stable (e.g. some cases of dementia due to cerebrovascular disease) or rapidly progressing (e.g. dementia due to prion disease).'

As with the ICD-10 there are exclusions, including clouding of consciousness/delirium (but noting that this is commoner in dementia), other causes of cognitive decline such as depression. It is also highlighted that 'Normal ageing is typically associated with some degree of cognitive change. Dementia is differentiated from normal ageing by the severity or magnitude of neurocognitive impairment relative to expectations for age, and by functional impairment in everyday skills and tasks.' In people who have Down's syndrome cognitive decline due to ageing can be difficult

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to determine by standardised assessment as implied in the ICD-11 as we lack appropriately normed measures (Videla et al., 2022). The distinction between prodromal phase of dementia in Down's syndrome (or 'mild cognitive impairment in Down's syndrome') can also be challenging to make in the early stages of the illness not just because a functional decline may not be reported as such if additional support is provided by the carers (Pape et al., 2021).

DSM-5 CRITERIA (AMERICAN PSYCHIATRIC ASSOCIATION, 2013)

The DSM-5 has renamed dementia as 'neurocognitive disorders' and it recognises both minor and major neurocognitive disorder.

Major neurocognitive disorder (dementia) is defined as:

1. Evidence of a significant decline from a previous level of performance in one or more cognitive domain (such as attention, executive function, learning and memory, perceptual motor or social cognition) which is based on:
    a. report of significant decline in cognitive function by the individual themselves, a knowledgeable informant, or a clinician;
    b. a substantial impairment in cognitive performance is documented by clinical assessment, preferably standardised neuropsychological testing.
2. The cognitive deficits interfere with independence in everyday activities (which is defined as at a minimum requiring assistance with complex instrumental activities of daily living such as paying bills). In people with intellectual disability, this may mean requiring further assistance than pre-morbidly.
3. The deficits do not occur exclusively in the context of a delirium.
4. The deficits are not better explained by another mental disorder (e.g. major depressive disorder or schizophrenia). Subtypes should be specified (e.g. Alzheimer's disease).

When the DSM-5, ICD-10 and DSM-IV criteria for dementia were evaluated in adults who have Down's syndrome (Pape et al., 2021), DSM-5 performed better than the older versions of criteria as judged by the clinical gold standard assessments undertaken by experienced clinicians. In the general population, DSM-IV criteria have been found to be more inclusive compared to ICD-10 criteria, which was also the case in people with intellectual disabilities (Strydom et al., 2007). ICD-10 and DSM-IV dementia criteria both showed substantial reliability and satisfactory validity in older adults with intellectual disabilities without Down's syndrome, although caution is advised when using these criteria in people with more severe intellectual disabilities and/or co-morbid sensory disabilities (see below) and predictive validity was slightly worse than in the general population (Strydom et al., 2013). ICD-10 criteria were more likely to accord with clinician diagnoses than DSM-IV criteria in people who have Down's syndrome who have been diagnosed clinically with dementia, possibly due to the inclusion of behavioural symptoms in the ICD-10. However, both sets of criteria underdiagnosed dementia compared to clinician judgement, suggesting that experienced clinicians used their clinical knowledge of the slightly atypical dementia presentation in Down's syndrome to diagnose the disorder at an earlier stage than would be possible if they applied the diagnostic criteria (Sheehan et al., 2014).

In a study of dementia in people with intellectual disability with more severe disabilities (Wissing et al., 2022a, 2022b), the most frequently observed change was a decline in activities of daily living functioning, followed by behavioural and psychological changes (especially in irritability,

eating/drinking, and in anxiety and apathy behaviours); changes in cognitive and motor functioning were less frequently reported.

With the fast development of biomarkers and the aim in disease modifying clinical trials to target the underlying neuropathology of Alzheimer's Disease in Down's syndrome (Davidson et al., 2018), a framework has been developed to address this (Jack et al., 2024). According to this approach the genetically determined dementias such as in Down's syndrome (Fortea et al., 2020) would at birth be considered as being in stage 0 of Alzheimer's Disease (asymptomatic but will develop the syndrome of dementia) out of a total of six stages. This approach, although designed as a presymptomatic biomarker based staging of disease such that the outcome of disease modification can be monitored, it raises some ethical questions (Jack et al., 2024; Zhou et al., 2024). A person who has Down's syndrome may be born with the syndrome, but it may not be appropriate to say that the newborn is also stage 0 of a genetic form of Alzheimer's disease as the disease will not manifest clinically until the person reaches their mid-adulthood. It may therefore be prudent to wait until we have further characterised and discovered biomarkers for the earliest stages of the disease and there are safe and effective disease modifying treatments available. Our view is that this approach is not ready to be implemented into current clinical practice.

6.2 COURSE OF THE DISEASE

In the general population each of the different types of dementia have characteristic clinical features. The presentation and course of dementia has been studied in people who have Down's syndrome but less so in people with intellectual disabilities. However, some general observations can be made.

6.2.1 PEOPLE WHO HAVE DOWN'S SYNDROME

People who have Down's syndrome are at high risk for additional co-morbid illness that might impact on both the way that dementia presents, and its progression over time. Baksh et al., (2023) used data from the UK Clinical Practice Research Datalink and compared the prevalence of illness in the general population compared with those with intellectual disabilities not due to Down's syndrome. From a sample of 10,204 people who have Down's syndrome, 39,814 controls, and 69,150 people with intellectual disabilities they calculated the incident rate ratios (IRR) for people who have Down's syndrome to be higher for, dementia (IRR 94·7, 95% CI 69·9-128·4), hypothyroidism (IRR 10·6, 9·6-11·8), epilepsy (IRR 9·7, 8·5-10·9), haematological malignancy (IRR 4·7, 3·4-6·3), but lower for, asthma (IRR 0·88, 0·79-0·98), cancer (solid tumour IRR 0·75, 0·62-0·89), ischaemic heart disease (IRR 0·65, 0·51-0·85), and hypertension (IRR 0·26, 0·22-0·32) than in controls. Unexpected deterioration or changes in presentation or course should be investigated in case there are treatable additional physical or psychiatric co-morbid illnesses or environmental factors.

The most common form of dementia in people who have Down's syndrome is Alzheimer's disease. It is known that the brain pathology of Alzheimer's disease is almost universally found in later life in people who have Down's syndrome. The risk of a vascular dementia compared with Alzheimer's disease is less common (Baksh et al., 2023), possibly due to the low prevalence of hypertension and atheroma (Buss et al., 2016). However, despite this MRI findings reveal micro-bleeds and infarcts that correlate with cognitive decline and the onset of dementia (Lao et al., 2024). Post mortem studies reveal congophilic amyloid angiopathy which are deposits of amyloid in vessel walls (predominantly in medium-sized and small-sized leptomeningeal and cortical arteries, arterioles) of the brains of people with Down's syndrome (Head et al., 2017).

Further research is likely to provide evidence for a close relationship between neurovascular function and neurodegeneration.

Dementia in people who have Down's syndrome has been shown to present with the earliest changes in attention and memory function (Startin et al., 2019; Benejam et al., 2020), although carers may report behavioural changes as the 'first' concern rather than functional memory decline. It is important to note that reports from carers of change in behaviour/personality may be masked by measurable decline in memory functioning.

There is evidence for a non-amnestic 'prefrontal lobe syndrome'-like presentation in a subset of people with Down's syndrome who later present with memory symptoms (Ball et al., 2006; Fonseca et al., 2019, 2020). Longitudinal neuropsychological studies have found that some discrete cognitive abilities, as measured using established neuropsychological tests, show evidence of increasing impairment over time and starting in the early and pre-clinical stages of dementia. Thus memory and orientation are affected early, with praxis, language and visuo-spatial skills becoming impaired later in the progression of the disorder (Ball et al., 2006). More recent data confirm that memory changes are amongst the earliest changes before a diagnosis of dementia is made, alongside difficulties in attention and verbal fluency; these are strong neuropsychological markers indicating the onset of the dementia syndrome, and optimised assessment batteries have been proposed to target these changes in individuals with DS during the preclinical and prodromal stages of Alzheimer's disease (Aschenbrenner et al., 2021, Hithersay et al., 2021).

The behavioural issues associated with dementia in people who have Down's syndrome may take the form of behavioural excesses such as irritability, aggression or self-injury and the behavioural deficits would include slowness, apathy, loss of interest and lessened social engagement (Oliver et al., 2011; Dekker et al., 2021).

The middle course of Alzheimer's disease in people who have Down's syndrome and for most of those with other causes for intellectual disability are comparable in characteristics to those experienced by people at a similar stage of dementia but without pre-existing intellectual disabilities, although in adults who have Down's syndrome neurological symptoms are common, including the first onset of seizures.

Late stage symptoms are characterised by the individual's lack of response to the environment, loss of mobility, loss of communication skills, incontinence, seizures due to epilepsy and may include Parkinsonian features (Visser et al., 1997; Strydom et al., 2010).

The deposition of amyloid and abnormal tau in the brains of individuals who have Down's syndrome can be tracked using specific radiotracers during positron emission tomography (PET). Studies (e.g. Schworer et al., 2024) have confirmed that amyloid deposition is followed by tau deposition and then by cognitive decline. From amyloid PET one can define an amyloid age as the length of time from the first detectable deposits of amyloid. It was shown (Schworer et al., 2024) that mild cognitive impairment was observed at a mean amyloid age of 7.4 years (standard deviation of 6.6 years) and dementia diagnosis was observed at a mean amyloid age of 12.7 years (standard deviation of 5.6). After the onset of detectable amyloid positivity, tau deposition was seen at a mean of 2.7–6.1 years. Furthermore, the modified cued recall test, which has been shown to be one of the earliest cognitive tests to change during the prodromal phase showed changes at 2.7 years after the first PET detectable amyloid deposits.

6.2.2 DOWN SYNDROME REGRESSION DISORDER (DSRD) CAN MIMIC DEMENTIA

People who have Down's syndrome who were previously functioning well may show a rapid (sub-acute) deterioration in their teens or early adult life, often following a life event, and either never fully or, only after many months or years, recover (Santoro et al., 2022). The characteristics of the decline may superficially resemble that of dementia or depressive illness but it neither seems to progress (as would be expected with dementia) or resolve (as would be expected with depressive illness). The clinical picture is dominated by the development of a general slowness in mental and/or physical activity, apparent loss of interest in previous activities, and a level of functioning that is below that previously observed, often accompanied by other features of catatonia such as mutism. In some people the presentation may include autistic features. The likelihood of dementia is very small in those aged under 30 years of age.

A comprehensive assessment to exclude both physical and mental health conditions needs to be undertaken, including for auto-immune conditions, sleep apnoea and encephalopathies. Treatment of DSRD is usually symptomatic, but ECT has been used successfully in those with prominent catatonic features (Walpert et al., 2021). If depressive disorder symptoms are a feature, then a trial of anti-depressant medication may be indicated, with careful monitoring of outcomes. Other conditions such as Hashimoto's encephalopathy catatonia and neurological diseases need to be excluded (Brodtmann, 2009; Jap & Ghaziuddin, 2011). Therapeutically the approach taken is primarily a rehabilitative one with attempts to help the person progressively back to their previous state of function. More recently, some patients have responded to intravenous immunoglobulins (Santoro et al., 2024) but as yet as these are not widely recognised standard treatments by the NHS, and it is not clear whether improvements are sustained.

6.2.3 PEOPLE WITH INTELLECTUAL DISABILITIES WITHOUT DOWN'S SYNDROME

For those people with intellectual disabilities not due to Down's syndrome, the picture may be variable. There is more likely to be a range of pathologies resulting in dementia, as is the case in the general population, and for the same reason there will be differences in presentation and the course of the dementia.

Experience from the study of older people who have Down's syndrome suggests that the clinical presentation may be affected by an interaction between how brain development is affected due to having underlying neurodevelopmental disorder and acquiring the pathology of Alzheimer's disease. As with people who have Down's syndrome, people with intellectual disabilities not due to trisomy 21 will have a great variation in terms of level of pre-morbid abilities.

The following are likely to be useful guiding principles with respect to the presentation and course of dementia in those with intellectual disabilities not due to Down's syndrome.

- The presentation and course of dementia among people with mild intellectual disabilities is likely to be similar to that which is observed in the general population.
- The presentation and course of dementia in people with more severe intellectual disabilities may initially be atypical and present with changes in behaviour and for this reason dementia may not be suspected, which becomes a challenge when trying to avoid diagnostic over-shadowing. As the illness progresses careful questioning of staff and carers may identify evidence of developing memory and functional impairments or neurological symptoms such as incontinence and dysphagia (Wissing et al., 2022a, 2022b).

- The age of onset of dementia in this group of people may be a few years earlier than is commonly found in the general population but not as early as in people who have Down's syndrome (Strydom et al., 2007, Baksh et al., 2023). However the prevalence is double that found in the general population.
- As with those in the general population it is important to investigate the likely cause of dementia as the full range of causes for dementia are likely to be found in this group of people and this may have important therapeutic and management implications.
- There is evidence that the onset of epilepsy in later life for the first time may be a marker for developing dementia in people who have Down's syndrome (Altuna et al., 2021). The incidence of epilepsy in people who have Down's syndrome increases rapidly with the onset of dementia by several fold when compared with the group with non-Down's syndrome causes of intellectual disability (Baksh et al., 2023), but the onset of epilepsy in later life for the first time in the latter group should always be investigated and increasing difficulty controlling pre-existing epilepsy may also be an indication of the possibility of the onset of dementia.

KEY POINTS

The course of dementia in people who have Down's syndrome has been well studied and may be atypical with early development of behavioural or personality change, though memory problems are also prominent.

New onset of epilepsy or worsening of existing epilepsy in an older person who has Down's syndrome should always raise the possibility of Alzheimer's disease.

Diagnostic criteria are reliable in the intellectual disability population, but dementia is more difficult to diagnose in those with severe disabilities or comorbid problems and may require sequential assessment. Clinicians should also keep in mind the slightly atypical presentation of dementia in people who have Down's syndrome.

A small number of young people who have Down's syndrome seem to present with decline in their teens or early twenties, which may be due to DRDS.

People with intellectual disabilities without Down's syndrome who develop dementia may have the same range of pathologies as the general population although the prevalence rates are higher.

Section 7 – Assessment

7.1 SUMMARY

Multidisciplinary assessments should include direct assessment of the person together with multiple-informant based questionnaire/assessments measured over time. The consensus is to formulate using a biopsychosocial framework and identifying any predisposing, precipitating, perpetuating and protective factors.

Best practice is to:

- assess and compare a person to their own baseline level of functioning;
- assess/investigate for other co-morbid conditions (including physical and mental health);
- consider environmental and staffing factors;
- formulate whether the person's presentation is related to dementia;
- consider issues around mental capacity and consent throughout.

There is great variability of functioning within the population of people with intellectual disabilities. Comparison with 'peer-related' norms is not possible as it is with mainstream dementia assessments. Assessment of decline needs to be personalised to each individual, with their own unique 'baseline of functioning' being the comparison when concerns arise. Holistic assessment should also encompass wider systemic issues. These issues can be identified through informant and carer interview, direct observation as well as gathering knowledge from members of the multidisciplinary team.

NICE Quality Standard QS184, Dementia (NICE, 2019a) states in Quality Statement 2 that: 'Referral to dementia specialist diagnostic services ensures that diagnosis is timely and accurate, and dementia subtypes, such as Alzheimer's disease and dementia with Lewy bodies, can be identified.' The process of specialist assessment essentially has three stages that follow NICE guidance for dementia (NICE, 2018a). For people with intellectual disabilities, this usually occurs within the context of the intellectual disability service rather than in mainstream memory services due to the specialist skills and expertise in assessing people with learning disabilities (Barrett & Burns, 2014).

When looking at the latest NICE guidance on Dementia NG97 (2018a) this directs the reader to the following NICE guidance:

'Mental Health Problems in people with learning disabilities: prevention, assessment and management for assessments for people with a learning disability' NG54 (2016).

This suggests supplementing an assessment of dementia with an adult with learning disabilities with:

- Measures of symptoms such as the Dementia Questionnaire for People with Learning Disabilities (DLD), the Down Syndrome Dementia Scale (DSDS) or the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID);
- Measures of cognitive function to monitor changes over time, such as the Test for Severe Impairment;
- Measures of adaptive function to monitor changes over times;
- Complete a baseline assessment of adaptive behaviour with all adults who have Down's syndrome.

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The recent survey completed by 73 services (Dodd, 2025) indicated that most services used either the NAID/NAID-R or the CAMDEX DS/ CAMDEX DS II for direct cognitive assessment. A far wider range of instruments and assessments were being used for assessment with informants.

Assessment should include a file review and systematic history-taking from the person and multiple informants across settings and services, who have known the individual for a significant period of time.

Assessment should include physical and mental state examinations, cognitive assessments and other investigations to enable the evaluation of present functioning and the identification of other possible causes of decline. The medical investigations should be guided by the clinical picture but invariably include investigations of a person's basic physical state and specific tests, such as measures of thyroid function and B12, or specialist assessment of hearing and/or vision. Where the clinical picture is unusual, the diagnosis in doubt, or there are features that prompt concern (e.g. focal findings on neurological exam, a recent fall/head injury, rapid or sudden decline) a CT or MRI brain scan may be indicated (refer to Section 5 for detail regarding differential diagnosis and section 7.1.5 for further details regarding scans).

The diagnostic process leads to a formulation that brings together all the information from the various interviews, assessments and investigations and finally determines the likely cause of the observed clinical changes and sets them in the context of the individual and/or their system. This forms the basis for making a possible diagnosis and developing an individualised care plan.

7.1 ASSESSMENT PROCESS

The section outlines in more detail the key factors to be considered during the assessment process.

7.1.1 HISTORY AND INFORMATION GATHERING

- Nature of the presenting problem(s), origin, rate/pattern of progress (sudden or gradual or stepwise decline), presence of seizures and other associated conditions, impact on the person's overall functioning, personality and behaviour.
- History of significant physical and medical history including past and present medical conditions, e.g. diabetes, hypertension, thyroid or cerebrovascular disease, B12 deficiency. Establish if the person is menopausal.
- History of or current presence of psychiatric symptoms such as depression, anxiety or other mental health problems.
- Ask about sleep difficulties (sleep apnoea is very common in people who have Down's syndrome) but bear in mind that relationship between caregiver reports and diagnosis of sleep apnoea in particular is poor, with symptoms often overlooked or under-reported.
- Changes in eating and drinking (e.g. concerns related to dysphagia), diet and weight.
- Record developmental history and best level of historic functioning. Ascertain if there are any previous neuropsychological test data on record and compare data with previous assessment results. Record historic daily living skills, communication abilities, interests/hobbies/skills and changes in personality.
- Family history: dementia or other mental health and medical conditions (particularly in first-degree relatives).
- Assess for psychosocial issues, changes or life events. These include house moves, health decline/death of loved ones, change of caregivers or in support levels, changes to or ending work/day services.

- Information gathering should be undertaken through a combination of informant interview (preferably with a family member, when relevant and appropriate) or an informant who has known the person well for a prolonged period of time (for a minimum of six months) and directly from the person where possible.
- Consider whether there is a family history of dementia, which may raise the possibility of a genetic aetiology of the dementia (for individuals without Down's syndrome). The Royal College of Psychiatrists Report 237 on genetic testing in mental health settings and SIGN guideline 168 provide guidance on when genetic testing should be considered in individuals who present with dementia.

7.1.2 MENTAL STATE EXAMINATION

Observation of level of alertness, orientation to time, place and person, any evidence of alterations in consciousness, psychomotor activity, mood, thoughts, evidence of any abnormal mental beliefs or experiences, and perceptual abnormalities. Evaluation of memory and other cognitive functions via formal assessment (see below).

7.1.3 PHYSICAL EXAMINATION

Where possible a complete physical examination should be undertaken, but a neurological examination is especially relevant (including vision and hearing). This should occur in the context of primary care, although support may be provided by specialist services. All people with an intellectual disability in England and Wales are entitled to an Annual Health Check from their GP (NHS Long Term Plan, 2019; Welsh Government, 2022). In Scotland these checks can be carried out by a nurse or medical practitioner and service models vary across Scotland (Scottish Government, 2022). The findings from these should be used to inform the below assessment process. Every effort should be made to review physical health, but on occasions when this is not possible, it is still important to proceed with a dementia assessment.

The key assessment areas are:

- Neurological examination – including focal deficits, dysphasia, cardiovascular accident (stroke), evidence of upper motor neuron lesions (upgoing plantars etc.), Parkinsonian features, gait, primitive reflexes, hearing and vision.
- Cardiovascular system – note any congenital heart operations, arrhythmias (atrial fibrillation), hypertension, evidence of peripheral vascular disease, ischaemic heart disease, carotid murmurs, heart failure. Note that asymptomatic bradycardia and hypotension are common in people who have Down's syndrome,
- Endocrine system: signs of hypothyroidism (often biochemical screening test results will be available), diabetes.
- Careful recording of historic/newly added/current medications (with particular attention to those that are psychoactive, anti-epileptic, sedating or anticholinergic).
- Continence issues, including constipation.
- Bone and joint problems.
- Assess mobility, footwear and foot health (association with falls).
- Menopause (early menopause is common in Down's syndrome).

Complete physical examination may be difficult in a significant proportion of individuals. The physical health issues could be addressed in these individuals by a combination of:

- brief physical checks, e.g. blood pressure, pulse examination;

- observations for any evidence of physical health issue;
- observational tools (e.g. pain questionnaires);
- information from carers, e.g. Health Action Plans (DoH, 2001) or bespoke nursing assessments developed to meet the needs of local intellectual disability services can be used to structure this process.

7.1.4 PHYSICAL INVESTIGATIONS

Recommended routine investigations are:

- full blood count;
- urea and electrolytes;
- blood glucose (preferably fasting); HBA1c;
- thyroid function tests;
- liver function tests;
- B12 and folate level;
- Vitamin D levels (although not specific for dementia, important to treat deficiency);
- lipid profile;
- sensory screening – vision and hearing;
- dental review;
- in people with Down's syndrome, consider sleep clinic referral for sleep apnoea assessment.

Optional tests are:

- Electro encephalograph (EEG) – if there is evidence of the occurrence of seizures, and myoclonic jerks.
- Neuroimaging: this may not be practical as a routine investigation for the assessment of dementia but may be of value when vascular dementia or other brain lesions are suspected (see section 7.1.5 on 'Neuroimaging' below).
- Electrocardiograph (ECG) – particularly if anti-dementia medication is to be used and there is evidence of cardiovascular problems.
- Mid-stream urine test if indicated (to exclude other physical illnesses such as if suspect delirium).
- In females with Down's syndrome where the early onset of menopause is a risk factor for earlier onset of dementia; a hormonal profile may be indicated.

7.1.5 NEURO-IMAGING

INDICATIONS

The most consistent structural change in the early stage of Alzheimer's disease is the atrophy of the medial temporal lobe (hippocampal atrophy is used in staging the disease). People who have Down's syndrome have medial temporal lobe atrophy even without dementia. However, normative values have not yet been established, so neuro-imaging currently has limited value in the early diagnosis of Alzheimer's disease in people who have Down's syndrome. Its value is mainly to rule out structural lesions other than atrophy (e.g. space occupying lesions). Although it should be used only when the clinical picture suggests the possibility of such lesions, recent MRI findings show vascular changes (enlarged perivascular spaces, microbleeds, and infarcts) and white matter changes (small vessel disease) which are beginning to be characterised clinically [SZ1] (Lao et al., 2024; Morcillo-Nieto et al., 2024).

MRI scans have a number of advantages over CT scans. MRI scans are used to identify brain microbleeds, white matter lesions and to exclude strokes. MRI scans will, in the future, be required in order to gain access to the new treatments described in Section 6.2. In the context of these new disease-modifying treatments such as monoclonal antibodies against amyloid becoming available, MRI scans will be required before and during treatment to monitor for complications such as brain oedema (ARIA-E) and microbleeds (ARIA-H).

INFORMING AND PREPARING

Neuro-imaging requires explicit informed consent. Detailed information regarding the rationale and the procedure should be given to the person in an appropriate user-friendly format. Assessment of capacity will be needed to identify whether the individual is able to provide valid consent for the procedure. Where the person does not have capacity, best interest principles will need to be applied.

Anxiety about the procedure can be allayed by a visit to the radiology unit and familiarisation with the procedure, and occasionally sedation may be required.

PROCESS

People with intellectual disabilities should access appropriate reasonable adjustments to help them understand and cope with the scanning process. This may include: showing a virtual reality or video of the scanner process, having a caregiver in the scanning room, supplying ear muffs for the noise, being able to watch a video on a screen during the scan.

Many people with intellectual disabilities will, with adequate preparation and the reasonable adjustments described above, be able to go through the procedure without any other interventions. However some people with intellectual disabilities may benefit from the use of one dose of oral anxiolytic medication such as lorazepam or diazepam an hour beforehand. Some clinicians prefer to use buccal midazolam, which provides rapid and short-term sedation and therefore may be given immediately before the procedure. Some individuals may find it difficult to have a scan even with all these measures.

Generally, the MRI procedure is longer and more anxiety provoking, however some hospitals may have newer wide-bore MRI scanners which may be more acceptable. Discussion with the radiologist may be helpful in deciding if CT can be used as an alternative. New generation CT scans are potentially more user friendly and less anxiety provoking.

If the individual clearly needs neuro-imaging but is unable to co-operate in spite of all these measures, it can be undertaken under general anaesthesia. However, risks and benefits should be evaluated and thorough discussion held with the carers and other professionals to arrive at a best interests decision, if the person lacks the capacity to consent to this specific investigation. If the person has the capacity to consent to the scan it is for them to decide whether or not to have the scan, after being given clear information on the procedure, risks and benefits.

SHARING THE FINDINGS

It is important to share the findings of the scan with the person with intellectual disabilities, carers and other professionals. This should include the nature of the findings as well as implications for the management. This discussion should be clearly documented.

7.1.6 ENVIRONMENTAL ASSESSMENT (SEE ALSO SECTION 12)

- Quality of the person's physical environment;
- Staffing levels (day and night);
- The mix of people with intellectual disabilities in the residential and day care settings;
- Quality and quantity of day activities;
- Staff characteristics: attitudes and competence, including consistency of approach;
- Scrutiny/review of historic/current support package;
- Wider systemic issues such as Care Quality Commission (CQC) concerns and ongoing Safeguarding Adult investigations.

KEY POINTS

Carrying out investigations may be difficult in some individuals with intellectual disabilities. In this situation, clinicians have to make a decision using information from the history, physical assessment and direct observation as to whether investigations are essential or not. There may be scope to work with the person to improve the chances of success in engaging with physical assessments (e.g. systematic desensitisation for blood tests, brain scans, eye-tests etc.).

Relevant Mental Capacity legislation and its code of practice guidelines must be followed where investigation is considered and the person is unable to consent and cooperate.

A minimum reactive dementia assessment should include/consider:

- Thorough medical history, with a focus on common co-occuring conditions Physical health check.
- Longer-term and recent life events.
- Semi-structured interview exploring negative change in relation to functional skills, memory, behaviour, orientation, mood and consider potential alternatives for these changes.
- Mental state examination (may utilise a depression or anxiety measure). Objective assessment of cognitive, social and adaptive skills and abilities – See Section 7.3 onwards.
- Physical investigations, including for HbA1c, vit D, TFTs, sleep apnoea. Neuro-imaging (CT/MRI) is not an essential investigation for the diagnosis of dementia in people who have Down's syndrome, but will be required if treatment with MAB's are considered.
- Neuro-imaging may be of value where other brain lesions/vascular dementia are suspected.New generation CT scanners are as sensitive as MRI scanners and may be more acceptable for people with intellectual disabilities.
- Amyloid and tau PET scans may become more available in the near future, but its value in the diagnosis of dementia in individuals who have Down's syndrome who all have amyloid deposits in their brains remain uncertain.

7.2 INFORMATION TO SUPPORT THE ASSESSMENT PROCESS

A systematic review (McKenzie et al., 2018) found some measures currently used in the UK were neither designed for the assessment of dementia, nor for people with intellectual disabilities. Whilst there are a range of assessments available, the most commonly used tests designed specifically for people with ID are the NAID/NAID-R and the CAMCOG-DS-II (with validation data shortly to be published) and these should be the assessments of choice.

Assessment tools for dementia in the general population are not appropriate for people with intellectual disabilities. For example, widely-used tools such as the Mini-Mental State Examination (MMSE) (Folstein & Folstein, 2001) or the Addenbrookes Cognitive Examination – 3rd Edition (Hodges, 2012) assume the pre-morbid level of functioning to have been within the average range, and these should not be used.

Screening tools such as the Early Detection Screening Tool (NTG-Early Detection Screen for Dementia – Esralew et al., 2013), which was subsequently reviewed (Silverman et al., 2021), DLD and DSQUID may be useful tools but need to be supplemented by additional sources of relevant information.

- Always look for evidence from previous assessments on file that might indicate pre-morbid functioning. Where possible, the same test should then be repeated for comparison.
- The tests used should include (where possible) direct assessment with the person and questionnaire/interview-based assessments with well-informed carers. Information should be collected from both carers at home and from carers within the person's day services to ensure concerns are not situation-specific.
- For some individuals with profound intellectual disabilities, pre-morbid cognitive ability may be at a level where changes may not be detected by any available standardised testing. Carer reports have to take precedence which inevitably will focus on behaviour and motor ability.
- Whatever battery of assessments is chosen, it should be used longitudinally within the service to enable comparison of performance over time for that individual.

7.3 DIRECT TESTING WITH THE PERSON WHO HAS DOWN'S SYNDROME AND/OR INTELLECTUAL DISABILITIES

Caregivers report that the early changes associated with dementia in people who have Down's syndrome can often relate to behaviour or personality rather than memory functioning and may be more prominent than in the general population (Oliver et al., 2011; Powell et al., 2014; Lautarescu et al., 2017; Deb et al., 2022). These studies suggest that there is often compromised function associated with the frontal lobes early in the course of the disease. For this reason, assessments that tap into executive functioning are important to consider, especially in terms of establishing baselines when a person is still healthy and well.

Assessments should cover as a minimum (although may be dependent on intellectual functioning and ability to engage in direct assessment):

A validated instrument for the cognitive assessment of dementia in people with intellectual disabilities (see 'Neuropsychological Assessments and Informant Questionnaires' sections below for examples). These typically include:

a. prospective, short- and long-term memory (visual and verbal);

b. executive functioning;

c. orientation;

d. language (expressive and comprehension); and

e. recording of evidence of new learning.

Other assessments to consider (especially where the person is unable to complete a cognitive assessment):

- Direct questioning of known previous skills or knowledge personal to the individual (e.g. order of potting balls in snooker, knowledge about a favourite celebrity).
- Observation of a change in functional/practical skills e.g. sequencing a task, in reading, writing, mathematic skills (might be apparent when compared to historic information).
- Mood state.

This is not a complete list and the assessor needs to be responsive to assessing specific issues in greater detail if required (e.g. praxis, attention, perception). The tools listed below are those most commonly used in services in the UK. Many services have developed their own 'assessment battery' combining a variety of psychometric measures and assessments that tap into the areas of functioning described above, but this is now discouraged. Bespoke assessments will not be useful longitudinally if people move or services change. Some direction and recommendations are outlined below.

7.3.1 DIRECT NEUROPSYCHOLOGICAL ASSESSMENT

It is important to note that if an earlier version of an assessment has been used, continue to use this to ensure accurate comparisons over time.

The below assessments are the main assessments that can be used for people with an intellectual disability.

Neuropsychological Assessment of Dementia in Adults with Intellectual Disabilities Revised (NAID-R) (Crayton & Oliver, 1993, revised by Gleave et al., 2023) is designed to assess areas of cognitive ability known to decline with the onset of dementia: memory, language (e.g. anomia, aphasia), praxis, and orientation. Details of the tests used in the initial development of the NAID are detailed in Crayton et al., (1998) and summarised in Oliver, et al., (1998). Normative data enabling interpretation of single point assessment results are now available (see Oliver et al., 2021). The NAID-R contains amendments to the administration and scoring of the tests and test materials, which are easy to follow and are freely available without cost. This battery takes about 45 minutes to administer. The majority of people who have Down's syndrome can attempt most of it. It is said by the authors to be in use in over 30 intellectual disabilities services in the UK, and since the revision this number is now increasing.

CAMCOG DS – II (Beresford-Webb & Zaman, 2021) is a cognitive assessment designed to assess the cognitive ability known to decline with the onset of dementia. It is part of the CAMDEX DS II which is an updated second edition of a validated assessment for diagnosing dementia in people with intellectual disabilities and emphasises establishing change from the person's best level of functioning. When combined with the informant assessment included in the CAMDEX DS II it is described as a comprehensive assessment for dementia in people who have Down's syndrome and others with intellectual disabilities. The CAMCOG-DS II is the participant component of the CAMDEX-DS-II and includes assessments of orientation, language, memory, attention, praxis, abstract thinking and perception, giving individual subscale scores as well as a total score. The update includes more tests/items for aspects of executive functioning (including attention), and

revised memory items. It also provides guidance around interviewer observations. CAMDEX DS II validation data is due to be published by the Horizon-21 European Consortium for Down's syndrome.

Where a person has a more significant intellectual disability the following assessments should be considered:

Severe Impairment Battery (SIB) (Saxton et al., 1993). The SIB is designed to assess cognitive abilities at the lower end of the intellectual range in the general population (age range 51–91). There are 40 items and administration is said to take about 20 minutes. It is composed of very simple one-step commands which are presented in conjunction with gestural cues (e.g. 'what's your name?', 'please write your name here', 'what do you call the thing you drink coffee from?'). The SIB is divided into scoreable subscales, each sampling within the range expected of the severely-impaired individual. The six major subscales are attention, orientation, language, memory, visuospatial ability and construction. There are also brief evaluations of praxis and the person's ability to respond appropriately when their name is called (orienting to name). In addition, there is an assessment of social interaction skills. It yields scores out of 100, to assess mild to moderate dementia. There is no cut-off for 'normal' as the test should only be used with people known to be severely impaired.

Test for Severe Impairment (Albert & Cohen, 1992). This is a 24-item test covering eight domains which was designed for people with severe cognitive dysfunction, but not specifically intellectual disabilities. This test may not be sensitive to change over time, and only includes a few memory items although this test is referred to in the NICE guidance as mentioned above (NG54, 2016).

TESTS OF EXECUTIVE FUNCTIONING

Whilst there have been some recent studies exploring the measurement of executive functioning in people with intellectual disabilities (e.g. Ball et al., 2008) there is currently no clear agreement as to which tests should be adopted for the assessment of dementia.

Executive test batteries developed for the non-intellectual disabilities population (such as the Delis-Kaplan Executive Function System – D-KEFS (Delis et al., 2001) or the Behavioural Assessment of the Dysexecutive Syndrome – BADS (Wilson et al., 1996) tend to be too difficult for many people with intellectual disabilities.

The BADS–ID (Webb & Dodd, 2020) is a validated adaptation of the BADS (Wilson et al., 1996) for people with intellectual disabilities. Two of the subtests have been used in clinical practice in assessments for people who have Down's syndrome at baseline – the Key Search and the Supermarket map. However, it is important that the person has sufficient receptive language to understand the instructions, so that performance measures executive functioning rather than language skills.

The Measure of Everyday Planning (MEP) (Webb et al., 2014) is a flexible tool designed to help identify the issues or underlying difficulties that adults with intellectual disabilities may have with independently initiating, planning and carrying out everyday activities. It explores subtle factors that can impair the performance of individuals who, superficially, appear to have the ability to carry out tasks but, in reality, struggle with them. It can be completed both with carers and with the individual with intellectual disabilities.

In practice however, it may not be necessary to include an executive functioning test battery during a dementia assessment, as some of the comprehensive test batteries mentioned above, such as the CAMCOG-DS-II, cover this sufficiently.

7.4 INFORMANT QUESTIONNAIRES

These should aim to cover those areas of function that are known to deteriorate with the development of dementia including: short and long term memory, general mental functioning, dyspraxia and dysphasia, daily living skills, personality and behaviour. All informant questionnaires need to be completed by family members/carers that know the person well. These can be separated into screening assessments; diagnostic assessments; and assessments of adaptive behaviour.

SCREENING ASSESSMENTS

Dementia Questionnaire for People with Learning Disabilities – DLD – formerly known as the DMR (Evenhuis et al., 2007). The DMR and its successor, the DLD, is widely used to longitudinally assess the development of dementia in adults with intellectual disabilities in the UK and Europe and is recommended by NICE (NG54, 2016). It is a screening tool for the early detection of dementia in adults with intellectual disabilities consisting of 50 items. There are eight sub-scales: short term memory, long term memory, orientation (making up Sum of Cognitive Scores), speech, practical skills, mood, activity and interest and behavioural disturbance (making up Sum of Social Scores). A prospective 14-year longitudinal study (McCarron et al., 2014) stated the DMR/DLD to be the most sensitive tool in their battery for tracking change in symptoms over time. Williams (2016) reported that the DMR had sensitivity of up to 100 per cent in identifying dementia and suggested change scores and cut-off scores that might be indicative of dementia. The latest version of the DLD no longer includes single completion cut off scores due to poor reliability and validity associated with these and instead relies on change scores over time.

Dementia Screening Questionnaire for Individuals with Intellectual Disabilities – DSQIID (Deb et al., 2007). The DSQUIID is designed to be 'a user-friendly observer-rated dementia screening questionnaire with strong psychometric properties for adults with intellectual disabilities', according to the authors. It covers areas such as loss of memory, loss of skills, social withdrawal, behaviour change, psychological symptoms, physical symptoms, sleep disturbance and speech changes. It comprises 43 questions in three sections. The scoring system overcomes the floor effect found in some other assessments. The measure includes cut off scores for a single completion indicative of dementia but can also be used to monitor change over time. The DSQIID is an appropriate and feasible screening instrument, which is easy to administer, and is well evaluated in relation to measurements properties (Zeilinger et al., 2022).

The Dementia Scale for Down Syndrome – DSDS (Gedye, 1995). This is designed for use with people who have Down's syndrome but may also be useful for people with intellectual disabilities generally according to NICE (2016). It gives a measure of early, middle and late stages of dementia and includes the time course of the deterioration and a differential diagnosis scale. The psychometric property of the DSDS has never been published in a peer-reviewed journal. Its administration is restricted to clinical and other qualified psychologists and trained psychometricians.

It is important to note that screening assessments need to be used alongside gathering other information and should not be used alone to screen in/ out a potential dementia.

DIAGNOSTIC ASSESSMENT

CAMDEX DS-II (Beresford-Webb & Zaman, 2021) is an informant questionnaire that can be used as a diagnostic assessment as it is based on taking a history of symptoms and identifying change over the past six months or more. It also aims to exclude other causes of cognitive and functional

decline, such as mood disorders. Guidance is provided to align the outcome of the assessment with diagnostic categories in the ICD-11 and DSM-5. The CAMDEX DS-II is a valuable assessment of information relating to cognitive decline and dementia provided in semi-structured interview with caregivers, especially for people who cannot engage with a cognitive assessment. This helps to generate a likely diagnosis.

7.5 MEASURES OF PSYCHOLOGICAL ISSUES

Seeking general information about the person's mood from the person and their family/carers is essential in terms of diagnostic overshadowing (and potentially dual diagnosis). There are various measures of mental health adapted for people with an intellectual disability that have been found to be reliable and valid in this area (e.g. The Clinical Outcome in Routine Evaluation-Learning Disabilities (CORE-LD), The Moss Psychiatric Assessment Schedules, 2019).

7.6 ASSESSMENTS OF ADAPTIVE FUNCTIONING

7.6.1 ASSESSMENTS OF DAILY LIVING SKILLS THROUGH DIRECT OBSERVATION OF THE PERSON

If repeated at intervals, these can shed additional light on changes in skills. This might be more important where the person has a more significant intellectual disability and they have more difficulty with the individual cognitive assessment.

Adaptive Behaviour Dementia Questionnaire – ABDQ (Prasher et al., 2004). This is a 15-item questionnaire derived from the AAMD Adaptive Behavior Scale (Nihira et al., 1993) which is used to detect change in adaptive behaviour. It has been developed to screen specifically for dementia in Alzheimer's disease in people who have Down's syndrome but can also be considered a measure of adaptive functioning (please see section 7.6). It sets out to collect information on how the person compares now to their previous normal level of social functioning. It gives criteria for the presence of Alzheimer's disease and a rating of severity, but the threshold scores may require revision as these do not appear to be accurate in clinical practice.

The Assessment of Motor Process Skills (AMPS, Fisher, 2006) is one example of this type of observation, utilised in some services, although its delivery is limited to occupational therapists who have received specialist training. It is a standardised tool which can be used for different groups of people in different settings and can be useful as an observational measure of performance of daily activities with people with intellectual disabilities, which allows for time specific and longitudinal comparisons. However, there is a paucity of research, it may be hard to generalise the findings and support for the AMPS has now been withdrawn from the company, meaning that practicing OTs will no longer be able to renew their AMPS license. OTs and others will need to look at alternative assessments to the AMPS going forward given its usefulness in practice as an observational tool of functional skills. The Pool Activity Level (PAL) instrument (Pool, 2012) may be a useful contender.

7.6.2 ASSESSMENTS OF DAILY LIVING SKILLS COMPLETED WITH A CARER

If repeated at intervals, these can shed additional light on changes in skills. There are many to choose from including:

- **Adaptive Behavior Scale – Residential and Community (ABS – RC2) (1993)** is a standardised measure of daily living skills and maladaptive behaviour. It can be useful for assessing those with profound intellectual disabilities, who cannot undertake direct assessments, but may

be cumbersome to complete. A 24 item short form entitled The Adaptive Behavior Scale – Residential and Community (part 1) short form (SABS) has also been developed that may be useful which was adapted by Hatton et al. (2001).

- **Hampshire Social Services – Staff Support Levels Assessment** (Hampshire Social Services, 1987) – a 32 item assessment which has behavioural anchors and therefore reports excellent test – retest validity and inter-rater reliability.
- **Vineland Adaptive Behaviour Scales: Third Edition** (Cicchetti et al., 2016) provides analysis of a broad range of skills and behaviour. These include communication, daily living skills, socialisation, motor skills and maladaptive behaviour. Vineland Adaptive Behaviour Scales: The Second Edition is available in both long and short form, providing either a summary assessment of adaptive behaviours or a more detailed assessment. Semi-structured interview and questionnaire formats make it easier to assess those who have difficulty performing in test situations. It covers 0–90 years. It is an American tool and hence some of the items will be unfamiliar to UK users, and like the ABS and ABAS-II may be cumbersome to compete.
- **Adaptive Behaviour Assessment System-III** – ABAS-III (Harrison & Oakland, 2015) provides a comprehensive norm-referenced assessment of the adaptive skills of individuals aged from birth to 89 years. The clinician can use the ABAS-III to diagnose and classify disabilities and disorders; identify an individual's strengths and limitations; and to document and monitor the individual's performance over time. It provides standard scores that are directly comparable to those found in the Wechsler IQ tests. It too is an American publication.

When looking at changes in adaptive functioning, it is important to assess not only the ability of the person to complete each task, but whether there is a qualitative change in performance of each task and in fact whether there is an opportunity to use the skill at all.

7.7 WHO CONDUCTS ASSESSMENTS AND HOW ARE THEY ORGANISED?

A dementia care pathway is helpful to guide the multidisciplinary team through the sequence of events from referral, through screening and diagnosis, to treatment/intervention and end of life care. It helps to ensure a co-ordinated approach and effective multidisciplinary working. Typically, a community nurse may conduct the health screen as the first stage of assessment, in partnership with the GP. The intellectual disabilities psychiatrist will undertake assessments of/exclusion of mental health conditions and order and conduct necessary additional tests or investigations, and to liaise with other members of the multidisciplinary team to confirm together a diagnosis of dementia.

The assessments of memory, mood and behaviour are often conducted by clinical or other qualified psychologists but in some cases, may be undertaken by other multidisciplinary team members. The need to refer for specialised psychological assessment for people with intellectual disabilities was identified in Department of Health guidelines for GPs in 2014 (Barrett & Burns, 2014). There is a need to ensure that non-psychologists undertaking such assessments are suitably trained in undertaking psychometric assessments and are well supervised in the formulation and interpretation of the data. This is commonly provided by clinical or other qualified psychologists.

AMPS assessments, if used, require special training (usually occupational therapists). The role of the intellectual disabilities' psychiatrist or clinical or other qualified psychologist is crucial to making the differential diagnosis once all the assessment data have been collected.

Some services have a dedicated or virtual team using an agreed battery of assessments (e.g. Jervis & Prinsloo, 2007; Cairns et al., 2010; Starkey et al., 2014). This may be known as a memory clinic or dementia assessment/screening programme. The team should as the minimum include a psychiatrist in intellectual disabilities, clinical or other qualified psychologist and community nurse. Occupational therapy and Speech and language therapy input may also be helpful additions.

7.7.1 WHERE TO SEE PEOPLE/OBSERVATIONS

Careful attention needs to be paid to where, when and how to assess individuals. A holistic assessment should include meeting the person being assessed and their carers in their normal living and daytime environments. Cognitive assessments may be more effectively offered in a healthcare or similar setting if this can provide consistency for repeat assessment and provide standardised testing conditions that are free of distractions and give an appropriate context. However, this would need to be balanced with potential anxiety and a better picture of functioning which can be achieved at the person's home or other place preferred by them.

7.7.2 EXPLAINING ASSESSMENTS TO PEOPLE WITH INTELLECTUAL DISABILITIES

It is important that the assessment process is discussed with the person with intellectual disabilities, and that their consent to participate is obtained. People will need to have different communication methods used that are tailored to the individual, including clear verbal communication and the use of picture booklets to explain the assessment process. Explanations should be related to people's prior understanding of the issues and couched in a way as not to cause the person anxiety, with an emphasis on helping people to understand the process and the support available. Assessment of the person's capacity may need to be undertaken, and where the person does not have capacity, the decision about the assessment needs to be made using a best interest process.

7.7.3 CONDITIONS FOR REASSESSMENT

Repeat cognitive assessments need to be rigorously administered and interpreted to take account of normal fluctuations in the assessed person's performance (e.g. tiredness, mood, good day/bad day), specific changes (e.g. hearing aids, glasses, medication effects), testing environment changes (place, layout, distractions) and tester effects (skills, experience, relationship with the person with intellectual disabilities, testing style, administration and scoring anomalies). Ideally the same tester should use the same tests in the same environment using strict criteria for similar administration/prompts, and where possible seeking information from the same informant on each occasion, although this may not be possible in practice. The standard error of measurement and normal ageing deterioration must also be considered when considering results showing some evidence of cognitive deterioration.

KEY POINTS

Multidisciplinary assessment is important, with psychiatrists leading on mental health assessments and psychologists on cognitive, adaptive functioning and social and physical environmental assessments.

Assessments should include direct assessment of the person together with preferably, multiple-informant based questionnaire/assessments.

Staff undertaking psychometric assessment as a part of the assessment process need to be suitably trained in psychometrics and receive appropriate supervision.

Assessment for other co-morbid conditions is essential.

Consideration should be given to practical issues in assessment (e.g. location).

Consider test re-test issues (e.g. different informants/testers).

Consider whether there is a family history of dementia, which may raise the possibility of a genetic aetiology of the dementia (for individuals without Down's syndrome). The Royal College of Psychiatrists Report 237 on genetic testing in mental health settings and SIGN guideline 168 provide guidance on when genetic testing should be considered in individuals who present with dementia.

Section 8 – Establishing the diagnosis and breaking the news

8.1 BACKGROUND TO AN EFFECTIVE AND PERSON-CENTRED APPROACH

The increased risk of developing dementia at an earlier age is well-established for people with intellectual disabilities, and particularly for people who have Down's syndrome (see Section 2 – Epidemiology). This knowledge raises the ethical dilemma of how this information should be sensitively communicated to the individual and to families and carers. It can be helpful to begin conversations during the transition process, building from people's current understanding of the aetiology of their intellectual disabilities. Ongoing conversations can explore people's awareness of health risks that may develop over their lifetime, together with specific risks associated with different syndromes.

The awareness of difference is personally challenging and it is likely that this process will be painful and it will be necessary to give ongoing support.

There is much work to be done in this area as currently many individuals with intellectual disability have not been informed about the nature of their intellectual disability and any associated health risks. The individual and their network of support need to be given the opportunity to understand how age-related risks can be monitored and identified at the earliest possible stage by regular health screening and the promotion of healthy ageing (see Section 3 – Baseline assessment, prevention of dementia and brain health). They also need to be informed of what assessment and interventions, including adaptations, accommodation, support and care, are available if difficulties associated with dementia do develop (see Section 12 – Environments and Section 13 – Meeting changing needs/interventions).

8.2 ESTABLISHING THE DIAGNOSIS OF DEMENTIA

The first step in establishing the diagnosis is to bring the assessment information from different sources together (see Section 7 – Assessment). It is important for the multidisciplinary group to combine the assessments of the psychiatrist, psychologist, occupational therapist, community nurse, speech and language therapist and other relevant professionals with the results of the investigations and physical examination that the GP or psychiatry team may have carried out. The clinical or other qualified psychologist and psychiatrist will be the key disciplines involved in reviewing the outcome of multidisciplinary assessment and then arriving at a diagnosis, with support from the multidisciplinary team.

8.2.1 DIAGNOSTIC PROCESS

For a significant proportion of individuals, it may not be possible to reach a clear diagnosis at an early stage. It may only be possible to have a range of differential diagnoses with a true picture emerging over a period of time (see Section 5 – Possible reasons for decline). The diagnostic evaluation may need to be repeated regularly, e.g. at six to twelve monthly intervals. It is worthwhile remembering that for some individuals at this stage the diagnosis of dementia may be clearly ruled out and the presenting problems formulated in a different way and appropriate interventions offered.

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Assessment information may need to be referred to regularly or may not need to be referred to again for several years, therefore it is important to ensure copies are securely held where they may be found in future. Some services copy their assessment reports to the GP, the residential home or family carer as well as to the person's NHS file held within the local service for people with intellectual disabilities. Accessible reports should be considered for the person with intellectual disabilities.

8.3 SHARING THE INFORMATION WITH THE PERSON WITH INTELLECTUAL DISABILITIES

Consistent with national guidance concerning sharing information about diagnosis of serious illness with the patient, all UK dementia strategies state that everyone should be told their diagnosis and this has been conceptualised as a human right.

A person-centred approach that does not further isolate, depersonalise and marginalise the person means steps should be taken to share the information with the person with intellectual disabilities as early as possible, and at all stages, so that they can be actively supported to understand and cope with their changing experiences (Watchman, 2012; Tuffrey-Wijne & Watchman, 2014, Harwood, 2024).

This will also help them be involved as much as possible in decisions about their support and care and medical treatments, including establishing their views and preferences about future care before their illness progresses (Harwood, 2024).

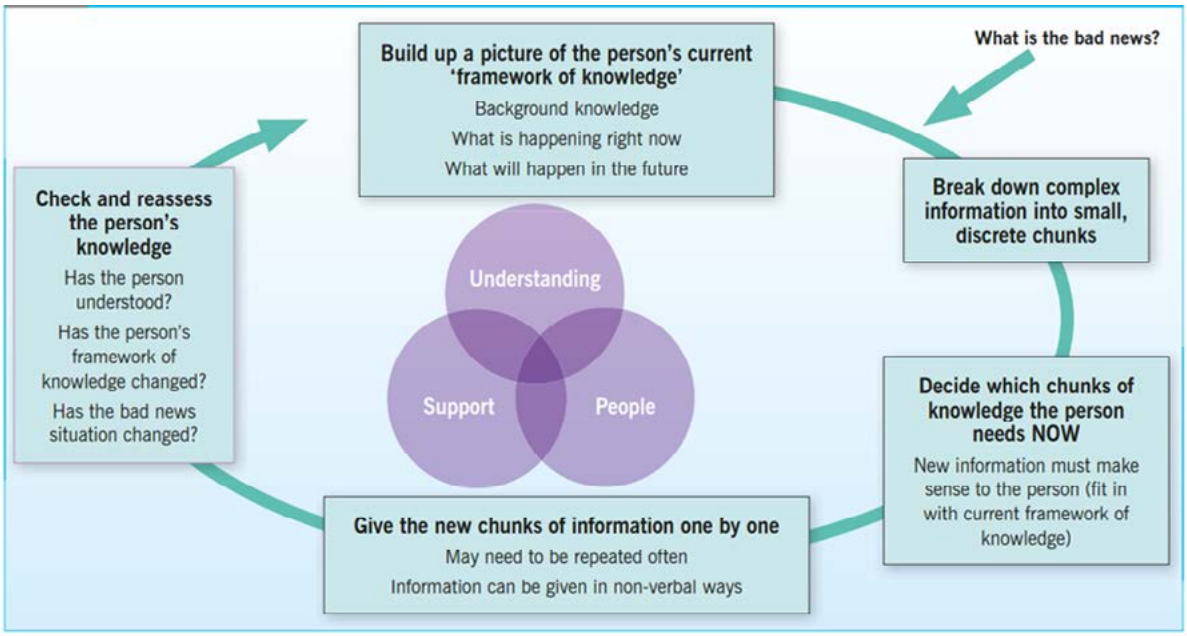
Where health professionals from services other than specialist teams for people with intellectual disabilities are in direct communication with the person concerning their diagnosis and illness, they may need support and guidance concerning the communication needs of the person with intellectual disabilities, as generic breaking-bad-news models are not likely to meet their needs. However, they can act as an aide to help guide individuals in delivering the news in a dignified way. Further information can be found in the BPS document, *Communicating a Diagnosis of Dementia* (Watts et al., 2018).

The process of sharing the diagnosis needs to be sensitive to the expressed wishes of the individual concerning knowledge of their physical health and illness and, as for the general population, it is likely to be painful for the person to hear this information and accept their diagnosis. However, it must be undertaken as good practice irrespective of the mental capacity of the person concerned so that the person is sensitively given opportunities to know about the health changes they are experiencing and a psychological approach, with additional direct psychological interventions when necessary, should be used to give them emotional support and lessen anxiety and distress.

A wide range of personal factors, including culture, personal history and current relationships, also need to be taken into account when deciding how to share the diagnosis and to facilitate an understanding of the illness and experiences.

There has been work on adapting breaking-bad-news models for people with intellectual disabilities (Tuffrey-Wijne & Watchman, 2015); The circular model advocates breaking down the information to be shared into small chunks, deciding which chunks of knowledge the person needs now, providing the small chunks of information one by one, checking the person's understanding, and building up a picture of the person's current 'framework of knowledge'. The model is presented below. Further information can be found in Tuffrey-Wijne's book: *How to Break Bad News to People with Intellectual Disabilities: A Guide for Carers and Professionals* (2012).

FIGURE 2: BREAKING BAD NEWS TO PEOPLE WITH LEARNING DISABILITIES: AN OVERVIEW (TUFFREY-WIJNE & WATCHMAN, 2018)



All those who know the individual can contribute to a current understanding of the person's information needs and preferences and how material can be presented to maximise understanding and retention. This process may involve additional input from a speech and language therapist to make the information as accessible as possible, including when the person no longer communicates verbally. As the illness progresses the person's framework of knowledge will change and is likely to be related to an earlier period of their life.

Practice guidelines, developed within the multidisciplinary team, concerning how to approach communicating with the person about their dementia and with suggestions about how to personalise this, can be helpful.

In order for the person to have adequate support it will generally be appropriate to share the diagnosis with family, friends, carers and support workers around the time of telling the person themselves.

This is an ongoing process and all involved with the person, whether multidisciplinary professionals, carers in different contexts, and family members, need to feel confident to give accurate and accessible information to the person and to be supported to give this information repeatedly and helpfully in the context of changing information needs. The psychologist and other members of the multidisciplinary team are an important resource that needs to be available to support those in day to day contact with the person about their continuing communications concerning the diagnosis and the person's changing experiences, whilst still maintaining a positive approach to support. The use of a 'communication passport' that incorporates the communication needs linked to the progression of dementia can be very helpful.

Booklets such as *The Journey of Life* and *About Dementia* (Dodd et al., 2005 a & c), *What is Dementia?* (Kerr & Innes, 2000), *Jenny's Diary* (Watchman et al., 2015) and the Alzheimer's Society easy read dementia information leaflets (www.alzheimers.org.uk) are useful resources for helping the person with intellectual disabilities understand their condition and experience, although it is clear they should always be introduced with sensitivity and care.

8.4 SHARING THE INFORMATION WITH FAMILY AND CARERS

This is also a complex process as it will involve giving information on the diagnosis, including likely course and prognosis, and many family members and carers and support workers will understandably find it painful and difficult to be given this information.

In some cases families and carers will have had no prior knowledge of the increased risk of people with intellectual disabilities developing dementia and they will require both emotional support, psychoeducation and, where relevant, training. Families can find it devastating to learn that their loved one is developing an impairment additional to their intellectual disability. However, it is very important to help family and carers understand how dementia is affecting the person with pre-existing intellectual disabilities and to maintain an awareness of both diagnoses so that they can understand and cope with the changing situation.

Families may need a lot of support to accept that the person with intellectual disabilities needs to be told their diagnosis and that not knowing is likely to be linked to increased confusion and distress. Once again a helpful approach needs to be informed by an awareness of how family and carer factors, such as culture, religion and personal history, might influence their attitude and understanding of the needs of the person with intellectual disabilities and dementia. On occasion family members may need focused psychological interventions concerning their acceptance of the diagnosis.

A partnership approach needs to be adopted with the person, their family and friends, and their carers. A palliative approach also needs to be adopted from the point of diagnosis and effort should always be made to keep families and carers informed and involved at all stages (see Section 16 – Palliative care and end of life). Family and carers are understandably anxious about future care and they need help in planning and thinking ahead including concerning specific supports and accommodation. Their understanding of the support and management plans and the rationale behind them can be increased by their involvement in structured meetings such as those using the Quality Outcome Measure for Individuals with Dementia (see Section 19 – Outcomes).

Families and carers will need support and information to prepare for end of life care at the later stage of illness and they need to be sensitively informed about this early on to minimise their sense of isolation and anxiety about the future.

There are information booklets to assist carers to understand dementia, for example, *Keep Talking about Dementia* (Watchman, 2006) and *Down's Syndrome and Alzheimer's Disease: A guide for Parents and Carers* (Holland, 2013). Useful information can also be found on the Alzheimer's Society website.

8.5 SHARING THE INFORMATION WITH FRIENDS AND PEERS

Those involved with the person with intellectual disabilities who is affected by dementia also need to inform the friends and peers of the person, who may themselves have intellectual disabilities, about the diagnosis and help them understand what this means. They also need to consider the impact a dementia diagnosis may have on friends and peers (Harwood, 2024). Friends and peers benefit greatly, both personally and in their capacity to support the person with dementia, from the guided use of specific resources and psychological work or group work aimed at helping them understand what is happening to the person. However, the person's privacy and confidentiality should be considered when sharing a diagnosis, and where possible, consent to share information should be obtained. When the person lacks capacity and the decision to share

information about the diagnosis is made in their best interest, documentation and process should be in line with the Code of Practice for the Mental Capacity Act (2005)/Adults with Incapacity Act (Scotland), (2000).

There are resources to help friends and peers with intellectual disabilities, e.g. *About My Friend* (Dodd et al., 2005b), *Jenny's Diary* (Watchman et al., 2015), *Ann has Dementia* (Hollins et al., 2012) and Easy Read Factsheets (BILD, 2014).

8.6 MULTIDISCIPLINARY DISCUSSION AND CARE COORDINATION

In the first post-diagnostic multidisciplinary meeting, which wherever possible should include social work practitioners, it is important to agree on the process of care planning at this early stage and identify an appropriate professional to be the care coordinator. This should form part of the Care Pathway and lead into the development of a new Health Action Plan (HAP), or a Health Profile (HP) for those living in Wales, and a reviewed person-centred support plan (see Section 11 – Philosophy of Care). The HAP / HP and support plan will need to be reviewed regularly in the context of the person's changing condition and anticipated needs.

The Quality Outcome Measure for Individuals with Dementia (Appendix 3) is a useful tool to use in this process and can involve family, paid carers and professionals in partnership. Individuals in Scotland are entitled to a Post Diagnostic Link worker for one year after dementia diagnosis from mainstream Post Diagnosis services or from a professional within the local Learning Disability Team. The model of post-diagnostic support is based on Alzheimer's Scotland 8 Pillars and Advanced Care model.

8.7 MANAGEMENT

Irrespective of the degree of certainty attached to the diagnosis, interventions focused on the needs of the individual and management of any risks should be thoroughly discussed in the first care planning meeting. All interventions and management plans need to have the person as the centre of focus and this will therefore require a holistic approach that takes into account the person's expressed views and a wide range of personal factors, including profile of abilities and communication needs, cultural background, life experiences, significant relationships with family, carers and peers, and preferred activities, as well as working to minimise known risks.

Decisions about specific interventions and treatments that are likely to be effective in supporting the person to live well, maintain independence and minimise disabilities, need to be discussed and reviewed in regular multidisciplinary meetings. The frequency of such meetings will vary depending on the current needs of the person, and are likely to range from monthly to six monthly.

Please refer to other relevant sections of guidance for details of evidenced-based interventions and treatment currently available.

As the person's physical care needs intensify and they approach the later stage of dementia, the team of professionals around the person needs to consider NHS Continuing Care Funding. In addition there will be an increasing need for palliative care and end of life planning (see Section 16 – Palliative care and end of life).

KEY POINTS

People with intellectual disabilities, their families and carers need to be given opportunities to understand the nature of the intellectual disability and information about any associated health risks from an early point in their life and particularly from transition to adulthood onwards.

People with intellectual disabilities need to be told about their diagnosis of dementia and given ongoing opportunities to understand their diagnosis and their experience of dementia.

Family members and carers need to be informed about the diagnosis and involved as much as possible in support and management plans and, as appropriate, be given opportunities for education and training.

The person's peers and friends are also important people to involve in giving information about the diagnosis and this will both help them cope and help them support the person affected by dementia.

People with intellectual disabilities and their families and carers may need psychological interventions to enable them to feel emotionally supported and to begin to understand the diagnosis.

Section 9 – Additional health co-morbidities associated with dementia

As we get older we become more susceptible to additional health challenges, and this is no different for people diagnosed with dementia. However, there are some health conditions that are specifically associated with advancing dementia and these should be taken into consideration.

9.1 EPILEPSY

9.1.1 PREVALENCE

Over 80 per cent of people who have Down's syndrome and dementia develop seizures (Menendez, 2005; Gholipour et al., 2017; Altuna et al., 2021). There are two peaks for the development of epilepsy in people who have Down's syndrome, one in adolescence and one in later life. Older people who have Down's syndrome (over 45 years) are more likely to have seizures than younger people, and the development of epilepsy in later life should raise the possibility of Alzheimer's disease. Late-onset myoclonic epilepsy in Down's syndrome (LOMEDS) is the term used to describe this form of seizures (Corniello et al., 2023). A younger age of onset of dementia is associated with a higher risk of developing seizures (Menendez, 2005; Altuna et al., 2021).

9.1.2 THE NATURE OF SEIZURES

The most common seizures in people who have Down's syndrome and dementia are myoclonic (LOMEDS) and tonic-clonic types although the whole range of generalised and partial seizures may be seen.

- In the general population, people with Alzheimer's disease generally develop seizures at a late stage of dementia but in people who have Down's syndrome seizures can be a presenting symptom and are likely to be a sign of a poorer prognosis including mortality (Sinai et al., 2018; Hithersay et al., 2019; Altuna et al., 2021). Seizures are generally thought to occur earlier in the course of the illness in people with intellectual disabilities than is found in the general population.
- A proportion of people who have Down's syndrome who develop dementia will have a previous history of epilepsy, and there may be a change in seizure frequency, pattern or severity with the onset of dementia.
- Myoclonic seizures tend to occur more frequently and may initially present as mild jerks, although the intensity and frequency can vary considerably. As the dementia progresses, they can become both more severe and more frequent. Tonic clonic seizures are more obvious and similar precautions, as in people without dementia, should be taken.

9.1.3 INVESTIGATIONS AND DIAGNOSIS

The diagnosis of epilepsy is clinical, and is usually made following two witnessed, unprovoked seizures. Where people with a progressive condition such as dementia, which is associated with the development of epilepsy, have a seizure, many clinicians will initiate treatment after the first seizure rather than waiting to confirm a second seizure (particularly where the person has had seizures before or where the person has had a tonic clonic seizure).

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Investigation guidance for the diagnosis of epilepsy suggests a range of investigations including EEG, CT/MRI scans, ECG and blood tests. Whilst a full physical examination and blood tests should always be considered, neuroradiological investigations and EEGs should be undertaken if there is a suspicion of a space occupying lesion or some other potentially treatable cause of dementia.

9.1.4 RISKS

Seizures are associated with additional physical health problems ranging in severity from physical injury to death. The risks increase with poorly controlled seizures and polypharmacy. Increased seizure activity may potentially accelerate the progression of the dementia. It is important to establish a monitoring system so that staff and carers can take responsive action when needed. Staff and carers should be encouraged to maintain regular seizure charts to record the nature, frequency, intensity and duration of seizures, and to complete appropriate risk assessment. Issues relating to both the seizures and associated treatments should be addressed, including eating and drinking guidelines, management of falls and personal care.

9.1.5 MANAGEMENT

Drug management – seizures in people with dementia generally respond to a single anti-epileptic drug. Drugs with a broad spectrum of action are normally used as the first line treatment. It is important to note, when choosing a drug, the potential for further impairment of cognitive function because of the sedative effect of the anti-epileptic drug. For this reason, newer, less sedating drugs are usually chosen. Where the presenting seizures are myoclonic, Levetiracetam, Brivaracetam or Sodium Valproate are first line choices but Perampanel can also be considered; remember that myoclonic seizures can be worsened by administering Carbamazepine, Gabapentin, Pregabalin and perhaps Lamotrigine. Valproate is teratogenic and is contraindicated in females with reproductive capacity (which in Down's syndrome is greatly impaired) as it is also not recommended in males around the time of conception as it can increase the likelihood of developmental disorders in newborns. Where the presenting seizures are tonic-clonic in nature, Lamotrigine, Levetiracetam and Sodium Valproate (with precautions) are first line choices. The following good practice principles should be borne in mind:

- Promote the use of a single medication whenever possible.
- When starting a medication side effect issues can be avoided and are better managed if the dose is lower than recommended for the general population and the titration is slower than recommended. A final therapeutic dose may be reached which is what would be expected for the general population.
- The treatment goal should be a healthy balance between quality of life and seizure control.
- Unacceptable side effects should not be present and the prescriber should take immediate action if side effects are reported. Careful monitoring of the side effects by staff and carers is the key and it is important for clinicians to explain what to look for in relation to side effects.
- The care plan should cover how to minimise seizure related risks especially in relation to falls and injuries.
- Avoid Phenytoin as this causes significant cognitive slowing and can debilitate an individual with limited cognitive reserve.

Use of rescue medication – Midazolam (buccally administered) is currently the treatment of choice for prolonged or clusters of seizures. This can be administered via buccal or intranasal routes. The standard doses of both are 10mg for adults weighing more than 50kg. Training for staff and carers

in the use of rescue medication is essential. The use of rescue medication should be documented in the person's care plan.

Side effects – The main side effects of Sodium Valproate are weight gain, gastrointestinal problems, and a negative impact on cognitive function, but as mentioned above it is not advised in females who are able to get pregnant due to its teratogenicity or in males during conception (however, in older people and in people with Down's syndrome this issue may be less relevant). The main side effects of Levetiracetam are cognitive slowing, (particularly if the dose is escalated rapidly), and gastrointestinal issues. Some clinicians report behavioural change, this is almost certainly related to side effects and rapid dose escalation for which an alternative is Brivaracetam. With Lamotrigine, the concerns are typically related to skin rash and gastro-intestinal side effects. With diminishing cognitive reserve, drugs that affect cognitive function have a much more dramatic effect meaning that, for example, sedation can be a significant problem.

DO'S AND DON'T'S

- Do not use rescue medication unless there is a clear indication and this is documented in the care plan.
- Do train carers how to recognise seizures, keep people safe, administer medication appropriately and provide appropriate information.
- Remember that quality of life has a higher priority than total seizure freedom.
- Remember that the presence of active epilepsy should not limit community participation.
- Do monitor seizures and the side effects of anti-epileptic drugs.
- Remember that both seizures and drug side effects can affect the person's ability to eat, drink and function effectively.

KEY POINTS

The occurrence of seizures for the first time is very common in people who have Down's syndrome who have developed dementia.

The use of a single anti-epileptic medication should be encouraged.

Careful monitoring is required of seizure patterns and side effects of medication.

9.2 PAIN

Poor recognition and treatment of pain in people with intellectual disabilities and dementia is common. Many issues contribute to the low level of pain recognition. These include:

- Staff attitudes towards, and experience of, 'behaviour that challenges';
- Diagnostic overshadowing;
- Problems with communication;
- Beliefs about pain thresholds;
- The impact of past treatment on willingness of the person to complain of pain;
- The use of temporary agency/bank staff who are less likely to observe a change in a person's level of distress.

Sometimes staff are not sufficiently aware that people with intellectual disabilities who are getting older will experience painful conditions, such as arthritis, that can be associated with older age. Difficulties are sometimes ascribed to the dementia process rather than there being a consideration of whether people are in pain.

Research and practice both indicate that there is inadequate training for dementia and people with intellectual disabilities of staff, at all levels and from all professional backgrounds. In addition, little attention is paid to the recognition and management of pain in this group of individuals.

There is also little use of pain assessment and recognition tools. There is a range of effective pain/distress tools available for staff and carers to use to identify pain or distress in people with intellectual disabilities and dementia. Tools to consider include the Abbey Pain Scale (Abbey et al., 2004) and the Disability Distress Assessment Tool (DisDAT) (Regnard et al., 2007).

KEY POINTS

Pain recognition and management for people with intellectual disabilities and dementia is often very poor.

Diagnostic overshadowing is a frequent occurrence, and staff are often unaware of the range of painful health conditions that may present with increasing age.

There are tools available to help staff and carers identify pain in people with intellectual disabilities.

9.3 SLEEP DISORDERS

People with intellectual disabilities including those who are autistic have a high prevalence of sleep difficulties which worsen with age and with associated conditions such as dementia. In Down's syndrome the prevalence ranges from 13 to 86 per cent (Gimenez et al., 2022) and is a major factor in treatable cognitive decline (Desai et al., 2024). The sleep disturbances in dementia typically include a reversal of the sleep-wake cycle (sleeping during the day time and awake at night time) and a reduction in the slow wave sleep; which may be due to the loss of cholinergic nerve cells.

Clinicians should aim to exclude the following treatable conditions or situations in people with sleep difficulties before considering biological effects due to dementia:

- Co-morbid psychological problems including depression, anxiety, fear and nightmares;
- Alcohol/substance misuse;
- Physical health problems, e.g. pain, epilepsy, sleep apnoea, heart-failure, respiratory disorders, nocturnal enuresis;
- Side-effects of medication, e.g. stimulant drugs;
- Lack of activity and exposure to sunlight;
- Poor sleep hygiene – uncomfortable bed, noisy household, poor light and temperature adjustment, late evening coffee, caffeinated drinks, and recent change in the environment.

People with intellectual disabilities and dementia should have a routine assessment of sleep hygiene. Associated factors can be easily overlooked, especially in people with intellectual disabilities who may have poor communication skills. The assessment and the sleep history from the carer should include the following:

- The person's sleep pattern;
- Information on sleep hygiene, bedroom and bedtime routine;
- Onset, duration and nature of the problem (e.g. difficulty in going to sleep, frequent awakening, early morning insomnia, motor activities, snoring during sleep and evidence of daytime sleepiness);
- Effect of insomnia on the person and others including family and/or carers;
- Past sleep difficulties and previous treatments;
- Psychiatric and medical diagnoses (including epilepsy);
- Current medications;
- Family history of sleep problems;
- Risks associated with sleep difficulties, e.g. wandering behaviours or falls.

Accurate information is required to make an informed decision about the nature of an individual's sleep pattern. This can be difficult if there are no informant reports available. An assessment by a sleep clinic should be undertaken. The use of assistive technology or waking night staff has helped greatly in trying to provide some of the answers, but is not a panacea. Some effort may be required to get adequate sleep data; however, accurate information is required to inform the appropriate management strategies. Obtaining two weeks of sleep diaries, potentially adapted diaries so these are accessible for the person with an intellectual disability can be helpful.

The approach to managing sleep disorders is, first and foremost, to ensure the problem is appropriately understood and that there are adequate checks and balances in place to ensure that interventions can be monitored, in order to understand the outcome of each intervention. The least restrictive options should be used first.

- Treat any associated physical and/or psychological problems.
- Use non-pharmacological strategies (sleep hygiene).
- Encourage daily activities and if possible exercise.
- Avoid day time napping.
- Reduce caffeine and alcohol intake before bed time.
- Eliminate factors that impede sleep (watching TV into the early hours).
- Use the bed just for sleeping.
- Set and maintain a regular routine of rising and retiring at the same time everyday.
- Ensure sleeping environment is conducive to sleep.
- Review medication to ensure that existing medications are not contributing to the sleep issues.

If the above approaches do not produce any significant benefits and the risks continue, a pharmacological approach may be considered along with non-pharmacological approaches. When using medication for sleep in dementia, some patients will be more likely to have serious side effects including delirium and falls. Short-term use is recommended.

The pharmacological approaches include the use of:

- Melatonin – available under various names, such as the slow release versions of melatonin such as Circadin licensed for use in patients over the age of 55 (there is an age-related decrease in endogenous melatonin secretion which contributes towards age related insomnia).
- Z-drugs (Zopiclone, Zolpidem and Zaleplon).
- Benzodiazepines (Temazepam, Loprazolam or Lormetazepam).

The choice of medication should depend on the individual's needs and should be based on NICE Guidance CG 76 (Clinical Update, 2019b):

- Melatonin can be used for long-term insomnia in those over 55 (with or without dementia). Monitor results, if improvement after three weeks, treatment can be extended to 10 weeks in the first instance.
- Use short acting benzodiazepines (Temazepam, Loprazolam or Lormetazepam), but be careful about the long-term effects of such drugs.
- Consider use of z-drugs (Zopiclone, Zolpidem and Zaleplon) as an alternative.
- There are no differences in the efficacy of z-drugs and if one of them is not effective the others should not be used.
- Switch from one z-drug to another only if there is an adverse effect directly related to that particular drug.
- Use the minimum effective dose.
- Use medication on an 'as and when necessary' basis (every second or third night if required) rather than on a regular basis.
- Do not continue hypnotics for longer than four weeks.
- Discuss the discontinuation with the person and carer, and taper/stop it very gradually.
- Warn the person and carer of withdrawal symptoms and rebound insomnia.
- Advise on adverse interactions with alcohol and other sedative agents.
- Do not use in hepatic failure, chronic respiratory diseases and people who have a history of substance misuse.
- Be mindful of the side effects including daytime sedation, falls and sun downing (confusional state in the evening).

KEY POINTS

Sleep difficulties are commonly experienced in people with intellectual disabilities as they get older and/or develop dementia.

Assessment should include ruling out co-morbid mental health problems, substance misuse, physical health problems and poor sleep hygiene.

The management of sleep difficulties in dementia should be based on non-pharmacological approaches including good practice of sleep hygiene.

Medication should only be used if other approaches have failed, or risks are significant.

NICE recommendations should be adhered to if pharmacological approaches are used.

9.4 GASTROINTESTINAL DISORDERS

Gastrointestinal disorders are common in people with intellectual disabilities. Gastro-oesophageal reflux disease (GORD), constipation, dysphagia and nutritional issues are all found in people with advancing dementia and should be monitored. Disorders of the gastrointestinal tract can cause changes in behaviour due to pain or food refusal and so should be included in any analysis. People who have been prescribed anticholinergic medication will be prone to side effects of constipation and urinary retention, while anticholinesterase inhibitors may be associated with nausea and diarrhoea in the short-term.

A swallowing assessment as part of the baseline investigation of dementia would be best practice. This is due to the fact that dysphagia (swallowing difficulties) and apraxia (purposeful movement difficulties) are both associated with feeding difficulties in people with dementia but might not be the presenting feature.

Swallowing difficulty (with resulting aspiration) is a major risk for the development of aspiration pneumonia. Often, secretions are aspirated during sleep; however, a normal cough reflex and normal immune mechanisms protect the airways from repeated infections. As dementia progresses, however, this simple aspiration will extend to aspiration of food and drinks during eating making the chance of developing pneumonia much more likely.

Choking during eating usually starts with liquids because the swallowing of liquids requires the best coordination of the muscles involved. Choking can sometimes be prevented by switching from thin liquids to thick liquids, e.g. from milk to yogurt. This should be part of the assessment completed by a qualified speech and language therapist and or dietitian (see Section 15 – Eating and drinking).

Apraxia or dyspraxia results in inability to use utensils but people with dementia may be still able to feed themselves with finger food. With the progression of dementia, individuals may ultimately be unable to feed themselves or drink without assistance. However, adequate nutrition can be provided by hand feeding using a modified diet that is adapted to the ability of the individual paying attention to their individual chew and to their swallowing difficulties. Hand feeding can often be provided until the time when all physiological processes start to shut down.

At the point where food refusal starts to become an issue and where there are concerns about malnutrition, considerations turn to the use of nasogastric tube feeding or the insertion of percutaneous endoscopic gastrostomy (PEG) tube. The Cochrane review (Sampson et al., 2009) concluded that nasogastric and PEG tube feeding do not prevent or improve pressure ulcers, does not reduce the risk of infections, does not improve functional status or comfort of the patient, does not decrease aspiration pneumonia (and could increase it) and does not prevent the consequences of malnutrition. Tube feeding should therefore be carefully considered and appropriately indicated. The most appropriate use of this treatment is where it is likely to be short term to allow an individual to recover from an acute illness.

KEY POINTS

All people who have been diagnosed with dementia warrant a dysphagia assessment and should have eating and drinking guidelines in place.

Eating and drinking guidelines should include the opportunity for ‘finger foods’ in order to allow the individual to maintain their ability to feed themselves.

Nasogastric and PEG feeding is not associated with significantly improved outcomes and should be carefully considered.

9.5 INFECTIONS

People with dementia commonly succumb to a number of infections including, most commonly, urinary tract infection (UTI), respiratory tract infection, skin infection, gastrointestinal infection and eye infection.

These infections are almost an inevitable consequence of advanced dementia; the reason includes reduced immune responses. People with Down's syndrome are likely to be prone to infection due to immune dysregulation but also to co-occurring conditions with ageing (Ramba et al., 2023). The risk of development of urinary tract infections is increased by incontinence (especially in women) and by urinary retention (in men). Swallowing difficulties with aspiration increase the risk of developing respiratory infections and reduced physical activity increases the risk of urinary and respiratory infections, deep vein thrombosis and infected pressure ulcers.

Communication difficulties in people with intellectual disabilities and dementia further complicate the diagnosis of illness as they are even less likely to report cough, rash, gastrointestinal symptoms, and joint pain than people with intellectual disabilities alone. Functional impairment is also an important factor because dependence in feeding and oral care is a significant factor in the development of aspiration pneumonia.

Ultrasound can be useful in the detection and future management of residual urine. This is usually the remit of the continence teams who are well equipped to manage these situations. The avoidance of internal urinary catheters, where possible, is an important prevention strategy for UTIs because the bladder is colonised with bacteria soon after the insertion of an indwelling catheter. Prophylactic antibiotics can seem like a tempting solution; however, this can lead to the development of antibiotic-resistant bacteria.

Strategies to prevent aspiration pneumonia include oral hygiene, avoidance of smoking and endotracheal intubation, and potentiation of the cough reflex. Bad dental hygiene is a risk factor for the development of pneumonia. Oral care has been shown to decrease the incidence of pneumonia (and death) and the number of febrile days.

KEY POINTS

People with dementia have a high rate of infection and so any change in presentation should include an assessment for an infection.

Infections and the causes of these need to be addressed and, where possible, changes should be made to prevent recurrence.

Where possible, steps should be taken to prevent infections rather than to treat each as they arise.

9.6 MENTAL ILLNESS AND BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS POST-DIAGNOSIS

The approach to addressing mental illness and behavioural and psychological symptoms requires the clinician to initially exclude any medical causes (such as those described above), after which behavioural problems can be evaluated (for further details see Sections 12 and 13). With the progression of the dementia process and declining abilities it becomes harder for the individual to function as before and to cope with the demands of the environment. This can lead to diagnostic overshadowing and inappropriate use of psychotropic medications with their associated complications of for example, delirium, sedation, falls, increased mortality. Once these factors have been excluded as a cause of the change in presentation, then one can look for evidence of mental illness with greater confidence.

Depressive disorder is a risk factor for dementia and it may persist after a diagnosis has been made or it may present for the first time. However, if depression is well managed, then a previous diagnosis does not preclude a diagnosis of dementia – indeed, in people who have Down's syndrome at least, the presence of stable or treated depression and anxiety was not associated with cognitive decline, and subsequent decline is therefore likely indicative of Alzheimer's disease rather than a consequence of mental disorder (Idris et al., 2023). Some people may have been treated for a major mental illness prior to being diagnosed with dementia and the presentation may be the relapse of that mental illness (such as a psychotic disorder or bipolar affective disorder).

There is an increase in the incidence of psychotic disorders, anxiety and depressive disorders post-diagnosis but there is much overlap with behavioural and psychological symptoms of dementia (see Sections 13 and 14). If medication is thought to be necessary, one aims to keep the dose as low as possible to avoid side effects as the propensity for adverse effects is increased in those who have intellectual disabilities and neurodegeneration, and to monitor and review closely.

KEY POINTS

Exclusions (including other health problems and a challenging environment) have to be made before a diagnosis of mental illness can be made with confidence.

Section 10 – Conceptual understanding of the dementia process

Conceptual understanding of the psychological and social consequences of dementia is essential for senior staff to guide timely decision-making about interventions and approaches to individuals/service developments.

The social model (NICE/SCIE, 2006) proposes that whilst people with dementia have an impairment, they may be further disabled by the way they are treated by or excluded from society. The advantages of this framework are that carers and staff will understand:

- that dementia is not the fault of the individual;
- that the focus is on the remaining skills rather than losses;
- that the individual can be fully understood (their history, likes/dislikes, etc.);
- the influence of an enabling or supportive environment;
- the key value of appropriate communication; and
- opportunities for stress-free and failure-free activities.

This means that the responsibility to continue to reach out to people with dementia lies with people who do not have dementia. Carers and staff need to change their approach to 'go with' the person and their continuing changes. Brawley (1997) concluded that '90 per cent of the catastrophic behaviours in dementia are induced by carers or the environment'.

10.1 MODELS OF DEMENTIA

Downs et al. (2006) show how different models, e.g. as a neurological condition; as a neuro-psychiatric condition; as a normal part of ageing; and seeing dementia from a person-centred perspective; can be used to understand dementia.

One approach to understanding dementia and its psychological consequences has been put forward by Buijssen (2005). He proposes two laws of dementia, and asserts that by understanding them, and their consequences, we have a framework to understand and respond to people appropriately.

LAW 1: LAW OF DISTURBED ENCODING

In this law, the person is no longer able to transfer information successfully from their short-term memory and store it in their long-term memory. This means that the person is unlikely to remember things that have just happened to them.

The main consequence of disturbed encoding is that the person is unable to form any new memories for the things they experience or for things they are told. This means that:

- They experience disorientation in an unfamiliar environment.
- They experience disorientation in time.
- The person asks the same questions repeatedly.
- The person quickly loses track of conversations.
- The person is less able to learn anything new.
- The person easily loses things.

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- The person is unable to recall people whom they have recently met.
- Appointments are quickly forgotten.
- The person experiences anxiety and stress.

LAW 2: LAW OF ROLL-BACK MEMORY

Long-term memory contains all the memories that have been acquired starting with the most recent memories, and working back toward childhood memories. When dementia develops, the person will be less able to form any new memories after this time. At first their long-term memories will remain intact, but as dementia progresses, long-term memories will also begin to deteriorate and eventually disappear altogether. Deterioration of memory will begin with the most recent memories and will progress until only memories of early childhood remain, hence memory can be said to be 'rolling back'.

The consequences of roll-back memory are:

- Loss of daily skills such as using kitchen appliances.
- Memory loss for events, beginning with the most recent, e.g. last holiday.
- Decreased social skills and increased inappropriate behaviour.
- Decreased vocabulary and inability to find words.
- Disorientation towards people, e.g. inability to recognise family and relatives.
- The person may begin to have 'flashbacks' and see people from their past.
- Self-care skills will begin to deteriorate.
- Changes in personality.
- The person believes that they are younger and that time has actually 'rolled back'.

10.2 UNDERSTANDING THE PROCESS OF CHANGE

It is important that staff and family carers understand that dementia is a progressive disease, and that the skills, abilities and needs of the person will be constantly changing.

Within the general population, health providers may use the Global Deterioration Scale (Reisberg et al., 1982) to identify the timeline of symptoms. This approach, adapted here to account for a more advanced understanding of the dementia process, identifies 7 stages of disease and 3 levels of dementia:

LEVELS OF DEMENTIA	STAGE EQUIVALENT
Pre-dementia or early-stage pathology (such as Alzheimer's disease)	Stage 1: No cognitive decline. Stage 2: Age-associated memory impairment. Stage 3: Mild cognitive impairment.
Moderate or middle-stage pathology/early to middle stage dementia	Stage 4: Mild dementia. Stage 5: Moderate dementia.
Severe or late-stage dementia	Stage 6: Moderately severe dementia. Stage 7: Severe dementia.

In the future, the Alzheimer's Association biologically based criteria for staging and diagnosing of Alzheimer's disease (Jack et al., 2024) is more likely to be adopted. The proposed staging takes into account the long latency (over a decade) between the appearance of neuropathology in the absence of symptoms, and the further progression of the disease and the development of signs and symptoms. The focus has therefore changed from defining the disease from the syndromic to the biological perspective. The neuropathological phases of the disease that occur in the absence of symptoms are beginning to be characterised by a range of biomarkers. This presymptomatic stage is characterised by fluid biomarkers such as the ratio of the levels of amyloid-beta-42/amyloid-beta-40, total phosphor-tau, various forms of phospho-tau and neurofilament light in the plasma and/or cerebrospinal fluid, and by neuroimaging biomarkers as measured by PET (positron emission tomography) using amyloid and tau tracers. One ethical issue that this approach highlights is that the genetic forms of Alzheimer's disease (as is the case with Down's syndrome) will be at stage zero at birth (see Table 2).

Seven stages are described from stage 0 to 6:

TABLE 2: CLINICAL STAGING FOR INDIVIDUALS ON THE ALZHEIMER'S DISEASE CONTINUUM (MODIFIED FROM JACK ET AL., 2024).

STAGE		CLINICAL AND BIOMARKER FEATURES
0	Asymptomatic, deterministic gene (including extra copy of APP – as in Down's syndrome)	No evidence of clinical change. Biomarkers in normal range.
1	Asymptomatic, biomarker evidence only	Performance within expected range on objective cognitive tests. No evidence of recent cognitive decline or new symptoms.
2	Transitional decline: mild detectable change, but minimal impact on daily function	Normal performance within expected range on objective cognitive tests. Decline from previous level of cognitive or neurobehavioral function that represents a change from individual baseline within the past 1 to 3 years, and has been persistent for at least 6 months. Maybe documented by evidence of subtle decline on longitudinal cognitive testing, which may involve memory or other cognitive domains but performance still within normal range. Maybe documented through subjective report of cognitive decline. Maybe documented with recent-onset change in mood, anxiety, motivation not explained by life events. Remains fully independent with no or minimal functional impact on activities of daily living (ASL)
3	Cognitive impairment with early functional impact	Performance in the impaired/abnormal range of objective cognitive tests. Evidence of decline from baseline, documented by the individual's report or by an observer's(e.g., study partner) report or by change on longitudinal cognitive testing or neurobehavioral assessments. Performs daily life activities independently but cognitive difficulty may result in detectable functional impact on complex ADLs (i.e., may take more time or be less efficient but still can complete—either self-reported or corroborated by an observer).

TABLE 2 (CONTINUED)

STAGE		CLINICAL AND BIOMARKER FEATURES
4	Dementia with mild functional impairment	Progressive cognitive and mild functional impairment on instrumental ADLs, with independence in basic ADLs.
5	Dementia with moderate functional impairment	Progressive cognitive and moderate functional impairment on basic ADLs requiring assistance.
6	Dementia with severe functional impairment	Progressive cognitive and functional impairment, and complete dependence for basic ADLs.

This staging is an attempt to bridge the latest research findings with current clinical practice. It will become more used when we have disease modifying treatments available.

Alzheimer's disease in people who have Down's syndrome is currently thought about in three stages: early stage, middle stage and late stage. The person's cognitive ability will deteriorate across these three stages and their level of dependence will increase.

It is important to remember that the person may appear to move into the next stage, often because of an illness such as pneumonia or a urinary tract infection (UTI), and may return to the previous stage once the illness has been treated, although the recovery can take time. Therefore when there is a sudden decline, a physical health cause should always be considered and appropriate investigations undertaken.

EARLY STAGE DEMENTIA

At this stage, the person is showing signs of decline from their usual level of functioning in the following areas:

- Subtle changes in behaviour and mood.
- Performance at day placements deteriorates.
- Memory problems, particularly for recent events.
- Ability to learn new information is affected.
- Language and word finding problems.
- Decline in social, community and daily living skills.
- Disorientation.
- Difficulties with steps, stairs and kerbs due to depth perception problems.

MIDDLE STAGE DEMENTIA

- Memory loss becomes more pronounced and the individual may forget personal information or the names of familiar people.
- Language problems become more evident.
- Confusion and disorientation around time, place and may have problems finding their way around familiar environments.
- Difficulties with and then loss of self care skills.
- More severe changes in personality and social behaviour, e.g. mood changes, inactivity or apathy, behavioural disturbances such as wandering, sleep problems, agitation, hallucinations and delusions.
- Problems with eating and drinking.
- Disturbed sleep patterns.
- Increasing incontinence.

LATE STAGE DEMENTIA

- Myoclonus and epilepsy.
- Incontinence (bladder and bowels).
- Loss of eating/drinking skills.
- Problems with walking and balance, individuals become chair- or bed-bound.
- Problems with recognising people.
- Often require 24-hour care.
- Will become bedridden and inactive.
- Greater risk of infections, particularly pneumonia.

Deterioration of people with intellectual disabilities and dementia is not predictable. People will deteriorate at different rates and patterns. Some deteriorate steadily, others less predictably, and this can change at any time. Furthermore, people will often not be clearly in one stage and will show signs of more than one stage.

Frequently people offering care and support on a daily basis to a person with dementia adapt to the changes in the person as they occur. It is often when the person is assisted to have a holiday and is out of their familiar environment that staff and carers realise the extent of the change. Similarly, if staff are new to caring for the person, they might not know the person's history and not understand the abilities of the person before they were diagnosed with dementia.

CASE STUDY

John has Down's syndrome and Alzheimer's disease. He resides in a supported living home with a staff team that have known him for many years and have learnt to support him effectively. The staff team has been supported through 'whole staff team' training and regular reviews of John's care needs. The psychologist was contacted as the psychiatrist raised concerns that the staff team was beginning to struggle with understanding John's needs, and that he was losing weight. The psychologist offered a consultation session to the manager and senior support workers.

As a result of the consultation, it became apparent that staff who regularly supported John had not recognised that John's dementia had progressed. This meant that the style of support and prompts that they used were no longer helpful for John and not appropriate for his current needs. Once this was clarified, the team was able to reflect on John's changing needs and put in place a more appropriate care plan to support him effectively, especially with regard to his eating and drinking. This led to John gaining weight.

KEY POINTS

The social model gives a conceptual model for staff and carers to understand dementia.

Understanding what happens as dementia progresses and its consequences gives a framework to understand and respond appropriately.

Think about what the person is actually experiencing, and use that to inform the care and support that is required.

Section 11 – Philosophy of Care

11.1 RELATIONSHIP-CENTRED PHILOSOPHY OF CARE

There are a number of models of person-centred dementia care in existence within the general dementia literature, including Person-Centred Care (Kitwood, 1997); VIPs (Brooker, 2006); and Feelings Matter Most (Sheard, 2008).

Person Centred Care focuses on valuing each person as a person who has continued strengths and capabilities (Koren, 2010). Despite the considerable attention that Kitwood's person-centred care has gained, lack of empirical evidence supporting person-centred care has led to a critique of the model (Davis, 2004; Epp, 2003; Adams, 1996; Harding & Palfrey, 1997).

More recently, this critique has related to the failure of person-centred care to 'fully capture the interdependencies and reciprocities that underpin caring relationships' (Nolan et al., 2002) and an absence of the 'mutual appreciation of each other's knowledge, recognition of its equal worth, and its sharing in a symbolic way to enhance and facilitate joint understanding' (Nolan et al., 2002). Person-centred care has been criticised for focusing too closely on the individual and failing to consider the social and political contexts of care (Nolan et al., 2008).

Sheard (2013) has introduced the concept of 'mattering' which he says 'brings together the core elements of; emotional care, skills, quality of life and environment with the culture of a shared relaxed community, thereby evidencing that individuals matter'.

The State of Care report from the Care Quality Commission (2014) showed that those services that maintain people's dignity and treat them with respect all have a number of things in common: they recognise the individuality of each person in their care, help the person to retain their sense of identity and self-worth; take time to listen to what people say; are alert to people's emotional needs as much as their physical needs and give the person control over their care and the environment around them.

Relationship-centred care (RCC) has emerged as a response to the critique of person-centred care. This approach recognises that quality care happens when there are strong reciprocal and interdependent relationships among everyone involved in care, including the resident, family members, and staff. The underlying idea within these approaches is that dementia care is often provided within 'dementia care triads' comprising the person with dementia, the informal carer(s), and one or more health and social care professionals (Keady & Nolan, 2003; Nolan et al., 2003). However, it should be noted that while the triad is often the focus of counselling, there are often many other members of the family who play a role in care (Keith, 1995) and that the notion of relationship extends beyond just three people to other members of the care team, which can include not only family members but also professionals.

Relationship Centred care is a personalised and collaborative approach of forming and maintaining important relationships. Within care homes there is a web of relationships between the staff team, residents, families and the local community. Each of these connections allows for effective exchanges and communication which is vitally important for maintaining a good quality of life on a day to day basis. Relationship centred care means recognising that meeting residents' needs and wishes are essential through a partnership approach based on strong and positive relationships.

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WHAT ARE THE ADVANTAGES OF RELATIONSHIP CENTRED CARE?

Positive Environment and Positive Engagement

- Approach to care ensures an environment where the team share the philosophy of valuing care; involving residents and their families; focus is on people not tasks.
- Care staff selected not only for their qualifications and experiences but also for their compassionate and caring natures.

Don't shy away from emotions

- Care staff empathise with and get to know residents on a personal level. Being emotionally neutral is not beneficial to the wellbeing of residents and empathy helps residents experience and express their emotions.

Authentic Mutual Respect

- RCC emphasises the importance of authenticity – care staff not simply acting as if they have respect for the person, but to actually have the respect that they display.

A Sense of Belonging

- RCC ensures that all parties feel significant, including the person and their friends and family.

In summary, Relationship Centred Care **reflects the importance of interactions among people and recognises that these provide the foundation of any therapeutic care activity**. For residents in a social care environment, relationship centred care can be illustrated by a 'relationship triangle'.

THE SENSES FRAMEWORK

The Senses Framework developed by Nolan et al. (2006, 2008), includes six senses that are essential for strong relationships in the care context. Quality care happens when the six senses are experienced by all involved in the care relationship:

1. **A sense of security**
   Residents feel safe and receive knowledgeable and sensitive care; staff feel safe, free from threat, and work within a supportive culture; family feel confident in their ability to provide good care and have the support they need.

2. **A sense of continuity**
   Residents receive consistent care from people they know; staff have consistent positive work assignments; family and residents maintain shared pursuits.

3. **A sense of belonging**
   Residents experience reciprocal relationships and feel part of a community; staff feel like they are part of a team; family maintain valued relationships and feel like they have a support network.

4. **A sense of purpose**
   Residents have opportunities to engage in purposeful and meaningful activity; staff have clear, shared goals and direction; family have opportunities to contribute to life in the home.

5. **A sense of achievement**
   Residents have opportunities to develop and meet goals; staff and family feel they have grown because of their caring experience.

6. **A sense of significance**
   Residents feel recognised and valued; staff feel like their work matters; family feel that their care role is valued by staff.

Excellence in dementia care requires staff and family carers to work together as described above to understand and know the person, understand dementia and its consequences for the person, and consequently to be able to think ahead and predict 'stressors'. They need to adapt their approach as much as possible to ensure that the person with dementia has stress-free, failure-free but individualised care that is consistent but without time pressures. This needs to be incorporated into the person's person-centred plan and care plan.

11.2 LIFE STORY WORK

This can only be achieved by having a thorough knowledge and understanding of the person and their history. This can be aided by the use of Life Story work (Gibson, 1994). The individual themselves should be encouraged to participate in the making of the life story as much as possible.

- Where possible the individual should have the final say as to what is included in the book/box. People should only put things in their life story book that they are comfortable with – even if it means leaving out huge chunks of their life.
- A Life Story does not have to stick to one particular format – it should be whatever the person wants it to be. It can include sensory items that people can feel or smell which have a significance to the person.
- Life Story books/boxes should not finish. Staff, family and the individual can continually add to them.
- Life Story work can be a great way to increase an individual's self-esteem because the life story is all about them and what they like, etc. (without having to mention a diagnosis or any other labels they may have.)
- If including photographs of people it is important they are put into some sort of context, for example, what their name is, how they are known to the person, date taken, event, why it is important to the person. This means that anyone can pick the book up and be able to use it in a meaningful way with the individual. This is absolutely vital so that if someone loses the ability to remember, the staff still have the cues.
- If the person does not have many pictures of their life/growing up, an alternative would be to use pictures from magazines, books and the internet of anything that the individual remembers or just likes.

11.3 CLARITY ABOUT FOCUS OF SUPPORT

Staff and family carers need to be clear about what they are trying to achieve. This is not the time for learning new skills, achieving goals or facing change. They need to consider the person's happiness, comfort and security. The focus of care should change from goal orientated to emphasis on enabling quality of life. Staff and carers need to remember that people compensate for their deterioration in functioning by making greater use of remaining abilities (e.g. earlier memories). This may mean that the person finds comfort in activities and objects from their childhood. Roll-back memory may also mean that the person is not oriented to the present day. Care needs to be taken not to challenge the person's beliefs repeatedly as this will add to their stress. This approach fits with the values and model of Positive Behaviour Support (Gore et al., 2013) that is central to services for people with intellectual disabilities.

Care includes not only the social aspects of the person's life, but an increasing awareness of the physical consequences of getting older and additionally having dementia. Care needs to be taken to ensure that diagnostic overshadowing does not occur, where all changes are attributed to the dementia. Research (e.g. Kerr et al., 2006) indicates that pain recognition and management is extremely inadequate in this group of people. All people should have comprehensive health checks and a Health Action Plan, updated annually at minimum.

Further information on health co-morbidities associated with dementia can be found in Section 9.

DEMENTIA CONSULTATION

Mary, a lady who has Down's syndrome, was diagnosed with mid stage dementia. The home manager was worried about how the staff team would manage the diagnosis and also changing their working practices. She was concerned that they would feel de-skilled.

A systemic staff consultation was held, exploring the meaning and beliefs that support staff had about dementia, and how support needs changed with the diagnosis. They highlighted the change in emphasis from valuing independence and choice to maintaining skills and reducing anxiety. Different perspectives of 'good support' were considered, for example: the organisation, intellectual disability team, person, person's family, home manager and support team. They discussed how organisational values were different to what they now felt might be best for Mary.

Personal stories of dementia, death, what might make a 'good death', were explored and the confusion of being a professional in someone's life and expectations around this, yet knowing someone and being sad about the changes in the person they supported. We talked about space that can be made for all of this. The home manager noticed changes in the way staff communicated with each other about their emotions as well as the practical issues. She noticed that staff seemed more confident and creative in changing their practice to suit Mary. For example, the staff team asked for training in intensive interaction so they would be able to communicate with Mary as she could no longer speak. Mary was able to stay at home until she died.

KEY POINTS

Staff and carers need to ensure that people with intellectual disabilities and dementia have stress-free, failure-free and consistent care.

This approach leads to a more supportive environment and lower levels of behaviour and distress.

Relationship-centred care reflects the importance of interactions among people and recognises that these provide the foundation of any therapeutic care activity.

Services need to review regularly the support given to people with intellectual disabilities and dementia, particularly the amount of staff support provided both during the day and through the night.

Section 12 – Environments

This section of the guidance focuses on how carers and services can create capable environments that enhance the quality of life for people with intellectual disabilities and dementia.

12.1 WHERE SHOULD PEOPLE WITH INTELLECTUAL DISABILITIES AND DEMENTIA LIVE?

Janicki and Dalton (1998) proposed a potential pathway that someone might follow after a diagnosis of dementia. This has been adapted to reflect the current position of the Care Services Improvement Partnership and the Department of Health, with the options given in order of preference for people with intellectual disabilities and dementia.

Preferred option:

'Dying in place' where the person can stay where they are currently living with appropriate supports adapted and provided. This means that the person stays with what is familiar in their long-term memory.

Compromise option:

'Moving to more specialist intellectual disability provision' where the person has had to move from their current home, but moves into provision supported by intellectual disabilities services.

Least preferred option:

'Referral out of intellectual disability services' where the person will be moved to services for older people, either residential or nursing.

By staying where they are, the person will stay with familiar people (family, peers, familiar carers) and in an environment that they know. Although their needs will change as the dementia progresses, every effort should be made to maintain their home life. This may necessitate:

- environmental changes and adaptations to support the person,
- increases in staffing levels,
- careful thinking about the supports required.

In some instances it is not possible to maintain the person in their existing home:

- It may be that the design of the building is inappropriate and cannot be changed.
- The person may be being looked after by older family carers who may not be able to continue caring as the needs of the person increase, or their own health changes.
- Risk assessments should be completed regularly to ensure that the environment remains safe for both the person and their carers.
- Staff may reach a 'tipping point', where there are insurmountable problems with the placement (often the quality of life for the other residents or staff issues).
- Funding may be an issue.

If the person has to move then the most appropriate provision may be a specialised intellectual disability service which is able to meet the person's increasing health needs and provide palliative care (Thompson & Wright, 2001). Although some moves may be of benefit to the person, the majority of the evidence suggests that moving increases the rate of decline and can precipitate

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deterioration in health and behaviour and lead to an earlier than expected death (Wilkinson et al., 2004). Multiple moves must always be avoided. The use of an advocate or an Independent Mental Capacity Advocate (if the person has no family) should be appointed to support decision-making, particularly where the person is lacking capacity (Mental Capacity Act, 2005/Adults with Incapacity Act (Scotland), 2000). Relationships with significant others e.g. families, staff, friends and advocates must be considered and maintained.

If the person has to move, it is vital that other opportunities for continuity, for example, day activities, leisure and social opportunities which are in the person's long-term memory, are maintained. Maintaining social networks will also involve working with the person's peers to help them understand dementia and the changes in the person. This is discussed further in Section 18. There is a range of materials to assist with this (Dodd et al., 2005 a, b & c).

12.2 WHAT ARE THE FEATURES OF A CAPABLE ENVIRONMENT?

There is a wealth of literature within general dementia care, and a smaller amount within the intellectual disabilities arena about the importance of the environment in enabling the person with dementia (Watchman et al., 2010; Kerr, 1997, 2007; Dodd et al., 2009; Dodd, 2025). Most environments where people with intellectual disabilities live are not 'dementia-enabled'.

According to Marshall (1998) the environmental design should not impede an individual but should have positive and beneficial effects for both the person and the staff. The environment should:

- compensate for the disability;
- maximise independence;
- enhance self-esteem and confidence;
- demonstrate care for staff;
- be orientating and understandable;
- reinforce personal identity;
- welcome relatives and the local community; and
- allow control of stimuli.

Adaptations will need to be made to ensure that the environment does not add more stress. Many of the adaptations required are not too expensive but can have a very positive effect on the quality of life for the person with dementia.

Environments need to be:

- Calm;
- Predictable and make sense;
- Familiar;
- Suitably stimulating; and
- Safe and risk assessed.

Calm and stress free

Environments can easily become stressful for someone with dementia. To avoid this and keep the environment calm and allow the person to focus better, many aspects of the environment can be adjusted.

Noise

Noise is one factor which needs to be controlled, although not eliminated. People with dementia may have impaired hearing and in addition because of their cognitive impairments, do not know which sounds to attend to or not to attend to. For example it would be difficult for them to know whether they need to attend to the radio playing in the background or the staff talking to them. This impairment can be very distressing and is why noise levels should be controlled where possible. Two types of noise need to be considered – noise from the outside and noise from within the building.

- Noise from outside the building may cause the person to be distracted, or prevents them hearing conversation. Double glazing and lined curtains can help to reduce the level of external noise.
- Within the building, noise levels from competing sources need to be reviewed. Noise can be from TVs, radios and music systems, conversation or people calling out, telephones ringing.
- Staff need to consider the level of noise appropriate for each activity, person, and time of day.
- Music can be very calming but must be used selectively, and not be a constant background noise. Selecting music that is in the person's long-term memory can be beneficial, giving the person something that they can relate to (see Section 12).
- Distractions from other people – either staff, other residents or visitors – can also cause problems, especially if they are at times when you want the person to concentrate on a task, activity or interaction. Thinking about possible distractions and taking preventative measures can help, as can simple environmental measures such as moving the position of the telephone.

Predictable and making sense

It is important to have an environment that is both predictable for the person and makes sense to them, otherwise the result will be disorientation and confusion. To avoid this, it is important to first recognise two important visual changes within individuals with dementia. One is that their depth perception is increasingly lost and, secondly, that they see the red end of the colour spectrum better than the blue end, and as a result colours such as red, orange and yellow are more easily seen.

With regards to the loss of depth perception the consequences include:

- Stairs become increasingly impossible to use as the depth of each step is hard to judge. As a result they should be avoided. Similarly the person may increasingly struggle getting in and out of the bath (which is a very large step!). Peripheral vision may become more limited.
- Change in colour of flooring can be perceived as a change in level. For example the point at which one carpet changes colour to another in a different room may be perceived by a person with dementia as a step, and cause them to be hesitant in doorways, or unwilling to enter a room. Staff may not understand what is causing the person's distress and may wrongly ascribe it to the person being difficult, stubborn or challenging.
- Dark areas on light flooring can look like holes so the person with dementia will be inclined to avoid them by walking around them. Lighting which is not too bright or too dark is recommended to prevent shadow effects on the flooring which can look like holes.
- Bathrooms and kitchens typically can be problematic as they usually have shiny floors which can look like pools of water to someone with dementia. It is recommended to have matt flooring which is the same colour as the flooring in the room that leads to it.

With regards to the change in colour perception:

- It is recommended that red, orange and yellow are used to make certain objects or rooms more obvious, for example, painting a toilet door red, having red toilet seats, and using contrasting colours for crockery and table mats.
- Colours for decoration and furniture need to be reviewed, the most important issue is to ensure colour contrasts – so that the walls are a different colour from the flooring, which is different again from the furniture. This enables the person with dementia to be more able to distinguish items in their environment and helps to avoid accidents and incidents.
- As people get older, they need their environment to have more light. It is important that the tone of colours makes the environment look lighter and brighter, rather than having colours that make the environments seem darker and 'suck out the light'.

These issues can cause the person to get very distressed and can also increase the possibility of falls. Risk assessments for the environment need to be reviewed regularly to keep the person safe.

- Aside from the issues mentioned, memory impairments mean individuals cannot find their way around familiar settings. This can be frightening for them so simple changes such as adding good signage to doors (e.g. personalised acrylic boxes with personal/significant items of the person within them) at the right level for older people can make a difference.
- Nolan et al., (2002) showed that placing a portrait such as a photograph and personal memorabilia in a display case outside the room of each person with dementia increased room finding by 45 per cent.
- Changes such as using rooms for a single clear function wherever possible; using the same room consistently for an activity (e.g. always using one particular bathroom for washing).
- Using picture rather than verbal cues is vital for people with dementia, e.g. picture timetables, pictures to indicate where things are, signage, picture menus, etc.
- Camouflaging doors that people do not need to use by painting them the same colour as the rest of the wall or using curtains to make the top half of a fire door look like a window; all can reduce confusion dramatically.
- Memory loss means mirrors can become scary to look into as they do not recognise themselves. This is because they see themselves at a younger age, so mirrors may need to be covered up (e.g. at night).

Familiar

Due to roll-back memory (see Section 10 – Conceptual understanding of the dementia process) people will not recognise things that were not around at the age they are 'experiencing' now. For example, someone who is 60 years old but whose reality is now the 1970s will have problems recognising and understanding how to use mixer taps, futuristic looking kettles, lamps, chairs, clocks, etc.

- It is important to use traditional style objects that will be recognisable to the person from their own past. For example, clocks with hands, traditional style kettles, cookers, lamps, chairs, clocks and curtains rather than blinds, etc. Basically, it is best to avoid modern futuristic styles.
- Other adaptations to make the environment more familiar is to use small-scale, domestic, homely furnishings and to use objects/pictures for orientation (e.g. picture of a toilet on the toilet door). Cohen and Weisman (1990) stated that familiar objects, activities, and spaces can trigger personal associations and even encourage social interactions and meaningful activity.

Suitably stimulating

Although the environment needs to be calm, it is still important that the environment is sufficiently stimulating. There must be a happy balance between over stimulation and under stimulation. The study by Morgan and Stewart (1999) supported this notion and showed a curvilinear relationship between environmental demands and negative behaviour in people with dementia. Thus negative outcomes were associated with both under stimulation and over stimulation.

- To achieve this suitably stimulating environment, appropriate levels of noise for that person, activity and time of day are important.
- In addition clear views of the outside world and small quiet areas are important as they allow individuals suitable stimulation and allow peaceful and calming times.

Safe

Safety is of paramount importance and there are a number of issues which need to be considered with people with dementia in a home.

- One behaviour which people with dementia may exhibit is wandering, and although this can lead to some safety problems, it should not be totally discouraged. As a result it is important all exits are monitored and/or alarmed and that fire exits are camouflaged so they are not subject to misuse.
- It is important that steps, stairs and uneven flooring are all considered within the home due to the depth perception problems experienced in early and middle stages of dementia.
- It is important the garden is secure and safe for wandering, with safe plants and even surfaces. Ideally a home and garden should be designed with wandering in mind, thus a circular design is optimal for a home, allowing people to wander around and return to where they started. This notion of a circular arrangement would also be applicable to the garden in terms of a pathway.
- The temperature of water in the kitchen, bathrooms and toilets need to be controlled and all possible hazardous objects, such as knives, sharp corners, hot kettles, need to be stored away safely.
- Assistive technology, e.g. bed alarms, epilepsy monitors, are a useful adjunct to the environment for people with intellectual disabilities and dementia, but should not be used as a replacement for sufficient and competent support.

KEY POINTS

Wherever possible, people with intellectual disabilities and dementia should remain in familiar environments.

If the person has to move, then this should be within an intellectual disabilities service.

Environments can be adapted to make them dementia-friendly and enable the person with dementia to make sense of where they are living.

It is important that environments provide stimulation for the person without putting them under any stress.

Section 13 – Meeting changing needs/interventions

13.1 OVERVIEW OF APPROACHES TO INTERVENTION

It is important that the diagnostic process, which can be lengthy, does not preclude the implementation of interventions. Regardless of the eventual outcome of the diagnostic process, support is required to address current areas of need. Interventions need to be tailored to the individual, particularly the person's existing health, disability, interests and social circumstances. There needs to be an emphasis on enhancing the psychological wellbeing of the individual and minimising the impact of changes being felt by the person's carers and/or peers.

Most of the interventions required are ones that are not specific to dementia, and likely to be beneficial regardless of the eventual outcome of the diagnostic process. The interventions will be familiar as core to the work of intellectual disability professionals with emphasis on a person-centred approach with interdisciplinary and multi-agency working. For example; the provision of accurate and timely information; formulation; interventions to maximise and maintain independence, skills and health; and at the same time promoting safety, comfort, and dignity. Reducing excessive demands and simplifying routines are key, while minimising avoidable changes, especially any exclusion from appropriate services. It is notable that where someone is in a totally unsuitable environment for their needs (e.g. isolated or bullied) and may be depressed, then a change can be beneficial and aid the diagnostic process. Furthermore, awareness needs to be maintained regarding the person's changing needs and interventions reviewed at regular intervals.

The use of Person Centred Planning (DH, 2001), Person-Centred Care Plans (Mental Welfare Commission for Scotland, 2019), the Care Programme Approach (DH, 2008b) and similar approaches provide the same overall framework for individualised planning and care coordination as for anyone else with intellectual disabilities and changing or complex needs. All care planning, of course, has to be in the context of the individual and their family's religious/cultural context. Consent, capacity and risk management issues need to be considered at all stages, alongside the need for advocacy, advance directives/statements, living wills and other mechanisms to facilitate best interest or complex decision-making, according to changing legislative frameworks and ethical practice. Furthermore, the Quality Outcome Measure for Individuals with Dementia (Dodd & Bush, 2015) provides guidance in providing quality person centred care for people with Intellectual disabilities and dementia (see Appendix 3).

The Learning Disability Professional Senate (LDPS) advocates that services for people with a learning disability should be designed to deliver Relationship Centred Care, which incorporates the principles of person-centred practice. Quality care happens when there are strong reciprocal and interdependent relationships between everyone involved in care, including the person, family members, support staff and others in their circle of support. Relationship Centred Care means recognising that meeting the person's needs and wishes are essential through a partnership approach based on strong and positive relationships (LDPS, 2023). The principles of Relationship Centred Care are applicable to all, including those with dementia, and are outlined in more detail in the LD Professional Senate guidance document. Refer to section 11 for more information.

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13.2 MEETING CHANGING NEEDS

Maintaining personal independence and self-sufficiency is important when living with dementia, especially at the early stage of onset. At the same time, it is also important to know that people around you understand your condition, and are there for you when you need their support. In Northern Ireland, the use of a 'Just a Minute' (JAM) card (JAMcard, 2023) has been promoted by Dementia NI to raise public awareness of dementia, and to empower people who have dementia and intellectual disabilities to communicate with others when some patience is required or when some level of assistance is needed.

As the dementia progresses, the emphasis of care changes from enabling the person to maintain their skills with support to increasingly taking on tasks for the person with dignity and respect.

At the early stage of dementia, this will involve reminding the person of the day, time, place; simplifying routines and reducing choices; introducing memory aids such as diaries, timetables and objects of reference; simplifying communication, and using additional cues and prompts.

As the dementia progresses, care changes to trying to preserve abilities for as long as possible, using techniques of reminiscence, identifying favourite activities and strengths, and finding failure and stress-free activities. At this stage, health monitoring becomes essential. Attention to weight, adequate nutrition and hydration, physical health including epilepsy, continence, pain and mobility are all vital.

Towards the end of the person's life, swallowing and dysphagia, skin and pressure sore care, moving and handling all become paramount. Even at the end stage of dementia it is important that the person has positive interactions throughout their day (Sharp, 2007). The tasks of daily living often become the activities of the day and should be pleasurable and enjoyable for the person. Appropriate touch and verbal interaction are essential. There is further information regarding specific interventions for different stages of dementia within Watchman's (2014) book.

TABLE 3: SUGGESTED ACTIVITIES FOR EACH STAGE OF DEMENTIA. (SOURCE: KALSY–LILLICO ET AL., (2012) REPRODUCED IN WATCHMAN (2014).

EARLY STAGE	EARLY-MIDDLE STAGE	MIDDLE STAGE	END STAGE
Board games – card games such as snap are good, as are large sized dominoes Ball games – throwing soft balls to each other, standing or sitting Discussion – about people, places and things Relaxation – progressive relaxation, massage or aromatherapy activities Arts and crafts – painting, coloring in, making bean bags, poster End-product activities – anything where there is an immediate end results such as flower arranging, drawing, cooking, baking Use visual planners and cures to structures activities/day	Music – play something that resonates, is liked by the person and has a good bass and beat Dance – chair dancing is good, swaying and rocking in time to music Art and 'pottery' – working with dough, clay, plasticine or sand Movement – guided walks, progressive relaxation Drama Reminiscence – using familiar items, mementoes, touch, taste, smells, sounds, pictures or photosphots that reminds people of times gone by Storytelling – talking about old friends, stories about special times, memories or what's on TV Spiritual or religious activity	Movement and exercise – can be done standing or sitting Multi-sensory environments – use lights, sounds, smells, touch, Snoezlen Massage – hand and feet spa treatments One-step cooking tasks, such as mixing items, peeling food One-step gardening tasks, such as watering plants, digging pots One-step daily living tasks, such as plumping up cushions Walking: along routes that are circular, with focus points Stacking and folding – clothes, papers and magazines Soft toys – touch can help anxious feelings Baths, bubbles, balloons – remind people of fun	Smiling and laughing – don't underestimate this as an activity Singing – humming along to popular tunes, radio jingles or TV adverts Stroking – positive touch of people and objects that have different textures Gentle rocking – can relax and establish physical contact Holding – as above Cuddling – as above

To support these (sometimes rapidly) changing needs described above, it is good practice to keep a person diagnosed with dementia open for regular review, often until the end of their lives. This might be as part of a dementia reassessment pathway and/or through support from the learning disability health and social care team. It is recognised that this may well be dependent on resources available within teams but ongoing involvement with individuals who have a diagnosis of dementia helps monitor the progression of dementia over time and increases the ability to

respond quickly to the changing needs which will result. Alzheimer Scotland's Advanced Dementia Practice Model (2015) outlines the need for a dementia practice co-ordinator to be embedded in health and social care systems with the support of an Advanced Dementia Specialist Team when individual needs change in order to provide the necessary support consistently throughout the advanced stages of dementia and at end of life.

13.3 UNDERSTANDING BEHAVIOUR IN PEOPLE WITH INTELLECTUAL DISABILITIES AND DEMENTIA

By implementing the philosophy of care outlined earlier, for example, Buijssen (2005) psychosocial model of dementia, many of the difficulties that can occur in dementia can be prevented or minimised. However, there will often be times when people present with behaviours that staff or family find difficult to understand and respond to.

Positive behaviour support approaches (PBS) have become established as a preferred approach when working with people with intellectual disabilities who present behaviours that can be perceived as challenging. This is evidenced in Positive and Proactive Care: reducing the need for restrictive interventions (DH, 2014), British Psychological Society guidelines (BPS, 2004), NICE guidelines NG11 (2015a), Reducing Restrictive Practices (Welsh Government, 2022), The Coming Home Report (Scottish Government, 2018) and the joint guidelines of the Royal College of Psychiatrists, the BPS and the Royal College of Speech and Language Therapists (RCPsych et al., 2007, updated LDPS 2016).

PBS has developed over the past 25 years and is an evidence based multi-component framework for supporting people who engage in behaviours that can be experienced as challenging. Its primary focus is to improve quality of life through an understanding of the individual's behaviour and the needs they are trying to communicate or get addressed; and then to use this understanding to build better support, to support positive outcomes, and to improve the services that individuals receive.

PBS can be summarised as having four main components:

1. PBS is focused on improving quality of life. The most important goal of PBS is to improve the quality of life; this is a non-negotiable commitment, regardless of diagnosis, setting or behaviour. The aim is to make life better for the individual, so they have less need to engage in behaviours that can be experienced as challenging.
2. PBS is based on specific values. PBS is person-centred and only uses interventions which respect the dignity of the individual and support the reduction of restrictive practices. There is a commitment to the co-production of PBS guidelines, taking account of the perspectives of the people whose plans they are and those involved in their care including families. Punishment approaches are never used in PBS.
3. PBS uses tools to understand what the individual's behaviour means. This includes the use of assessment tools to find out the meaning for the individual and PBS guidelines to ensure people's needs are understood and met in safer ways. Families and carers are often a rich source of information in providing an understanding about the communication needs and meaning of a person's behaviour.
4. PBS is a system-wide approach. PBS is most effective and successful when it is implemented across a whole service or organisation, rather than just for an individual. It is also holistic and will often involve adapting the individual's whole environment to meet

their needs better as well as making sure they are able to develop new skills and have more opportunities. Active support is an important part of PBS as it enables individuals to have more engagement and choice in their daily lives.
(Taken from: Reducing Restrictive Practices, Welsh Government, 2022)

In all cases where there is behaviour that challenges, the standards of assessment of the behaviour and subsequent intervention should occur as outlined in Challenging behaviour: a unified approach (RCPsych et al., 2007, updated in 2016) This includes ensuring that any intervention addresses the person, the environment and the interaction between the two. As the report says:

'A comprehensive assessment should address: a functional assessment of behaviour, underlying medical and organic factors, psychological/psychiatric factors. Detailed functional assessment and diagnosis are both integral features of an assessment of challenging behaviour and should lead to a clear formulation of the presenting problem. Interventions should be delivered in a person-centred context and a framework of positive behavioural support. They should include proactive and reactive strategies. Interventions described include psychotherapy, communication, positive programming, physical and/or medical and psychopharmacological.' (p.10).

Additional aspects, related to the dementia, may need additional consideration in the assessment of the behaviour of concern:

- The problem behaviour may be transitory to the current stage of the person's dementia and not need an intervention. Similarly, it may be possible to withdraw interventions if/when the person's skills and behaviour change again.
- The situation should be viewed through the eyes of the person with dementia – i.e. their current reality. Continual correction by staff/carers of a false reality (e.g. person with dementia asking when a dead parent will visit) will not reduce their immediate confusion and distress. Emphasis should be on validation of feelings rather than the 'truth' of the situation.
- The behaviour should be viewed as an attempt by the person to communicate or to make sense of a bewildering environment (e.g. GP practice waiting room is confused with an airport lounge).
- The behaviour may be an exacerbation or return of previous behaviours. If the person had difficult behaviours/personality traits previously, these may return/reoccur with roll-back memory.
- The behaviour may be caused by a return to a long-term memory that is now inappropriate, e.g. childhood urinating outdoors in the countryside whilst on long walks.
- There may be an underlying neurological change, e.g. taste bud changes leading to food fads and a liking for stronger flavours, refusing baths resulting from problems with depth perception and/or stepping into the bath.
- Simple and practical solutions may work e.g. a net to catch items thrown out of the window.
- Simple environmental alterations may alter the behaviour e.g. removing a mirror.
- The behaviour or distress may be related to past trauma and so interventions should take this into account using a trauma informed care approach. This approach includes meeting the person's needs in a safe, collaborative and compassionate manner, preventing intervention practices that retraumatise people with histories of trauma, and building on the strengths and resilience of the person in the context of their environment and communities.

There is a good description of many of the most common problem behaviours seen in dementia in Dodd et al., (2009) Down's syndrome and dementia resource pack. Throughout the progression of the dementia, any changes should be clearly documented. There are tools available to facilitate

this, e.g. Down's syndrome and dementia workbook (Dodd et al., 2009), and care mapping approaches (Brooker & Surr, 2005).

13.4 PSYCHOLOGICAL INTERVENTIONS

Within the literature emphasis has been placed on assessment and diagnosis. However, psychological interventions described in the general dementia literature can be adapted for use with people with intellectual disabilities. Interventions need to consider the multiple influences on behaviour (behavioural, systemic and biomedical) in order to support the individual and carers to understand, cope and manage behaviour and emotional distress (Kalsy-Lillico, 2014). This approach places responsibility on the system to change and to both communicate effectively with the individual whilst enhancing the person's current capabilities. Kalsy-Lillico et al., (2012) describe psychological interventions in relation to four orientations: behaviour, emotion, cognitive and stimulation. Table 3 presents a framework for organising psychological interventions and practices into these four broad groups. We would also recommend the use of systemic approaches for working with families and staff teams. Intensive interaction also appears useful in enabling staff teams to communicate with a person at their current level of ability.

Cognitive stimulation therapy could also be of benefit, which is an evidence-based group intervention recommended by NICE guidelines for individuals with mild to moderate dementia. CST incorporates a range of activities to actively stimulate participants using techniques such as reminiscence and multi-sensory stimulation, along with an emphasis of person-centred care and building and strengthening relationships. Involving carer/family members in CST can also be helpful and can provide a way for carers to also have support and provide a valuable way to support interactions between them and the person with dementia. Jervis et al., (2021) found positive outcomes when using an adapted CST programme with individuals with learning disabilities and their carers.

These psychological approaches could be supported by local mainstream memory clinic services. Some learning disability teams have shared pathways of support at assessment and intervention (e.g. Salford Learning Disability Team, Hughes et al., 2016), enabling referrals to be made post-diagnosis back into mainstream dementia services for further post diagnostic support, while other services may provide post-diagnostic support from within the learning disability team. Building these connections between services takes time, resource and effort, but by doing so, enables mainstream services to make reasonable adjustments for other populations prone to dementia to access their service as well as enabling people with learning disabilities to experience better dementia quality care.

TABLE 4: A FRAMEWORK FOR PSYCHOLOGICAL INTERVENTIONS. SOURCE KALSY-LILLICO ET AL., 2012 QUOTED IN WATCHMAN, 2014.

Behaviour-orientated	A full functional analysis of the behaviour in question will enable a systemic understanding of the behaviour as a form of communication. The best practice principles that should be considered when supporting ageing adults with intellectual disabilities and dementia include simplifying multistep activities/skills, matching the level of demand on the individual with that of their current capacities, employing a range of prompts to facilitate communication and to modify the environment insofar as possible to compensate for deficits and capitalise on the individual's strengths. For carers, recommended practice also encourages the adoption of a proactive approach to identify potential stressors (or triggers) that can lead to distressed behaviours and moderate change as necessary.
Emotion-orientated	The underlying principles for such interventions are to reduce distress, validate a sense of self, enhance emotional wellbeing and support coping strategies. Psychodynamic approaches appear helpful for understanding intrapsychic concerns, cognitive/ behavioural techniques assist individuals in the early stage to build coping strategies and reduce distress, reminiscence and life review approaches provide individuals in the mild to moderate stage of dementia with interpersonal connections.
Cognition-orientated	The aim of these techniques is to compensate for cognitive deficits by utilising behavioural approaches to focus on specific cognitive and behavioural impairments and help to optimise remaining abilities. These techniques include skills training.
Stimulation-orientated	These treatments include recreational activities (such as crafts, games, pets) and art therapies (music, dance, art) to provide stimulation and enrichment that will engage the individual's available cognitive and emotional resources. Approaches such as life work that include life stories, valuables and memories pictures/photographs/objects are powerful ways of relating to the individual with dementia in a person-centred way. Reminiscence work is also important as a process of recalling experiences and events memorable for the individual by using different mediums such as verbal, visual, musical, tactile and smell. Anecdotally, in using reminiscence with groups of aging adults with intellectual disabilities, Kalsy-Lillico has found that its associative process is that one memory leads to another so that one person's shared recollection usually sparks off associated recollections or 'memoires' in others, has had positive effects on engagement and communication as reminiscence makes connections between a person's past, present and future. Cognitive Stimulation Therapy (both individualized and in a group) can also be helpful.

13.5 SPECIFIC INTERVENTION FOR CARERS

It is widely recognised that family and paid carers who support individuals with dementia require considerable support themselves to understand the needs of the person for whom they are caring, to adapt their approach to meet these needs, and to gain support around their own emotional needs as carers.

The START intervention (STrAtegies for RelaTives) is a manual-based coping intervention designed to address the needs of carers and family members supporting people with dementia (Livingstone et al., 2013). The focus is on: psychoeducation on dementia: carers' stress: where to access

emotional support; understanding the person's behaviour and learning behaviour management techniques; changing unhelpful thoughts; promoting acceptance; assertive communication; relaxation; planning for the future; increasing pleasant activities; and maintaining skills learnt. START is increasingly being utilised as part of routine clinical practice for carers of people with dementia, including those with learning disabilities (McClelland & Jervis, 2019).

13.6 OTHER INTERVENTIONS

There are also many useful non-dementia-specific interventions available. All depend on competent staff assessing and intervening as appropriate at the level that is required (i.e. individual/ family/service). The main interventions are outlined below in Table 5.

TABLE 5: SUMMARY OF USEFUL INTERVENTIONS TO IMPROVE THE CARE OF PEOPLE WITH DEMENTIA

Person-Centred Approaches to Support	• Person Centred plan. • Health Care Plan. • Communication Passport. • Life Story Book/Memory boxes. • Advanced Directives & end of life planning. • Personalised Music playlists
Physical Health	• Health checks leading to a Health Action Plan / Health Passport and any treatment. Tools available e.g. OK Health Check (Matthews, 2006) End of Life support – Gold Standard Framework (Thomas & DH, 2005). • Management of weight. • Management of pain. • Management of sleep. • Management of epilepsy. • Management of medication. • Management of constipation
Mobility	• Strategies to maintain mobility, promote exercise, address posture especially regarding respiratory function, correct gait and reduce the risk of falls. Consider equipment needed and promote safe manual handling. • Control of pain and discomfort. • Pressure area care. • Treatment of any difficulties of motor function, adaptation and teaching of skills to include compensatory techniques. • Equipment (e.g. hoists, profiling beds, etc.).
Eating/Drinking	• Eating and drinking, strategies for maintenance of adequate oral intake in a safe manner. Swallowing assessments, eating programme with dietetic advice and advice regarding posture. • Diet to reduce risk of constipation. • Dysphagia management.
Continence	• Aids/adaptations. • Help to maintain continence.
Communication	• Strategies to improve communication. • Use of a 'communication passport' i.e. information on how best the person receives information and expresses themselves. • Use of objects of reference, pictures. • Environmental signposting/signs and symbols. • Intensive interaction.

TABLE 5 (CONTINUED)

Environment	• The person lives and spends time in environments that are familiar to them. • Depth perception problems are minimized for example flooring colour is consistent. • Necessary aids/adaptations to help find their way around and meet their needs e.g. red toilets doors, toilets seats, good signage, handrails, chairs at a good height.
Self Help Skills	• Modelling/guiding/prompting/pacing. • Adding supports to maintain self-care and domestic skills. • Adaptation of the environment to aid daily living. • Assistive technology.
Occupation/Activity	• Sensory stimulation (including Snoezelen). • Aromatherapy. • Music and art therapy. • Support for people to engage in activities. • Other failure free activities e.g. looking at magazines, carers sitting with the person describing what is happening. • Music activities, including personalised playlists. • Sensory garden/outdoor activities utilising nature • Pet therapy
Orientation/Confusion	• The person is able to understand their daily routine through the use of appropriate cures and aids for example, daily picture timetable, picture menus and staff rotas. • Reminiscence. • Life story work. • Cognitive stimulation therapy
Mental Health and Behaviour	• Anxiety Management. • Intervention for Depression. • Relaxation techniques. • Promotion of positive behaviour and feelings of self esteem. • Intensive Interaction. • Observations to gain an understanding of behaviours. • Functional analysis and setting up of programmes for challenging behaviours utilising a Positive Behaviour Support Approach. • Setting up of crisis intervention plans. • Trauma informed care approaches • Self-soothe boxes, grounding approaches
Work with families and carers	• Education about dementia and how to care in a psychological way. • Training for staff team. • Support offered to family and carers, through systemic consultation opportunities for formulation and problem solving. • START intervention
Technology	• Using virtual assistants such as Alexa Echo, Ok Google etc • Using apps and other software packages to aid communication, engagement and activities, and orientation • Music download services to develop personalised playlists • Using environmental technology to reduce risks, eg, water monitor for bath, door alarms, fall alarms

KEY POINTS

It is important to utilise the skills of the multidisciplinary team to support the individual with intellectual disabilities and dementia and their network of support.

A range of interventions should be available to meet the person's need as their dementia progresses.

Other agencies as well as those in the statutory sector can help to support the person and their carers.

Section 14 – Medication

14.1 ACETYLCHOLINESTERASE INHIBITORS AND MEMANTINE IN PEOPLE WITH INTELLECTUAL DISABILITIES AND DEMENTIA

The degeneration of nerve cells in the brain leads to a reduction in neurotransmitters (a group of chemicals which have an important role in the transmission of signals between nerve cells). The neurotransmitter Acetylcholine is affected in Alzheimer's disease. Acetylcholine plays a key role in the way the brain processes and consolidates information.

Acetylcholinesterase inhibitors increase the level of Acetylcholine available for transmission of nerve signals by delaying its breakdown. This is achieved by inhibiting an enzyme – Acetylcholinesterase – which is responsible for Acetylcholine breakdown and normally helps to maintain the balance of chemicals in the brain. Another enzyme involved in the breakdown is Butyl Cholinesterase and one of the anti-dementia drugs (Rivastigmine) inhibits this enzyme in addition to its effect on Acetyl Cholinesterase. It is important to note that none of the drugs available for prescription to date are disease modifying; rather, they treat symptoms. Hence, they are unlikely to have a significant impact on the pathological processes and are therefore not considered to prolong life.

- Acetylcholinesterase inhibitors are used mainly in Alzheimer's type dementia, but also have demonstrable improvements in other dementia types, particularly Lewy Body dementia.
- NICE guidance – NG97 (2018a) recommends the use of Acetylcholinesterase inhibitors as monotherapy for mild to moderate Alzheimer's disease. Memantine monotherapy is recommended as an option to manage individuals with moderate dementia where Acetylcholinesterase inhibitors were contraindicated or not tolerated, and in individuals with severe Alzheimer's disease. NICE highlighted the need to consider complexities such as intellectual disability and the importance of not relying on cognitive scores alone for assessing the severity and need for treatment.
- Medications for the treatment of dementia should be used with appropriate caution in people with pre-existing health issues such as cardiac conditions, gastrointestinal conditions (e.g. upper GI ulceration, bleeding), epilepsy, respiratory conditions (e.g. asthma, COPD), hepatic and renal impairment. Necessary investigations and specialist advice may need to be sought to consider the most appropriate treatment in these conditions as well as ongoing monitoring.
- Common side effects of anticholinesterase inhibitors include nausea, diarrhoea, anorexia, weight loss, sleep disturbances, bradycardia and hypotension.
- Patients who are newly diagnosed with dementia should be advised of the role of cholinesterase inhibitors for symptomatic treatment of cognition and global functioning, expected benefits and risks. Initiation of these medications should be after appropriate informed consent. Decisions about continuation of such medications in the long term should depend on the patient's response and should be made in consultation with the patient and significant others. The possibility of medication withdrawal in future and the reasons should be discussed at the time of initiation of medication.
- Based on evidence in the non-intellectual disability population, NICE also recommends acetylcholinesterase inhibitors be considered for Lewy body dementia and dementia in Parkinson's disease but not for people with only vascular dementia or fronto-temporal

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dementia. Memantine may be considered for Lewy body dementia and dementia in Parkinson's disease if acetylcholinesterase inhibitors are not tolerated or contraindicated.

- Selection of an agent is therefore based largely upon ease of use, individual patient tolerability, cost, and clinician and patient preference.
- Dose of the medication should be carefully titrated and in general in individuals with intellectual disability starting at a low dose and slow upwards titration is preferred. The effect/side effects of the medication should be monitored closely. This can be done using a number of different tools, but as a general principle should include measures of cognitive, social and adaptive skills. Medication should be used for as long as it is effective (i.e. stabilises or delays the progression of symptoms).
- While combining Memantine and Anticholinesterase inhibitors has shown to improve cognition and global outcome in patients with dementia in the non-intellectual disability population, evidence for such practice is not available in the intellectual disability population. The only RCT that studied the effects of Memantine in people who have Down's syndrome (Hanney et al., 2012) found no benefit, although a low baseline prevalence of dementia (35%) may have contributed to the negative result.
- NICE recommends not stopping Acetylcholinesterase inhibitors in Alzheimer's dementia because of severity alone and recommends the option of adding memantine if they have moderate or severe disease. These recommendations, although aimed mainly for people without intellectual disability, may also be relevant for people with intellectual disability.
- Discontinuation of medication should be considered if there is lack of perceived benefit, intolerable side effects despite dose reduction, rate of decline greater on treatment compared with pretreatment baseline, increase in risk due to medication due to comorbidities or nonadherence and progression to an advanced stage of dementia.
- If a decision is made to stop treatment, medication should be tapered by 50 per cent (unless already on lowest dose) for two to three weeks and stopped to minimise the risk of worsening.
- If patients worsen after tapering and stopping therapy, medication may be reintroduced if the deterioration is linked to withdrawal.
- In Scotland, SIGN Guideline 168 (Healthcare Improvement Scotland, 2023) contains clinical practice guidelines for use of medication in dementia.

TABLE 6: CURRENT AVAILABLE MEDICATIONS AND REVIEWS OF THEIR EFFECTIVENESS

METHOD OF ACTION	DRUG	EVIDENCE
Cholinesterase inhibitors and NMDA antagonist	Donepezil, Rivastigmine, Galantamine and Memantine	Eady et al. (2018): A naturalistic longitudinal follow-up of a cohort of 310 people with Down syndrome diagnosed with Alzheimer's disease followed up in specialist community services showed that cholinesterase inhibitors appeared to benefit this population as the median survival time (5.59 yrs, 95% CI 4.67-6.67) for those on medication was significantly greater than for those not prescribed medication (3.45 yrs, 95% CI 2.91-4.31). The authors acknowledge that there were significant baseline differences between the people who were not prescribed medication as they were older and more likely to have severe-profound intellectual disability and had more severe dementia symptoms at baseline.
Acetyl & Butyl cholinesterase inhibitor	Rivastigmine	Prasher et al. (2005): In a non-randomised trial (17 treatment, 13 controls), people who were treated with Rivastigmine had less decline over 24 weeks in global functioning and adaptive behaviours but no statistical difference. Prasher et al. (2013): In a non-randomised trial (27 treatment, 13 controls) both oral and transdermal Rivastigmine treatment was associated with significantly less decline in both cognitive and global functioning over a six-month period.
Acetyl cholinesterase inhibitor	Donepezil	Prasher et al. (2002): Double blind placebo controlled trial of Donepezil, showed that the improvement at 24 weeks was statistically non-significant. The sample size of the study was too small to explore the efficacy in the subgroups of mild to moderate disease. Lott et al. (2002) in their open label study on Donepezil found that treatment resulted in significant improvement in scores on the Down's Syndrome Dementia Scale (Gedye, 1995). However, there were methodological drawbacks. Prasher et al. (2003), in their open label study on Donepezil treatment for people with Down's syndrome, found that treatment with the anti-dementia drug was associated with initial improvement in global functioning and adaptive behaviours. Follow-up at 104 weeks found that, whilst there was deterioration in both treatment and control groups, it was significantly less in the treatment group. Kondoh et al. (2011), in a 24 week, double bind, randomised, placebo controlled trial found that in a sample of 21 females (11 to Donepezil and 10 placebo) with Down syndrome aged between 32-58 years (mean 45.6 yrs) Donepezil significantly improved global and specific measures. The study included people with cognitive impairment but unclear if this meant dementia.
	Galantamine	No studies in people with Down's syndrome.

TABLE 6 (CONTINUED)

METHOD OF ACTION	DRUG	EVIDENCE
NMDA antagonist	Memantine	Hanney et al. (2012): Randomised, double-blind, placebo-controlled trial of Memantine for dementia in adults older than 40 years with Down's syndrome (MEADOWS); the authors included older adults with DS who did not have clear signs of dementia but argued that due to the high risk for AD in this population and the potential neuroprotective effect of memantine such an approach was justifiable. This was a well-designed study that included 88 patients actively in treatment and 85 patients receiving placebo and demonstrated no difference between the active and control group and concluded that Memantine was not beneficial for people with Down's syndrome and cognitive decline.
Antioxidants/Vitamin E	900 IU alpha-tocopherol 200 mg ascorbic acid & 600 mg alpha-lipoic acid Vitamin E	Lott et al. (2011): Randomised placebo controlled trial of antioxidants in adults with DS and dementia (N = 53). Antioxidant supplementation was found to be safe, though ineffective. In a large randomised double blind controlled trial in adults with Down syndrome over age 50 (n = 337; 1 in 5 had dementia at baseline) of vitamin E vs placebo over 3 years, there was no beneficial effect of 1,000 IU of vitamin E daily (Sano et al., 2016)
Few other trials have been done in people with Down syndrome assessing the effect of medication on cognition. These include Johnson 2003 and Kishnani 2009 (donepezil), Boada 2012, Costa 2022 (memantine), Cooper 2016 (simvastatin) and Pueschel 2006 (acetyl- L- carnitine). However, these studies focussed on young individuals in their 20s and did not include people with dementia diagnosis.		

14.2 DISEASE MODIFYING DRUGS

There is an increasing number of disease modifying drugs targeting the amyloid pathway immunologically being developed. In 2024 Lecanamab, a monoclonal antibody (mAb) targeting Amyloid-beta was approved for early Alzheimer's disease in the general population in the UK, except in those who are APOE4 carriers, or on blood thinning medication. However, NICE has not yet approved its use in the NHS and therefore it is not available in the NHS. NICE's decision was based on the relatively modest beneficial effect which does not at present justify the costs of providing the treatment, including fortnightly infusions in hospital and intensive monitoring for side effects, and therefore not considered good value for the taxpayer. Lecanemab (and other similar mAbs) carries a risk of significant adverse effects, including brain swelling and brain bleeds referred to as 'amyloid related imaging abnormalities' (ARIA), which necessitates regular monitoring with MRI scans.

It is important that these treatments are tested to establish their safety in people with intellectual disability and who have Down's syndrome. It is especially important to conduct trials in those who have Down's syndrome, not only to establish safety due to their increased risk for cerebral amyloid angiopathy that may predispose to ARIA (Mann et al., 2018, Costa, 2024), but also to establish

benefit in the context of a genetic predisposition for Alzheimer's disease, in which the impact of treatment may be different to the general population.

There is on-going and intense efforts to develop other treatments, including amyloid vaccines, antisense oligonucleotides and RNA interference therapies to 'silence' or turn off the production of specific genes. Several of these treatments are currently being trialled in people who have Down's syndrome. These treatments are targeted against the genetic mechanisms implicated in Alzheimer's disease and may have a different side effect profile to mAbs, and could eventually provide a targeted option to reduce or even prevent onset of Alzheimer's disease in people who have Down's syndrome.

In addition, there is an intense effort to discover more disease modifying drugs that target not just amyloid, but also for example tau aggregation.

14.3 PSYCHOTROPIC MEDICATIONS IN THE MANAGEMENT OF BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA (BPSD).

Behavioural and psychological symptoms of dementia (BPSD) are non-cognitive symptoms, which constitute as a major component of dementia regardless of its subtype. BPSD often occur in clusters such as hyperactivity, including agitation and aggression, affective symptoms including depression and anxiety, and psychosis, including both delusions and hallucinations (Van der Linde et al., 2013). The vast majority of people with intellectual disabilities and dementia with BPSD can be supported with environmental and other psychosocial approaches which are detailed in this guidance in Sections 12 and 13. Every effort should be made to carry out a thorough assessment to determine the reasons for such behaviours and take the necessary remedial actions (NICE guidance NG11, 2015a)

In spite of the use of environmental and psychological interventions, there may be a small group of individuals with dementia who may benefit from use of psychotropic medications. The following are examples where a use of a medication may be considered:

As a first line consider using AChE inhibitors as treatment to address symptoms of BPSD.

- The NICE guideline NG97 (2018a) on dementia states only offer antipsychotics for people living with dementia who are either:
- at risk of harming themselves or others or,
- experiencing agitation, hallucinations or delusions that are causing them and their carers severe distress.
- People with depressive symptoms may benefit from an antidepressant treatment.
- In addition, there will be a small number of people with behaviour problems where clinicians would consider psychotropic medications to minimise the risk to the individuals themselves or other people. In these situations, medications are considered as an option due to one of the following reasons:
  - the behaviour is continuing with significant risk to self or other people in spite of the use of the psychosocial/environmental approaches.
    Or
  - a short-term management where it is not practically possible to achieve the risk reduction with any other measures immediately.

The guidance further states that for people with dementia with Lewy bodies or Parkinson's disease dementia, antipsychotics can worsen the motor features of the condition, and in some cases cause severe antipsychotic sensitivity reactions.

It is important to follow good practice principles in treating people with intellectual disabilities and dementia:

- There should be a full discussion with the person with dementia and/or carers about the possible benefits and risks of treatment. In particular, cerebro-vascular risk factors should be assessed and the possible increased risk of stroke/transient ischaemic attack and possible adverse effects on cognition discussed.
- For people with intellectual disabilities and dementia, any such treatments should be considered on a best interest basis if the person is unable to provide informed consent.
- Target symptoms should be identified, quantified and documented.
- Changes in target symptoms should be assessed and recorded at regular intervals.
- The effect of comorbid conditions, such as physical illness, pain and depression, should be considered.
- All prescribed, over-the-counter and complementary medicines that the person is taking or using needs to be reviewed (including the possibility of side effects).
- When using antipsychotics (NG97)
  - use the lowest effective dose and use them for the shortest possible time,
  - reassess the person at least every 6 weeks, to check whether they still need medication.
  - Stop treatment with antipsychotics if the person is not getting a clear ongoing benefit from taking them and after discussion with the person taking them and their family members or carers (as appropriate).
- Side effects may not always be reported by the service users due to impaired communication in many, and it is therefore essential for the prescribing clinician to make both the users and carers aware of what to look for in terms of side effects. Consider use of validated tools for assessing side effect e.g. anticholinergic burden (for example, the Anticholinergic Cognitive Burden Scale – Campbell et al., 2012) or Glasgow Antipsychotic Side-Effect Scale (GASS – Bock et al., 2019)

These steps are also in line with the national NHS England work programme 'Stopping over medication of people with a learning disability and autistic people (STOMP)' to stop the inappropriate prescribing of psychotropic medications; and 'A Framework for the use of Non Pharmacological Approaches to Reducing Restrictive Practices in Wales' (Improvement Cymru and BILD, 2024).

KEY POINTS

Acetylcholinesterase inhibitors should be considered for people with intellectual disabilities when they develop Alzheimer's dementia, Lewy body dementia and dementia in Parkinson's disease, but not when they develop only vascular dementia or fronto-temporal dementia.

Disease modifying drugs targeting the amyloid pathway immunologically are being developed and need to be trialled with people who have Down's syndrome.

Psychotropic medications have only a limited role in the management of Behavioural and Psychological Symptoms of dementia (BPSD) in people with intellectual disabilities and dementia and should only be considered if other environmental/psychosocial approaches have produced only very limited or no benefit and the risk from the symptoms is assessed as high.

Antidepressant medications are useful in the management of depressive symptoms in people with dementia and intellectual disabilities.

Caution should be exercised in the use of antipsychotic medication in the context of the evidence of a high risk for cerebrovascular events and mortality.

Where psychotropic medications are used, target symptoms should be clearly recorded, risks and benefits discussed with the person and/or carers and the minimum effective dose should be used for the shortest length of time.

Section 15 – Safe eating and drinking

Eating and drinking are basic human functions. It is vital that the person with dementia is assisted to make eating and drinking as enjoyable and stress free as possible. Each person will have their own beliefs about food. Eating is often a social experience as well as a means of gaining nutrition. Individuals have different reactions to different foods that come from their experience, culture and taste, and these need to be taken into account in understanding the person with dementia.

As the dementia progresses people are likely to experience changes to their eating and drinking skills (e.g. dysphagia). Staff and families need to be flexible and person-centred, remembering that the person will have good days and bad days. This may mean that families and staff will need to completely rethink how to approach eating and drinking for the person in order to reduce risk at mealtimes, to maximise comfort, pleasure and enjoyment and to ensure adequate nutrition. Advice can be sought from the multidisciplinary team.

15.1 WHAT MAKES PEOPLE WANT TO EAT AND DRINK?

Each person will respond to a large number of cues that make them want to eat and drink. These include: time of the day, smell of food, rattle of crockery and cutlery, the table being set, the colour of the food, how the food is presented and the taste of the food. Similarly there are a number of reasons that make people less inclined to eat or drink. These include when the smell is off-putting, the place is noisy or dirty, the food doesn't look nice, the person doesn't like the people they are sitting with, they don't feel well or are too tired. A person may also not wish to eat if they do not recognise that the feeling coming from within is one of hunger, as the connection between the sensation in their stomach and the thought that they need to eat may be lost.

It is therefore essential that the chances of the person enjoying their food and successfully eating and drinking are maximised by paying attention to a number of factors.

These include:

- Preparing what you eat can improve levels of wellness and positively affects a person's ability to chew and swallow food. It also impacts on quality of life, not just from a nutritional perspective, but also in terms of wellbeing and it is a great social opportunity for people.
- Promoting people to do things for themselves can have a significant impact on improving a person's appetite. All stages of meal/snack preparation will stimulate saliva production and activate the centres in the brain involved in swallowing.
- People should be involved in every aspect of planning and preparing a meal, from creating a shopping list, selecting the produce off the shelves, to the final serving of the meal. Consider using visual supports to aid this process e.g. photographs, symbols, objects. This will often mean thinking creatively and it may not always be about preparing a main meal but may be providing the opportunity to do part of the meal which focuses on people's remaining abilities. Alternatively, it may be that the person can be supported to be near the kitchen to hear, see and smell the food being prepared.
- As well as being involved in choosing and preparing food it is important that people are supported to be as independent as possible in giving themselves food and drink. This might mean the use of specialist equipment such as adapted cutlery or cups, or hand-over-hand prompts.
- Dining environment: a communal environment may contribute favourably to food consumption as the person may benefit from seeing others who can model the process of eating and

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drinking. Set up an environment that allows the individual to wander, eating finger foods along their path; if they can safely manage this type of food. Keep auditory distractions to a minimum (noise from television, radio, and people moving in and out of the dining room). Avoid distracting items on the meal table e.g. patterned table coverings, vases, multiple condiments, as these can be distracting and reduce focus on food. Use contrasting coloured plates to help make food easier to see; primary colours are better.

- Posture and positioning of the person is important to safe eating.
- Understanding why people need to eat and drink and ways of encouraging eating are important. Look at what people are eating and when and ensure everyone supporting an individual to eat is aware of any recommendations that have been made by members of the MDT e.g. recommendations from a Speech and Language Therapist in relation to food textures that may be easier for the person to manage, or guidance around positioning from Physiotherapy.

15.2 EATING AND DRINKING DIFFICULTIES

As the dementia progresses, eating and drinking difficulties become more apparent. The types of difficulty can be characterised as follows:

- **Difficulty chewing, grinding or moving the food in the mouth:** this means that food does not break down and form a bolus and therefore cannot be propelled to the back of the mouth efficiently. Some people (particularly those who have Down's syndrome) may have a backwards/forwards motion of the tongue which is different from the more full range of movement that most other people have. This more restricted movement is also frequently observed in people who were unable to eat a normal diet requiring them to develop good chewing patterns e.g. people who have cerebral palsy or other physical disabilities. It can also be observed in people in the advanced stages of dementia. For people with dementia this may not be a motor problem related to chewing but instead being about being able to remember to chew and difficulty with the sensation in the mouth triggering the idea they need to chew.
- **General muscle weakness or stiffness in the face and neck area** may mean that the person experiences difficulty controlling liquids in the mouth. Liquids and soft foods may dribble out of the sides or front of the mouth or disappear down the throat in an uncontrolled fashion, possibly entering the unprotected airway.
- **Changes in sensation** in the mouth, whether reduced or heightened, can drastically affect the eating or drinking process for the person. Changes in sensation may affect someone's tolerance of extreme temperatures or their enjoyment of certain flavours. People with dementia often respond to stronger tasting foods.
- **'Holding' food in the mouth** may lead to aspiration. People can be supported by a stroke on the chin/neck to try and prompt a swallow. Sometimes being offered an empty spoon can prompt a swallow.
- **The swallow reflex sequence** can become uncoordinated. The swallow may be triggered too early or too late. This means that the bolus or liquid will pass down the throat at a point when the airway is not properly protected. This can lead to inhalation into the larynx or aspiration onwards towards the lungs. The mouth or the throat may become full and overspill. A swallow may be triggered, but some of the residue may be inhaled into the larynx or windpipe. It may be possible to hear this if the person's voice sounds 'wet' or more gruff than usual.
- **Saliva:** We produce a large amount of saliva which we normally swallow without even realising. Someone with a swallowing problem may appear to produce too much saliva, which then escapes from the mouth leading to drooling. Conversely, some people produce too little saliva, which can

produce a dry mouth. A dry mouth makes it much harder to swallow and bacteria and organisms may begin to build up, making the person much more prone to infections such as thrush.

- **Eating inedible objects:** Some people with dementia may try to eat or drink inedible items, either because they have confused them with food or drink, or because of pica (an eating disorder where a person compulsively swallows non-food items). Depending on what they eat, this can lead to a number of health issues including damage to teeth, blockages in the digestive tract and poisoning, and sometimes death. A risk assessment should be carried out to identify any issues related to eating non-food items and a safety plan put in place.

Once eating and drinking difficulties are suspected, it is important that an immediate referral is made to their local speech and language therapy department who can often provide training on eating and drinking difficulties, including dysphagia training. Carers and staff need to be aware of the key signs to watch for: coughing, choking, a red face, and watery eyes or loss of breath during eating or drinking.

Working with carers and staff needs to be ongoing to ensure that issues that help to minimise difficulties are recognised and acted on.

These issues include:

- A consistent approach is key. All persons who are going to assist an individual to eat and drink should ensure that they have consulted and understood any eating and drinking guidelines that are in place before they begin to support eating and drinking.
- Being aware (by keeping a food and drink diary) of what textures and liquids seem to cause problems and which do not. Staff and carers need to avoid those that cause problems and make sure that everybody knows what they are.
- Checking that dentures fit properly. It is important to minimise the number of teeth removed as this will cause gum shrinkage and gum muscle weakness and dentures will then be harder to keep in place. Oral hygiene is vital in promoting good mouth and chest health, as aspirating bacteria can cause infection.
- Correctly positioning the body and particularly the head may greatly assist people to eat and drink safely. If the individual is being fed by another, the position of the feeder should also be considered. It is important that the person is referred to the speech and language therapist who will assess and advise on this together with other multidisciplinary team members.
- Remembering that even if the mouth itself feels and looks empty, there may be a build up of residue in the throat. It is advisable to encourage people to take their time and to make additional swallows, in order to clear as much of the residue down the food pipe into the stomach as possible. If left this residue may silently drip down into the airway. This is known as ‘silent aspiration’. Food and liquids silently aspirated onto the lungs may cause chest infections (aspiration pneumonia).
- Treat each meal, snack or drink as a new episode as the difficulties will fluctuate and people need to be aware of how the person is ‘in the moment’.
- Timed snacks can improve hydration and nutrition as well as medication compliance.
- Successful feeding in dementia may take up to one hour depending on the severity of the disease. Remember that people can become fatigued and may need a break before feeding is restarted. Smaller, more frequent, mealtimes may be better. If concerned about nutritional/ hydration intake, consult with a dietician.
- Interruptions during mealtimes can distract people with dementia, resulting in reduced nutrition and calorific intake.

- Presentation of food is important and some people with dementia who are on a modified diet may struggle as the food might not look how they expect it to. Consider the use of moulds and try to keep different food separate on the plate.
- As the dementia progresses and the person is at the end stages of dementia, comfort and enjoyment need to be prioritised over nutrition. At the end of life some people may not want to eat at all and others may have a greatly reduced appetite and accept very small amounts of food or fluid.

Where staff or carers have concerns they need to keep a record of episodes of coughing, throat clearing, 'wet' voice quality, choking and also chest infections and consult a speech and language therapist.

Saliva can be an issue for people with dementia. If people with muscle weakness are experiencing loss of saliva from the mouth then staff and carers need to gently dab away the moisture – never wipe it, as the action of wiping across the lips has the effect of stimulating more saliva, as there is a salivary gland in the chin area. Where too little saliva is being produced, the person should be offered frequent small drinks to keep the mouth hydrated and care taken with a regular oral hygiene routine. Wiping the lips in this instance may be beneficial as it stimulates the sub-lingual salivary gland to produce saliva but this needs to be discussed with a speech and language therapist or other relevant specialist.

KEY POINTS

Eating and drinking are basic human functions.

It is vital that people supporting the person with dementia carefully consider and implement person-centred strategies to make eating and drinking as enjoyable and stress free as possible. These strategies should be reviewed regularly as the person's needs will change as their dementia progresses.

Any guidelines put in place must be made known to all carers and followed carefully to minimise risks to the individual.

All eating and drinking difficulties must be taken extremely seriously, and an urgent referral made to a speech and language therapist if concerns arise.

PEG feeding is not advised for people with an intellectual disability and dementia.

Extreme care needs to be taken regarding the risk of eating non-edible objects which may lead to severe harm and death.

Section 16 – Palliative care and end of life issues

Dementia is a progressive and, at present, terminal illness. Its course, whilst varying in detail from person to person, is by definition associated with the progressive loss of skills and the ability to communicate, ending in a final stage where the person becomes completely dependent on others for their every need. As the illness progresses, so it becomes harder for others to ascertain the wishes of the person suffering from dementia and this is likely to be particularly the case when the person has pre-existing intellectual disabilities.

Thus, if interventions such as the 'This is Me' leaflet (developed by the Alzheimer's Society & Royal College of Nursing) are being used by the person with intellectual disability, this can continue to be updated during palliative care and into end of life care to support staff to personally know the individual they are caring for, and to be aware of what the person's wishes and preferences are.

There is much evidence that historically, and currently, people with intellectual disabilities experience barriers in accessing quality health care for serious illness and underuse palliative care services.

For these reasons preparing for the end of life and taking a palliative care approach is of importance from the time of establishing a diagnosis onwards. Forward planning concerning these issues needs to be embedded in the person-centred plan. (See Section 8 – Breaking the news). The generally fairly long course of dementia allows time for the person themself and for others to prepare and to ascertain how they wish to be supported and to plan for how their health and wellbeing will be maintained and for how they will be supported at the end of life and when dying. In Scotland individuals are entitled to a one year Post Diagnostic Link worker after receiving a dementia diagnosis. This is based upon the principles in the 5/8 pillars and the advanced dementia care models developed by Alzheimer's Scotland. The initial support lasts for one year and involves supporting the individual and their carers to understand the illness, manage symptoms, plan for the future and access any activities/supports in the community. Following this, services can use the advanced dementia care model to help coordinate and plan care and prepare for the future and at end of life.

16.1 END OF LIFE STRATEGY

End of life issues have been addressed significantly over the last decade in all areas of Britain. Strategy documents in England, Scotland, Northern Ireland and Wales are consistent in the information, guidance and imperatives they give concerning the approach to palliative and end of life care and they all stress that this should focus on the person rather than the disease and aim to ensure quality of life for those living with an advanced non-curative condition.

In 2019 the National Institute for Clinical Excellence published service delivery guidance for commissioner, providers, practitioner and people (NICE, 2019c, NG142) approaching the end of their life. Support for carers and advanced care planning are highlighted needs. In addition, the 2018 NICE guidance for the Care and Support of People Growing Older with Learning Disabilities (NICE, 2018b, NG96) emphasises the importance of end of life care being person centred, that it involves family and support networks and that it ensures that staff have the necessary skills to support end of life care.

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For people with intellectual disabilities there is now a strong emphasis on involving them in their end of life care as for all other aspects of their life. This is made explicit in *Improving the Health and Well-being of People with Intellectual Disabilities: An evidence-based commissioning guide for clinical commissioning groups* (Learning Disabilities Observatory et al., revised 2013) which states that people with intellectual disabilities should be able to have the same end-of-life care planning and access the same palliative care services as everyone else, as this contributes to effective and coordinated care and a good death. The Route to Success in End of Life Care – Achieving quality for people with intellectual disabilities is a practical guide to improving end of life care for people with intellectual disabilities, within the NHS National End of Life Care Programme (2011). The NICE Quality Standard for End of Life Care (2012a) makes it clear that it is now an agreed standard that people with intellectual disabilities should receive the same palliative and end of life care as the rest of the population.

In England the Department of Health End of Life Strategy (DH, 2008a) set out the key areas for action to ensure that people have excellence in end of life care. This included developing strong links with specialised end of life services, e.g. hospices, palliative care services, and admiral nurses. Similarly in Northern Ireland, end of life care is to be delivered by services which are integrated and coordinated, with a focus on preparing a person for their death in a safe, dignified and comforted manner, and providing bereavement support for families and carers (Regional Dementia Care Pathway, 2018).

Welsh Government's Quality statement for Palliative and End of Life care for Wales (2022) outlines that anyone requiring palliative and end of life care in Wales should have access to the best possible care, and this should be safe, timely, effective, person-centred, efficient and equitable. It also outlines that partnership working between all agencies (e.g. health boards, local authorities, third sector, care homes, informal carers) should be strengthened.

NICE Quality Standard for End of Life Care (2012a) covers all settings and services in which care is provided by health and social care staff to all adults approaching the end of life and also covers support for the families and carers.

Alzheimer's Scotland Advanced Dementia Practice model (2015) promotes the wellbeing and quality of life of both the person with advanced dementia and those closest to them and provides guidance on how to best support individuals at the end of their lives, as do the Scottish Palliative Care Guidelines (2013). The Scottish Government set up a Palliative Care Steering Group in 2023, tasked with supporting the development of a new palliative and end of life care strategy for Scotland. This will include specific sections on both dementia and people with a learning disability.

16.2 ADDRESSING END OF LIFE ISSUES

The approach advocated by both the DH (2008a) and NICE (2012a) is a holistic one which addresses psychological and physical needs, social and practical needs and spiritual and religious needs. It also gives guidance on access to specialist palliative care, care of the body after death and support with bereavement. For all areas it specifies cultural sensitivity and dignity and explicitly states that a person should be offered spiritual and/or religious support appropriate to their needs and preferences.

Health and social care professionals are required to act to identify people approaching the end of life in a timely way and to give them and their family and carers opportunity to discuss, develop

and review a personalised care plan for current and future support and treatment. For people with intellectual disabilities this may mean utilising accessible resources such as Books Beyond Words.

The treatment plan is for symptom management and addressing for current and anticipated physical and specific psychological needs. The care plan needs to outline personalised support for their social, practical and emotional needs, appropriate to their preferences, and should aim to maximise independence and social participation for as long as possible. There is a focus on essential services being available and accessible at all times to those approaching the end of life who need them. The Resuscitation Council UK have easy read resources available as part of the ReSPECT process. This process supports people to make personalised recommendations for their clinical care and treatment in a future emergency in which they are unable to make or express choices.

This includes people approaching the end of life receiving specialist palliative care if their usual care team are unable to relieve their symptoms adequately. It is emphasised that people should be offered this care in a timely way at any time of day or night.

The Leadership Alliance for the Care of Dying People (LACDP) developed a new approach and new priorities in 2014. These priorities state that decisions about care and treatment are to be made in accordance with the needs and wishes of the person and should be reviewed and revised regularly, communication between staff and the person who is dying should be sensitive, the dying person is to be involved in decisions about their care, people important to the dying person are to be listened to and their needs respected, and that care should be tailored to the individual and delivered with compassion.

It is clear that good practice in dementia care for people with intellectual disabilities requires working with the individual with dementia, their families and carers from an early stage concerning palliative and end of life care and that this means being aware of and taking into consideration a range of factors in a person's life including their personal history and preferences, their family and other relationships and their cultural and religious background with particular reference to ideas and beliefs about serious illness, dying and death.

Good practice guidance also states that people in significant relationships to the person who has died need to be supported in their loss and bereavement and peers and co-residents with intellectual disabilities need to be included in interventions that give support after the person's death.

As new problems arise their occurrence should not be a surprise and should have been anticipated. In the early stages of dementia the issues listed below should be considered as these will all become relevant towards the end of the illness or at the person's death. The individual with intellectual disabilities and dementia should always be involved whatever their capacity. If they lack capacity or their capacity diminishes then it will be necessary for the appropriate professionals to make Best Interest decisions within the context of the Mental Capacity Act (2005)/Adults with Incapacity Act (Scotland) (2000). For complex and serious decisions or where there are conflicts concerning treatment, for instance between the family and the medical team, it will be necessary to involve an Independent Mental Capacity Advocate (IMCA) and the Court of Protection.

Early consideration needs to be given to:

- An understanding of where, how and by whom the person would like to be supported towards the end of their life and whether he/she would like to appoint someone to make healthcare decisions on his/her behalf when he/she no longer has the capacity to do so.

- Future management of financial affairs such as the appointment of a lasting power of attorney for property and affairs or guardianship or appointee arrangements.
- The making of a will.
- An understanding of the person's preference with respect to the use of or withholding of more invasive treatments in the advanced stages of dementia when he/she will no longer have the capacity to consent. These may include the use of artificial nutrition and hydration, ventilation, and the treatment of infections. If, at an earlier stage of the illness, the person has the capacity to do so they may be supported to make an advanced statement with respect to these matters. The approach and priorities outlined by the LACDP (LACDP, 2014), which emphasises that the person who is dying and the people important to the person must always be involved in decisions about care and treatment, should be followed.
- Funeral arrangements, again in discussion with the person and the people important to them.

16.3 PALLIATIVE CARE AND THE ROLE OF THE PALLIATIVE CARE TEAM

It is important to develop working partnerships and to have close collaboration between different health services and a mutual understanding of philosophies of care including professionals in intellectual disabilities services understanding the role and timing of palliative care in terms of access to specialist support and appropriate symptom management. This needs to include considerations about getting support in the home so that unnecessary hospital admissions can be avoided. The local intellectual disabilities hospital liaison nurse can be very important in promoting joint working. It is also helpful to have a clinician within intellectual disabilities services focusing on palliative and end of life care who can promote this collaboration and lead training within their services about end stage dementia and the role of palliative care.

The nature of dementia makes it difficult to predict whether a person is reaching the end of their life, and this can lead to difficulties in terms of access to palliative care services.

The aims of this approach are to support quality of life, to help the person die with dignity and without pain and in a place of their choosing and to provide support to relatives, carers and friends to help them prepare for the death.

The following are areas that may require particular attention towards the end of the person's life:

Eating and drinking:

People should be supported and encouraged to eat and drink by mouth for as long as possible, with specialist advice being obtained concerning any feeding and swallowing difficulties from multidisciplinary team professionals particularly speech and language therapists, occupational therapists and physiotherapists (concerning seating and posture) and also from dieticians. Weight loss is common in late-stage dementia. Nutritional support, including artificial (tube) feeding should be considered if dysphagia is thought to be a transient phenomenon. NICE guidance QS30 (2013) does not recommend that such artificial means are used in those with severe dementia for whom dysphagia or disinclination to eat is a manifestation of dementia severity. As specific ethical and legal principles apply with respect to withholding or withdrawing nutritional support expert advice should be sought if there is any lack of clarity or disagreement in this area. Further information can be found in Section 15.

Resuscitation:

It is generally considered that cardiopulmonary resuscitation is unlikely to succeed in cases of cardiopulmonary arrest in people with end stage dementia. For those people who have retained their capacity to make a decision on this matter, it is for them to decide whether or not to agree to resuscitation if it were needed. The ReSPECT process can support these discussions. For those who now lack the capacity to make such decisions, any wishes expressed in a valid and applicable advanced decision to refuse treatment must be respected if the circumstances are applicable. The policies and procedures set out in the Mental Capacity Act 2005 (or similar legislation in other jurisdictions) should be followed.

Pain relief:

Unexplained changes in behaviour or evidence of distress in a person with dementia may be indicative of underlying pain. The possible cause for pain needs to be investigated and necessary treatments undertaken and both pharmacological and non-pharmacological approaches to pain relief considered.

Posture:

Management of posture is important in order to optimise remaining abilities and prevent the development and/or progression of secondary complications such as pain, fatigue, muscle shortening, joint deformity, respiratory complications and pressure ulcers. There needs to be assessment of postural management equipment needs such as standing aids (where appropriate), specialist seating provision and sleep systems. Good postural management can also facilitate safe eating and drinking and improve respiratory function.

Resources:

Accessible booklets are available to help people with intellectual disabilities plan their end of life care, e.g. Books beyond words (Am I going to die? – Hollins & Tuffrey-Wijne, 2009, When somebody dies – Hollins et al., 2014), Let's Talk About Death (Down's Syndrome Scotland 2024, When I Die, Sunderland People First in association with the PCPLD Network (Palliative Care for People with Learning Disabilities 2006). The network is a voluntary organisation made up of people with intellectual disabilities and palliative care professionals concerned by their experience that people with intellectual disabilities who were facing a life-limiting illness did not seem to access the same services or receive the same quality of service as the rest of the population. This group also offers other useful resources Making a Will, an accessible leaflet for people with intellectual disabilities concerning writing a will, is available from Mencap (2014).

KEY POINTS

Preparation for palliative and end of life care should be ongoing as the dementia progresses from diagnosis onwards and embedded in personalised plans for care and support at every stage.

People with intellectual disabilities must be able to have the same end of life care planning and access the same palliative care services as everyone else.

All care should be provided in accordance with the provisions of the Mental Capacity Act/ Adults with Incapacity Act (Scotland). Care includes medical care, physical care and psychological and emotional care of the person, and psychological and emotional care of family, friends and peers, and carers and staff, and this needs to be delivered with cultural sensitivity and where appropriate, religious support.

Partnership working and close collaboration between professionals in intellectual disability and other health services, particularly palliative care, is very important in terms of ensuring appropriate access and timing to specialist support and appropriate symptom management. A mutual understanding of philosophies of care in these services needs to be developed.

Section 17 – Capable commissioning for people with intellectual disabilities and dementia

Commissioners of health and social care services are now far more aware of the increase in the prevalence of dementia in the general population, but it is still unclear about their knowledge and expertise in relation to commissioning services for people with intellectual disabilities and dementia, even though guidance was first distributed to commissioners in 2001 (Turk et al., 2001). There is a need for local services and local competent teams who have expertise in working with people with intellectual disabilities who develop dementia.

Commissioners of health services need to be clear about the care pathway for the assessment, diagnosis, interventions and support for people with intellectual disabilities who develop dementia from primary care, through to appropriate secondary care services, and on to palliative care services. In practice, good quality care will involve active partnership-working between intellectual disability services, older people's services, primary and secondary health care, palliative care and social care. These areas should develop an integrated dementia strategy for the care of people with intellectual disabilities and dementia. This should involve the development of an integrated care pathway involving all relevant agencies. Specialist health professionals e.g. speech and language therapists, physiotherapists, occupational therapists, dietitians, community intellectual disabilities nurses are all essential partners in providing excellence in care.

Commissioners of social care need to recognise that dementia is by definition a deteriorating condition, and that peoples' needs will increase over time, and therefore increased and timely funding will be needed to ensure safe practice. This will inevitably involve the funding of waking night staff as the dementia progresses. Best practice is that people with intellectual disabilities should receive their residential care within the intellectual disabilities arena rather than in generic services for people with dementia, as the quality of the services gives people the best opportunities for a good quality of life for both their intellectual disabilities and their dementia. 'My new home: Supporting people with an intellectual/learning disability and advanced dementia moving into a care home. Guidance for staff' – Healthcare Improvement Scotland (2022) can be helpful in the planning process. There will need to be efficient processes and understanding in place to ensure that Continuing Healthcare Assessments are undertaken promptly and funding agreed as needed.

Staff involved in assessment, diagnosis, interventions and support need to be trained in dementia care and be able to offer both holistic and specialist assessments and a range of interventions aimed at meeting the needs of people with intellectual disabilities and dementia. Care managers have an essential role to play in ensuring that services are actively monitored to ensure that they are responsive to the changing needs of the person. People with intellectual disabilities and dementia should have access to regular reviews (monthly–six monthly depending on the rate of deterioration) by an identified care manager.

End of life care needs to be planned in advance, using the same principles and services available to the general population. Good partnership-working with palliative care services is essential, both to support the person and the carers (see Section 16).

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17.1 WHAT ARE THE ELEMENTS OF AN EXCELLENT SERVICE?

Commissioners will want to ensure that there is:

- Knowledge about demographics, including having a database of all adults with intellectual disabilities which includes identification of people who have Down's syndrome and those in out-of-area placements.
- A multi-agency dementia strategy.
- A multi-agency care pathway for assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia without age limitations.
- A multidisciplinary approach to assessment and diagnosis and support.
- Prompt access to assessment and diagnostic services including baseline assessment for people who have Down's syndrome by the age of 30.
- Understanding of cultural issues within their area that may be relevant to dementia
- Annual Health Checks highlight risk factors for dementia, and possible deterioration and refer to the appropriate agreed service for assessment.
- Focus on prevention of dementia e.g. personalised brain health plans.
- Emphasis on relationship-centred dementia care.
- Effective care management and review system.
- Prompt access to the full range of medical, psychological, therapeutic and social interventions for both dementia and other conditions.
- All living and day service environments are dementia friendly.
- The person is supported to remain in their familiar home with additional support provided in a timely manner.
- When commissioning any service for people with Down's Syndrome, consideration should be paid to how appropriate that environment would be for them in the future should they develop dementia, to reduce the number of moves required.
- Support is available to family carers and service providers.
- There is a capable trained workforce in both health and social care able to deliver excellence in dementia care.
- End of life care follows the requirements of the National End of Life Strategy/Palliative and End of Life Care Strategy (Scottish Government, 2019).
- Quality Outcomes for the person are measured and actions taken where quality is less than excellent.

17.2 WHAT SHOULD THE COMMISSIONERS EXPECT AS OUTCOMES OF AN EXCELLENT SERVICE?

- Increase in prompt differential diagnosis of the person's difficulties.
- Increase in other conditions being treated promptly.
- Increase in activities that promote good brain health
- Increase in accurate diagnosis of dementia.
- Reduction in behaviours of distress.
- Increase in quality outcome indicators for the person.
- Reduction in moves to other placements, especially generic care homes.

- Reduction in the need for emergency one-to-one cover.
- Reduction in the need for hospital admissions.
- Reduction in out of area placements.
- Increased carer support and satisfaction.
- Reduction in staff stress.
- Excellence in End of Life Care

17.3 POTENTIAL RISKS IF SERVICES ARE NOT AVAILABLE/ NOT EFFECTIVE

- Poor health outcomes for the person, leading to earlier death.
- Increased costs of one-to-one, new in area or out of area placements.
- More complaints.
- Potential safeguarding issues.
- Increase in behaviours of distress leading to abuse or harm to self and others.
- Carer breakdown.

KEY POINTS

Each area should develop a dementia strategy and integrated care pathway to support the provision of high quality assessment, intervention and care for people with intellectual disabilities who develop dementia.

Section 18 – Capable support

Excellence in dementia care for people with intellectual disabilities and dementia is underpinned by the knowledge and skills of the people who support them, and their ability to continuously adapt to the person's changing needs. It is important to note that good quality care can have a significant impact on a person's dementia presentation, levels of agitation and quality of life (Surr et al., 2018)

18.1 FAMILY CARERS

Family carers need specific emotional and practical support. Many family carers find the diagnosis of dementia traumatic, as it may bring back emotions surrounding the birth, life expectancy and disability of the person. Furthermore, many families will also have prior experiences of family and friends being diagnosed with dementia and thus will have ideas about the journey ahead. Where the family are the main carers, they must be offered a comprehensive Carer's Assessment. Many carers, particularly the parents of people with Down's syndrome, may themselves be at risk of developing dementia or other age-related conditions. Often diagnosis of dementia comes at a time when family carers are themselves reaching a time when they are requiring more support due to their own ageing.

Services need to be sensitive to the needs and beliefs of families, and to see things from their perspective. Some carers believe that it is their duty to care and may find it very difficult to accept support and help into their own home (particularly if they have had a poor experience of services) or try to cope even when the person has needs that are greater than they can cope with. Carers need to have prompt access to appropriate information about support and resources available, including short breaks/respite (both within and away from the home), individualised budgets and direct payments, and aids and adaptations included assistive technology. They need to be involved in assessments and review meetings, even when their family member does not live with them.

Appropriate use of the National Framework for Continuing Health Care (DH, 2023) should be made to ensure that funding of health and social care is fair and transparent.

Staff need to be very sensitive to the small number of carers who struggle to cope with seeing their family member deteriorating, and may opt out of being involved. Life Story work/creating a memory box are positive ways of enabling family carers to maintain a relationship or to stay involved in the person's care. Carers can need a great deal of support to prepare for the eventual death of the person they are supporting. Advanced planning can help carers to be involved in sharing future wishes, and to talk through issues and plan for the last years/months of life.

18.2 PAID CARE STAFF CHARACTERISTICS

Staffing numbers need to be appropriate to ensure the person is safe and that staff are able to meet the person's changing needs. In practice, this means that staffing levels will need to increase as the dementia progresses. By mid-stage dementia, people usually require waking night staff to ensure safety, and often an increase in staffing levels to manage self care and to respond to the distress that people with dementia often exhibit.

Excellent dementia care can only be provided by a consistent staff group. Agency staff, unless very well known to the person, should always be avoided as this can add to the person's stress level. Staff will need to have access to regular training and resources to meet the varied demands of caring for people with intellectual disabilities and dementia.

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There are a range of resources available including the Resource Pack for Carers of Adults with Down's Syndrome and Dementia (Dodd et al., 2009), Keeping people who have Down's Syndrome well before and during Dementia: Workbook for families and staff (Dodd 2025), Supporting People with Learning Disabilities and dementia training pack (Watchman et al., 2018) and a range of DVDs from the Down's Syndrome Association. Dementia training may also be offered by local Community Intellectual Disabilities Teams. In our experience, the best care is provided by staff who are flexible in their approach, deal with changing situations with compassion and humour, cope with the person's declining abilities and can reach out to the person.

Staff need support to cope with the deterioration in the person with intellectual disabilities and dementia and to prepare for the eventual death of the person they are supporting. Research has indicated that caring for people at late stage of dementia raises specific issues related to their readiness to respond to end of life needs; fear of swallowing difficulties; and environmental concerns and ageing in place. See Section 15 for more details.

Staff are the key component in ensuring that people who live in any form of supported living or residential provision can 'live well' with dementia. The timing of training is important. It is important that a service is 'dementia-ready' early on in the course of the dementia. Staff need to have a thorough understanding of the person, of dementia and the consequences of having dementia, and then how to adapt their care as the dementia progresses. This can only be achieved by having a clear framework to underpin the training and support provided to services. Evidence suggests that where staff had received relevant and targeted training that was practice-based and person-centred, they displayed an appreciable difference in confidence, quality of care and support and they also reported reduced stress levels.

Evaluation of training models used with staff who are supporting people with intellectual disabilities with other comorbid conditions suggest that the best outcomes occur when there is interactive training which involves the development of care plans; follow-up consultation and support for implementing care plans; and where there are changes in how the organisation understands and responds to people with dementia.

The importance of developing a shared vision on which to build practice is now well-recognised as the pre-requisite of good care. Without this solid foundation, values, expectations and approaches are likely to differ greatly amongst staff. This will ultimately generate conflict and frustration and will in turn place unnecessary demands on the already confused person with intellectual disabilities and dementia. Sheard (2013) recently introduced the concept of 'mattering' which 'brings together the core elements of emotional care, skills, quality of life and environment with the culture of a shared relaxed community, thereby evidencing that individuals matter'. He emphasises that developing the emotional competency in staff is the only foundation on which progress in dementia care will be sustained and on which dementia care training will finally deliver effectiveness (see Sections 10 and 11).

18.3 DELIVERY OF TRAINING TO STAFF

Experience in training staff teams indicates that improving dementia care for people with intellectual disabilities and dementia requires a whole-system approach within staff teams.

Staff need to understand what is dementia, its specific links to people with intellectual disabilities, and the signs of symptoms that they need to recognise both at pre-diagnosis and at each stage of the disease. However, this needs to be underpinned by a model of dementia care

that helps them to really understand what is happening to the person they are supporting who is developing dementia, and to be able to put themselves in that person's shoes (see Section 10).

18.4 TRAINING CONTENT

Training should use a variety of mediums, e.g. didactic; group work; use of video clips; discussions; role plays; case studies; homework tasks. Training can be supplemented by the use of specific resources e.g. Keeping people who have Down's Syndrome well before and during Dementia: Workbook for families and staff (Dodd, 2025), Resource Pack for Carers of Adults with Down's Syndrome and Dementia (Dodd et al., 2009), Supporting People with Learning Disabilities and dementia training pack (Watchman et al., 2018), Happy Eating (Dodd, 2012).

Table 6 suggests types of training, support and outcomes that should be achieved for each stage of dementia (Dodd, 2014). Each stage builds on the information and supports from previous stages and knowledge and ideas can be re-iterated and developed with the staff team. For further details of the Outcomes required, see Section 19 on outcomes later in this guidance.

18.5 WORKING WITH OTHER RESIDENTS

The effect on other people with intellectual disabilities of seeing a peer deteriorate is rarely considered. Helping peers to understand dementia can reduce their distress and help them to be more considerate and understanding of the changes occurring with the person with dementia, in some cases helping to prevent placements breaking down.

Resources now exist to help explain dementia to adults with intellectual disabilities. Dodd et al., (2005 a ,b & c) published three booklets, *About Dementia, About My Friend* and *The Journey of Life*, to support this aspect of work. These booklets explain dementia in terms of the lifecycle. They can be used individually or in a group setting, as long as supported by confident staff/carers. Both Lyngaard & Alexander (2004) and Dodd (2008) have reported on successful short courses for people with intellectual disabilities living with someone with dementia.

Individual services may also have developed their own resources to share what is happening with their peer.

TABLE 7: SUGGESTED TRAINING, SUPPORT AND OUTCOME FOR EACH STAGE OF DEMENTIA

STAGE OF DEMENTIA	SUGGESTED CONTENT OF FORMAL TRAINING	SUGGESTED ON-GOING SUPPORT	OUTCOME REQUIRED
Prediagnosis	• Signs and symptoms of dementia • The diagnostic process and how to make a referral • Life Story work • Person-centred care plans including health action plan, communication passport, end of life plans	• Understanding the diagnostic process • Working with the person and their family/ friends to develop their life story work • Support to develop end of life plans whilst the person has capacity	• Person is supported through the diagnostic process • Other health issues are identified and treated • Social issues are identified and resolved • Plans are in place
Early stage	• Model of dementia (Buijssen) • Philosophy of care • Physical environments • Importance of picture cues • Medication	• Helping staff to accept the diagnosis and the changes • Grief and loss • Implementing the philosophy of care • Importance of consistency of approach	• Person is supported to maintain their current lifestyle with additional supports and prompts
Mid Stage	• Communication • Supporting the peers of the person with dementia • Failure-free activities • Maintaining health and additional health issues e.g. epilepsy, mobility, continence • Pain recognition and management • Reminiscence	• Understanding the meaning of behaviours and exploring solutions • Avoidance of confrontation • Understanding and coping with agitation and distress	• Person is supported to live as full a life as possible focusing on preferred activities and reminiscence activities and without unnecessary changes
Late and End stage	• Safe manual handling • Safe eating and drinking • Skin and pressure care • Mobility, falls management, posture and positioning • Meeting spiritual needs	• Support for end of life care for both the staff and their support of the person's peers and family • Support in getting appropriate aids in a timely manner e.g. specialist wheelchair, seating, profiling bed, hoist, bathing aids	• Person receives care that allows them to continue to experience activities and support that is familiar to them • Person is supported in all daily living needs in a dignified and safe manner • Person experiences end of life care that results in a 'good death' in their preferred place

18.6 ETHNICITY ISSUES

Ethnic background has been shown to affect the nature of care giving practices, carer stress and help seeking in people with dementia and their carers (Shiekh et al., 2021). Risk factors for dementia such as hypertension and diabetes are more common in a Black, Asian and other

ethnic minority (BAME) population yet dementia is under recognised/diagnosed later and may be associated with stigma. In people with intellectual disabilities in general there are significant differences in the nature of care giving, carer stress and carers' psychological and physical burden (Devapriam et al., 2008). Material disadvantage, lack of informal networks and high need for services are some of the key issues related to people with intellectual disabilities from an ethnic minority background (Hatton et al., 1998).

However, it is not clear how these processes are affected when an individual with intellectual disabilities from a BAME background develops dementia. Clinical experience suggests that the lack of availability of culturally appropriate respite and home care provision cause difficulty. Lack of awareness of services and language barriers may prevent people from ethnic minority communities from receiving appropriate levels of support or even a diagnosis. This can result in significant distress for both the person with intellectual disabilities and their carers.

This highlights the need for more cohesive action by health, social care and voluntary sector services together to improve access to and the experience of services by people with intellectual disabilities and dementia from black and minority ethnic (BAME) communities.

The plan of action should include the following:

- A clear strategy for staff training on diversity.
- Proactive measures to develop partnerships with community and voluntary organisations.
- Facilitation of active participation by people with intellectual disabilities and carers from BAME background in the stakeholder discussions about the development of culturally appropriate services for people with intellectual disabilities and dementia.
- Direct payments and individualised budgets may provide an opportunity for increasing the range of culturally appropriate services available.
- Further research is required to understand the views of people with intellectual disabilities with dementia from BAME communities and their carers about culturally appropriate ways of meeting their needs.

KEY POINTS

Staff are key to ensuring that people with intellectual disabilities and dementia can 'live well' with the disease.

Training must include developing a shared vision on which to build practice – this can only be achieved by training the whole staff team together.

Training is not a 'one-off' activity, but should be delivered on an ongoing basis as the person's dementia progresses to ensure that staff are capable of meeting the person's changing needs and achieving the best outcomes for the person.

Capable dementia services need to be aware of, and meet the needs of, the person with dementia, those of staff and carers and other people with intellectual disabilities who live with the person, including those from BAME communities.

Section 19 – Outcomes

There are a range of quality standard documents which have been produced by different nations to define the expected standards of care for people with dementia.

The National Institute for Health and Care Excellence (NICE) has updated its quality standard on dementia (NG97, NICE, 2018a) which defines what constitutes a high standard of care for people with dementia for people in England and Wales. It covers diagnosing and managing dementia (including Alzheimer's disease). It aims to improve care by making recommendations on training staff and helping carers to support people living with dementia. This quality standard now covers: Involving people living with dementia in decisions about their care; assessment and diagnosis; interventions to promote cognition, independence and wellbeing; pharmacological interventions; managing non-cognitive symptoms; supporting carers; staff training and education. NICE checked the evidence in September 2023 and proposed not to update the guideline at that time.

According to NICE (2018a), this guideline offers best-practice advice on care and support for people living with dementia and their families and carers. The principles of person-centred care underpin good practice in dementia care, and they are reflected in the recommendations. These principles assert:

- the human value of people living with dementia (regardless of age or cognitive impairment) and their families and carers;
- the individuality of people living with dementia, and how their personality and life experiences influence their response to dementia;
- the importance of the person's perspective;
- the importance of relationships and interactions with others to the person living with dementia, and their potential for promoting wellbeing.

Finally, the principles emphasise the importance of taking account of the needs of carers (whether they are family and friends or paid care-workers), and supporting and enhancing their input.

The guideline applies to:

- Healthcare and social care professionals caring for and supporting people living with dementia.
- Commissioners and providers of dementia health and social care services.
- Housing associations, private and voluntary organisations contracted by the NHS or social services to provide care for people living with dementia.
- People living with dementia, their families and carers.

Unfortunately this quality standard has been written as inputs rather than outcomes, and the measures for assessing compliance with these quality standards are purely quantitative in nature and that desired levels of achievement should be defined locally.

SIGN Guideline 168: Assessment, diagnosis, care and support for people with dementia and their carers was published in Scotland in 2023. In addition, The Standards of Care for Dementia in Scotland (Scottish Government, 2011) provide guidance on how each individual standard can be measured. Although people with an intellectual disability were out-with the scope of SIGN Guideline 168, this covers: identification and diagnosis, further investigative procedures, post-diagnostic support, non-pharmacological approaches for distressed behaviour, grief and dementia, changing needs of people with dementia and provision of information.

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The All Wales Dementia Care Standards (2021–2023) have been developed by Improvement Cymru and outline a delivery framework for the Dementia Action Plan for Wales 2018–2022 (Welsh Government, 2018). There are 20 standards which sit within four themes: accessible, responsive, journey, and partnerships and relationships.

In Northern Ireland dementia care outcomes can be assessed using the Self Assessment Tool which is included in The Dementia Learning & Development Framework (2016). This framework outlines thirteen core dementia care themes, and details the knowledge and skills staff are required to have when providing care for people with dementia.

19.1 MEASURING OUTCOMES FOR SERVICES FOR PEOPLE WITH INTELLECTUAL DISABILITIES AND DEMENTIA

In our original guidance on dementia (BPS, 2009) a self-assessment checklist with 15 standards was developed that can be used to evaluate the provision of dementia care across health, social care and voluntary agencies in a geographical area. Many areas have used this as a basis of developing their local dementia strategy for people with intellectual disabilities and to benchmark their services and develop an action plan (e.g. Surrey Learning Disabilities & Dementia Strategy, Surrey County Council, 2011).

The self-assessment checklist took a similar approach to that in the 'Green Light toolkit' (Cole & Gregory, 2004) and Challenging Behaviour: a unified approach (Royal College of Psychiatrists et al., 2007). The checklist reflected the content of the report, and translates the guidance into 'Standards you should see if the recommendations are being met'. However, it differs from previous quality standards in that each standard is written as an outcome rather than an input. The self assessment checklist has been updated and can be found in Appendix 1. Each standard should be rated using a red–amber–green system, with clear descriptors given for each of these for every standard.

19.2 MEASURING OUTCOMES FOR PEOPLE WITH INTELLECTUAL DISABILITIES AND DEMENTIA

Outcome measurement for people with intellectual disabilities and dementia is still in its infancy. Clinicians and professionals working with people with intellectual disabilities are often clear about what works, but this has not resulted in a substantial evidence base.

Specific areas have been looked at for groups of individuals, e.g. effectiveness of staff training, type of living establishment, use of personalised technology.

Within the general population of people with dementia, a range of measures have been developed and evaluated, but many instruments are not sensitive enough to detect change. However, it is clear from the literature that current measures see dementia as a 'stable' disease rather than one which is progressive. It seems vital that any measure is sensitive to the progression of the disease and not just for people with early or mid stage dementia.

One of the key components of excellence in dementia care is the ability of the system around the person with dementia to continuously adapt their understanding, care and resources as the person's dementia progresses. Staff who work in homes and day services for people with intellectual disabilities usually receive training as people are identified as having dementia. This allows them to become proficient at meeting the needs of people at the newly diagnosed/early stage. However, as the dementia progresses they are less able to adapt what they do in line with

the person's changing needs. This often leads to staff feeling that they cannot care for the person with changing needs and that they are always 'lagging behind'. In turn, this can lead to poorer outcomes for the person with mid or late stage dementia.

Outcome measurement needs to relate to the stages of dementia and how the care for the person is adapted as the disease progresses. It also needs to focus on outcomes for the person and not for processes.

The Quality Outcome Measure for Individuals with Dementia (Dodd & Bush, 2013; Dodd et al., 2015) has been developed from the BPS/RCPysch guidance (BPS, 2009). The measure has 17 domains. Each domain has a description of the required quality outcome for each of the three main stages of dementia – suspected/early, mid and late stage. The measure can be found in Appendix 4. A checklist to aid completion for each stage of dementia can be found in Appendix 5.

The QOMID should be completed by the professional in discussion with the relevant people for the particular stage of dementia that the person has. Wherever possible, and depending on ability, the person with dementia should be asked how they would rate their experience in each domain. Additional information for the professional to make an inclusive judgement may come from family, support staff, advocates, care managers or anyone else involved with the person and their support, often at a care review meeting.

In supporting the person with dementia, the aim is for them to have high quality outcomes throughout the progression of their dementia. As dementia is a progressive condition, it is vital to ensure that the person's changing needs are recognised and met. This may mean that scores may fluctuate during the course of the dementia as support 'catches up' with the person's changing needs.

The QOMID is also designed to help everyone involved supporting the person to work with the person and their carers to both prevent deterioration in quality outcome and to forward plan effective care. For each domain that is scored at less than the maximum, the support team is asked to specify what needs to be put in place to improve the person's quality outcome for that domain. These actions can then be included in the person's support plan. In addition, by looking at the descriptions for the next stage of dementia, the professional can begin to help the person and their supporters to think about what needs to be put in place to maintain the person's quality outcome.

Many services in the UK are now using the QOMID as part of their post-diagnostic pathway.

CASE STUDY

Brian was diagnosed with dementia. The clinical psychologist and occupational therapist met with the staff team and care manager. The QOMID was used to evaluate his quality outcome. The results were used to create a dementia care plan based on the interventions described in this guidance. This provided a clear overview of who was doing what in relation to Brian's support needs, e.g. the occupational therapist to source further equipment, the training that was needed, and the need for the community incontinence service to be involved. Regular reviews ensured that everyone was aware of any changes in Brian. It was hoped that this would reduce the need for crisis intervention. The home manager reported the reviews as helpful as they often did not notice deterioration until they had space to reflect, as they were with the person daily. It also meant better quality care for Brian as all those involved in his care were accountable for certain outcomes. The home manager felt that they were better supported by the community intellectual disabilities team whereas previously they felt that they had been left to struggle until a crisis occurred.

Further analysis of the use of the QOMID has been undertaken in a cohort from Surrey (Ryan & Dodd, 2023). This suggested that there were significant differences in achievability across the domains but that achievability did not vary between early and mid-stages of dementia. Domains of emotional reassurance to cope with changes, nutrition and mobility, were some of the more achievable quality outcome domains, whilst environment and person-centred approaches to support scored on average the lowest, meaning they were less likely to be 'completely and consistently achieved for this person'.

The authors also looked at the recommendations made after completing the QOMID. The main themes were: quality of paperwork and documentation; improving communication with the person with DS and dementia; and working together with health and social care professionals. In conclusion, the authors suggest that outcomes which fall outside of the typical learning disabilities skillset and are dementia specific are being achieved less often. Primarily, recommendations focused on practical solutions such as using visual timetables to communicate with the person and adapting their environment.

Further work on integrating the QOMID and stage-related team training for care staff is underway.

KEY POINTS

Each area should use the Self-Assessment Checklist to measure the Outcome of their services for people with intellectual disabilities and dementia, and to assist in the development of a local strategy document.

Individual quality outcomes for each person with intellectual disabilities and dementia can be measured using the Quality Outcome Measure for Individuals with Dementia (QOMID).

Section 20 – Future directions and research

20.1 POLICY CONTEXT

Alzheimer's disease and dementia are a key research priority for many countries, and the aim of the international community is to ensure that it has the same prominence as cancer research.

Within this context, the development of new treatments for dementia, and trials to assess such treatments, have a high priority for the NHS (Department of Health, (2020). Furthermore, the Down Syndrome Act (2022) aims to improve access to services and life outcomes for people who have Down's syndrome. The hope is that it will also increase opportunities for improvement in treatment through research in this population.

Whilst there is a major focus on medication to target the development of amyloid pathology in Alzheimer's disease, clinical trials of treatment are not just about pharmaceutical developments but also about psychological treatments and other approaches, the aim of which might be to maintain function and the dignity of those affected by dementia (Muralidhar et al., 2024). We recognise that new treatments for dementia are being, and will be, developed and it is imperative that people with intellectual disabilities, in general, and people who have Down's syndrome, specifically, have the opportunity to partake in trials and subsequently benefit from the treatments that are found to be safe and effective (Strydom et al., 2018).

20.2 ADVANCES IN BIOLOGICAL UNDERSTANDING

Advances in the understanding of dementia in people with intellectual disabilities, in general, and people who have Down's syndrome, in particular has become more possible with improvements in diagnosis and in the means of tracking the cognitive and functional changes associated with dementia over time. Research in the UK and internationally has clearly established that people who have Down's syndrome have a high risk for developing the clinical features of dementia from their 30s with a peak incidence in their early 50s (Holland et al., 1998, Wiseman et al., 2015, Baksh et al., 2023). Similarly, people with intellectual disabilities (not due to Down's syndrome) have a slightly earlier age-related prevalence profile of dementia than the typically developing population (Baksh et al., 2023).

For people who have Down's syndrome the focus of research has been on the role of the amyloid precursor protein (APP) gene on chromosome 21 (therefore inherited in triplicate in people who have Down's syndrome) leading to the 'amyloid cascade hypothesis' for dementia of the Alzheimer's type in this population (Wiseman et al., 2015). New structural (MRI) and ligand-based (PET) neuroimaging studies for measuring brain amyloid and tau provide the means for investigating this relationship and large scale genomic, proteomic and metabolomic studies could enable the influence of variations on the trajectory of the course of dementia process to be studied (Zammitt et al., 2024).

Particularly in people who have Down's syndrome, the longer term objective of research is the development of a preventative treatment. The initial aim is to characterise the pre-symptomatic and prodromal stages of disease using biomarkers, to enable trials of preventive treatments. Such trials are already on-going and are being conducted as formal double blind placebo controlled trials, both in the general population, and in people with familial Alzheimer's disease and people

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who have Down's syndrome. At present treatment developments aimed at preventing dementia in people with who have Down's syndrome are focused on the modification of beta amyloid dysregulation in the brain. For people with intellectual disabilities not due to Down's syndrome advances in treatment are likely to emerge from research in the typically developing population, however, these may need more formal evaluation (particularly with respect to side effect profiles as they may differ) in the intellectual disabilities population.

20.3 RESEARCH IN ENVIRONMENTAL AND PSYCHOLOGICAL STRATEGIES

Outside of pharmaceutical developments, there has been an increase of interest in research involving people with intellectual disabilities in the environmental and psychological strategies used in the general population to optimise function and maintain quality of life, such as the FINGER trial (Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability). The FINGER trial (Ngandu et al., 2015) demonstrated that in the general population that interventions of physical activity, cognitive training, social activity, and monitoring of cardiovascular risk factors, reduces the risk of cognitive decline pre-dementia in those who were identified to be at risk of dementia. However, the intervention may require adaptation for people with intellectual disabilities and the benefit of such as approach needs to be established using trial methodology.

Research, whether of a pharmaceutical agent or of some support strategy requires the identification and involvement of people with intellectual disabilities and those who support them.

20.4 CLINICAL TRIALS

The most significant progress that has been of importance for clinical trials has been the wider recognition of viewing Down's syndrome as a genetic form of Alzheimer's disease, the development of biomarkers and the advances in the biological staging of the disease. Encouraged by some success of immunotherapies that target to remove amyloid in the brain bringing about some clinical benefits in the non-intellectually disabled population, it is imperative that services can be developed to bring this for the benefit for people who have Down's syndrome.

However, there needs to be more progress made and further research needs to continue. Such research requires collaboration between people with dementia and their families, clinicians, social care providers and clinical academics and basic scientists. Research of this type has particular challenges if the right balance is to be achieved between enabling research that will lead to new treatments, on the one hand, and, on the other, ensuring the people with intellectual disabilities and dementia are not exposed to excessively intrusive research or to exploitation. It will be clinicians and support workers who are at the forefront when it comes to recruitment to such trials.

20.5 THE ROLE OF CLINICIANS IN RESEARCH

The following section highlights how clinicians can work in partnership to facilitate such research.

To enable research a major priority is to improve the recruitment of patients into research through building on the NHS Constitution pledge to inform patients about opportunities to participate in research and engaging the NHS in the implementation of RAFT (the Recruitment and Feasibility Tool – a database for patients to register their interest in dementia research). Clinicians and those who support people with intellectual disabilities are the gateway to recruitment and the attitude

taken to research by these two groups of people has a powerful impact on whether the potential participant is willing to meet those doing the research. Ultimately it must be for the person with intellectual disabilities to decide or, where he/she lacks the capacity to consent, the protocols and safeguards in the appropriate European and national legislations then apply (e.g. European Clinical Trials Regulation 536 (2014), Mental Capacity Act (2005), Adults with Incapacity [Scotland] Act (2000).

With the widespread use of electronic health records and health data repositories searches are now possible according to particular diagnostic categories. The identification of potential participants for research has therefore become more feasible. Specialist services for adults with intellectual disabilities should ensure that all people with intellectual disabilities seen and who have received a diagnosis of dementia are identifiable by the service and at the time of diagnosis those concerned and those supporting them are informed about the importance of research, including any trials that are taking place. Specialist services have a responsibility for the identification of people with intellectual disabilities and dementia and to be willing to approach those meeting the necessary criteria for inclusion in a study on behalf of the research group undertaking the study.

In clinical practice different clinicians and services may have their own approaches but for research it is usually necessary to have more formal and time-consuming assessments so that findings can be compared across studies – see Section 6 for examples of diagnostic instruments and cognitive and functional assessments. Whilst it is through additional research funding that these more extensive assessments can be undertaken than is possible in clinical practice the use of agreed diagnostic assessments and of standard cognitive assessments would enhance recruitment on a larger scale for studies of, for example, risk and protective factors or for treatment trials. Clinicians working in local specialist services should establish diagnostic and assessment protocols that are agreed and in general use.

20.6 INFRASTRUCTURE AND FUNDING

In England, the NIHR has established a Clinical Research Network (CRN) with regional hubs that support research recruitment and ensure that clinicians and patients from all parts of the country are able to participate in and benefit from research. The NIHR through its Networks provides the infrastructure and it is able to support clinical trials in adults with Down's syndrome or intellectual disabilities who have dementia. Similar networks have been established in Wales (Clinical Research Collaboration Cymru – CRC Cymru) and in Scotland (the Scottish Clinical Research Network). The Scottish Dementia network (SDCRN) has been very supportive of dementia research in the intellectual disabilities population. Intellectual Disabilities Services clinicians who are interested in research in this population could also join research groups associated with their professional organisations, such as the Dementia in Intellectual Disabilities special interest group (DID-SIG) associated with the Intellectual Disability Faculty of the Royal College of Psychiatrists.

There are no specific funding streams for dementia research in intellectual disabilities, and it may be seen as a 'niche' area for mainstream funders. Funders may therefore benefit from being made aware of the importance of research in this area.

20.7 RECOMMENDATIONS

1. Staff in services seeing adults with intellectual disabilities and, specifically adults who have Down's syndrome, where the diagnosis of dementia is being considered, should ensure that when a diagnosis of dementia is made the person concerned and those who support them

are made aware of research projects being undertaken and permission requested to pass on their details to any approved and relevant research project.

2. Services have the means to retrospectively identify any person with intellectual disabilities diagnosed as having dementia and specifically people who have Down's syndrome either in the age at risk for dementia or with a diagnosis of dementia and be willing to be a point of contact with them if approved and appropriate research is being undertaken that is looking for potential participants.

3. In specialist memory clinics and in services for adults with intellectual disabilities the use of standardised diagnostic and neuropsychological assessments for the diagnosis and monitoring of dementia, as it affects people with intellectual disabilities, is encouraged. This will ensure that comparison can be made across services and over time thereby providing consistent and reliable data on prevalence and incidence of dementia in this population and enabling recruitment into future trials of any new intervention or treatment.

4. Clinical trials are needed to improve the evidence base of treatments for people who have Down's syndrome (due to their high risk for Alzheimer's disease) particularly of disease modifying drugs, and non-pharmacological approaches such as FINGER, which is a multimodal approach involving all five 'fingers' daily: a healthy diet, physical activity, cognitive stimulation, social activities, and the monitoring of risk factors related to cardiovascular disorders.

5. There is a need to further develop the evidence base around new biomarkers (particularly blood-based biomarkers) in people who have Down's syndrome, a high risk population, in order to improve surveillance and early diagnosis in the context of new treatments that may require earlier stages of disease to be identified.

6. Family history of dementia, which may raise the possibility of a genetic aetiology of the dementia (for individuals without Down's syndrome). College Report 237 on genetic testing in mental health settings and SIGN guideline 168 provide guidance on when genetic testing should be considered in individuals who present with dementia.

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Appendix 1 – Early signs of dementia in people who have Down's Syndrome checklist

People who have Down's Syndrome are more likely to develop a 'frontal like' dementia prior to developing Alzheimer's disease.

The most common early signs to look out for are changes in:

- Mood
- Behaviour
- Executive function e.g. planning, initiative, problem solving, reasoning
- Personality
- Social skills

Signs of Alzheimer's disease are when the person shows the following changes that are different from how they normally are:

- Anxiety in unfamiliar places
- Change in ability to complete tasks of daily living including how the person does tasks, and the time take to complete them
- Deterioration in short term memory e.g. forgetting what they have said, losing their belongings, asking the same question repeatedly
- Loss of interest in previously enjoyed activities
- Change in ability to learn new things
- Reduced communication
- Difficulty in finding the correct word
- New or increased confusion and/or disorientation
- Changes in sleep pattern
- Difficulties with steps, stairs and kerbs, changes in colour of flooring due to depth perception problems
- Increased walking about without a clear reason

Misdiagnosis of dementia can occur because the signs are the same as those for a number of treatable conditions e.g.

- Depression
- Lack of sleep
- Urinary Tract Infection
- Adverse effects of medication
- Thyroid dysfunction
- Untreated pain (e.g. due to dental pain)
- Dehydration
- Constipation
- Hearing/Visual impairment

Please see the table attached to help think about possible causes and actions to take.

It is recommended that you visit the GP to express concerns in the first instance to rule out any of the above, prior to contacting your local CTPLD for an assessment.

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WHAT MIGHT THE EARLY SIGNS INDICATE?

Obtaining a correct diagnosis is extremely important in terms of ensuring that the person receives the correct treatment or intervention. Many of the early signs of dementia can also be the result of other factors. Below is a list of some of the other conditions that may mimic some of the early signs of dementia.

STRESS	UNDERACTIVE THYROID – MORE COMMON	FEATURES OF DEPRESSION/MOOD DISTURBANCE	SENSORY (HEARING OR SIGHT) IMPAIRMENTS	PHYSICAL CHANGES	DEMENTIA
Concentration Problems	Lethargy	Disturbed sleep	Ignores Instructions	Withdrawal	Loss of recent memory or impaired new learning
Irritability	Weight Gain	Loss of appetite	Mobility problems	Aggression	Loss of skills
Decline in abilities	Cold Intolerance	Low mood	Loss of confidence	Mobility problems	Changes in mood
	Changes in skin and hair	Withdrawal from usual activities	Shouting or raised voice	Self-injury	Orientation difficulties
		Tearful	Appears low in mood	Pacing	Sleep disturbances
				Crying	Language difficulties
				Screaming	Depth perception problems
If you notice any of these changes, carry out the following actions…					
Identity stressor; recent life event e.g. deaths, move, illness	See GP	See GP	Complete full health assessment	See GP; medical history and physical investigations	See GP; medical history and physical investigations
Offer support and reassurance	Annual blood tests (TSH, T3, T4)	Medication and/ or counselling	Check eyes, ears and feet	Medication changes	Refer to CTPLD
	Is it an under or overactive thyroid?		Access appropriate services	Check for Diabetes	
				Check for Pain	
				Check for urinary tract infections	
				Check for nutritional deficiencies/ dehydration	
				Check re perimenopause (endocrine profile needed)	

*This table has been adapted from Earnshaw & Donnelly (2000)

Appendix 2 – Good Practice Standards – Self Assessment checklist

This framework is designed to be used by members of Partnership Boards or their equivalent, and senior professionals (clinicians, social workers, managers, commissioners and those responsible for inspection and review) who have responsibility within a defined area or population for the provision of services to people with intellectual disabilities who develop or at risk of developing dementia. It is a self-assessment checklist that should be used to establish the extent to which local processes and practices reflect 'best practice' as described in more detail elsewhere in this document.

The current provision and practices that are followed by services should be reviewed against the standards that are described. Users, advocates and carers should also be involved in the review process. The standards apply to people living in family homes, health and social care provision (within the statutory and independent sectors). They also apply when out of area placements have been purchased by the relevant authorities.

The checklist should be:

- Reviewed in a multidisciplinary/multi-agency setting, with the aim of achieving a consensus view about how local services compare against the Good Practice Standards.
- The team that carries out the review of standards should ensure that they have the appropriate membership to achieve a broad view of services.
- The team should include: commissioners, practitioners from the Community Intellectual Disabilities Team, practitioners from the relevant Older Adults Mental Health Service, Social Services care managers, residential providers, day service providers, inspection teams, people with intellectual disabilities and carers.
- The reviewing team should refer to the relevant section in the guidance document to clarify the detail required to show compliance with the standard.
- Evidence for compliance with each standard should be demonstrated.
- A joint action plan should be developed to address any areas of need, or to build on current good practice.
- The action plan should be reviewed regularly to update on progress.

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1. Legal framework and guidance					
Standard		**Green Amber Red**	**Action Required**	**By whom**	**By when**
1.	People who develop, or are at risk of developing dementia have access to assessments and interventions that are delivered within current legislation and national guidance. Refer to Section 1.				
Green: People who develop, or are at risk of developing dementia have services delivered within current legal and best practice requirements. These will include: • Clear health and social care pathways that incorporate assessment of capacity, in line with the Mental Capacity Act. • The presence of a local advisory group with clear terms of reference, to consider issues of best interest for people who lack capacity. • Local care pathways are in place to ensure compliance with national clinical guidelines on dementia and their National Dementia Strategy. • All people with intellectual disabilities who develop (or are at risk of developing) dementia have a person-centred plan. • Annual Health Checks and Health action plans are offered to all people with intellectual disabilities who are at risk of developing dementia. • People with intellectual disabilities who are at risk of developing dementia have the opportunity to plan their future care and have considered advance decisions and end of life planning as part of their care package. • There is a published local Safeguarding Adults policy that people with intellectual disabilities, clinicians and carers can access. • Where people have 'out of area' placements purchased for them, the purchasing authority regularly checks that the provider also achieves these standards.					
Amber: There are a few elements that require action in order to meet national guidance and to comply with current legislation.					
Red: There are significant gaps between national guidance/ legislation and local practice.					

2. Population					
Standard		**Green** **Amber** **Red**	**Action Required**	**By whom**	**By when**
2.	Each area has a register / database of people with intellectual disabilities, which identifies people who have Down's syndrome that can be used to plan and deliver effective services. Refer to Section 2.				
Green: There is a regularly updated register / database of all adults with intellectual disabilities known to both health and social care in the catchment area. This includes the identification of people with Down's syndrome, and people who are the responsibility of the area but have services purchased for them in other areas.					
Amber: There is only a partial database, or it is not regularly updates, or it does not identify people with Down's syndrome, or it only identified people with Down's syndrome, or excludes people who are placed by the authority in out of area accommodation.					
Red: There is no register / database or it is not regularly updated.					

3. Multi-agency dementia strategy					
Standard		**Green Amber Red**	**Action Required**	**By whom**	**By when**
3.	Each geographical area has an agreed multi-agency intellectual disabilities and dementia strategy for people with intellectual disabilities with an agreed action plan that addresses the standards outlined in this document. Refer to Section 17.				
Green: There is an agreed comprehensive multi-agency intellectual disabilities and dementia strategy that addresses all of the standards that are detailed in this guidance document.					
Amber: There is either: only a single agency intellectual disabilities and dementia strategy, or: a multi-agency strategy for some aspects of the standards that are detailed in this document, but it is not comprehensive in scope.					
Red: There is no agreed strategy within any agency.					

4. Care Pathway					
Standard		**Green Amber Red**	**Action Required**	**By whom**	**By when**
4.	People who develop, or are at risk of developing dementia, have assessment, diagnosis, interventions and support delivered according to an agreed multi-agency care pathway which includes access to other services beyond the specialist intellectual disability areas as applicable (e.g. Older People's Mental Health Services, neurology, advocacy). Refer to Section 17.				
Green: There is a multi-agency care pathway for assessment, diagnosis, interventions and support of people who develop, or are at risk of developing dementia, which has been agreed by the Partnership Board or its equivalent.					
Amber: There is a single service care pathway, or only a partial care pathway or it is not fully agreed.					
Red: No care pathway has been agreed.					

5. Multidisciplinary approach to assessment, diagnosis and support					
Standard		**Green Amber Red**	**Action Required**	**By whom**	**By when**
5..	People who develop, or are at risk of developing dementia are offered assessments, diagnosis and specialist support from the full range of dedicated and skilled professionals within intellectual disabilities services. They have easy access to specialist assessments within the general health services (e.g. neurology) Refer to Section 17.				
Green: There is a full range of suitably trained professionals within the intellectual disability specialist services that fully matches the care pathway. They have easy access to specialist input from mainstream services such as neurology.					
Amber: The workforce only partially matches the care pathway.					
Red: There are significant gaps in staffing to deliver the care pathway.					

6. Assessment and diagnosis					
Standard		**Green** **Amber** **Red**	**Action Required**	**By whom**	**By when**
6.	People who develop, or are at risk of developing dementia have easy access to comprehensive assessment and diagnostic services according to an agreed protocol. Refer to Sections 3 – 8.				

Green: Within each area, people who develop, or are at risk of develop dementia have easy access to comprehensive assessment and diagnostic services where:

- Assessments are undertaken according to an agreed assessment protocol that includes decisions on whether the service offers baselines, reactive screening and / or prospective screening.
- Assessments follow an agreed assessment battery including both direct assessment of the person with intellectual disabilities and informant assessment.
- Assessments include physical, psychological, social and environmental factors.
- There is a timely response to referrals.
- Diagnosis is multi-disciplinary and based on established diagnostic criteria.
- There is a written formulation.
- There is a protocol for how to share the diagnosis of dementia both with people with intellectual disabilities and carers.
- Other illnesses / conditions are identified and treated promptly.

Amber: There are a few gaps that require action in order to achieve a comprehensive assessment and diagnosis service.

Red: There are significant gaps between the best practice standards for assessment and diagnosis, and the current local procedures.

7. Person Centred Dementia Care					
Standard		**Green** **Amber** **Red**	**Action Required**	**By whom**	**By when**
7.	People who develop, or are at risk of developing dementia, have their care provided according to person centred principles and this is individualised to meet the needs of the person. Refer to Section 11.				
Green: People who develop, or are at risk of developing dementia have: • A person centred plan that has been drawn up with the person to include future needs. • Dementia care provided according to an agreed philosophy of care that places the person at the centre of the process. • Care provided following the principles of the Mental Capacity Act and least restrictive practices. • Care able to meet their changing needs without risk or delay. • Care provided that promotes social inclusion.					
Amber: Most people will receive care that meets this standard, but there are some gaps for a few people.					
Red: Fewer than half of the people who have dementia or are at risk of developing dementia receive care that meets this standard.					

8. Care Management and Review					
Standard		**Green Amber Red**	**Action Required**	**By whom**	**By when**
8.	People who develop, or are at risk of developing dementia, have their care purchased, monitored and reviewed by an effective care management system, whether in the geographical area or in an out of area placement. Refer to Section 17.				

Green: There is a clear inter-agency care co-ordination system that ensures that all people with intellectual disabilities and dementia have:

- A named care manager.
- A written multi-disciplinary care plan incorporating the person's person centred plan.
- Regular care reviews.
- A health action plan that identifies pain signals and management.
- Proactive risk assessment and management plans in place.
- Access to flexible funding to meet changing needs without delay.
- Outcomes monitored regarding their quality of life.
- Staffing levels increased as required including the provision of waking night staff.
- Care that recognises that people with intellectual disabilities and dementia should not be moved unless absolutely necessary.
- No multiple moves.

Amber: Most elements of a comprehensive care management system are in place but there are a few gaps.

Red: There are significant gaps in the system.

9. Interventions

Standard		Green Amber Red	Action Required	By whom	By when
9.	People who develop dementia have prompt access to the full range of medical, psychological, therapeutic and social interventions as required. Refer to Sections 13 & 14.				

Green: People who develop dementia have, as required, prompt access to staff who deliver:

- Medications in line with NICE guidance, according to a locally agreed protocol.
- Strategies, equipment and aids to maintain mobility, promote exercise, address posture, correct gait and reduce the risk of falls.
- Specialist pressure area care.
- Strategies for maintenance of adequate oral intake in a safe manner. This includes swallowing assessment, eating programme with dietetic advice along with advice regarding posture, and diet to reduce risk of constipation.
- Aids / adaptations to help to maintain continence.
- Strategies to aid communication including communication passports, objects of reference, pictures, signposting, signs and symbols.
- Additional supports to maintain self care and domestic skills and adaptation of the environment to aid daily living.
- Support for people to engage in failure free activities including sensory stimulation, aromatherapy, and other therapeutic activities.
- Reminiscence, reality orientation, life story books, validation therapy.
- Dementia care mapping.
- Positive Behaviour Support including promotion of positive behaviour and feelings of self esteem, anxiety management, functional analysis and setting up of programmes for challenging behaviours, setting up of crisis intervention plans

Amber: Most elements of a comprehensive intervention service are in place, but there are a few gaps.

Red: There are significant gaps in the range of services that are required.

10. Dementia Friendly Environments					
Standard		**Green Amber Red**	**Action Required**	**By whom**	**By when**
10.	People who develop, or are at risk of developing dementia, have accommodation and day and leisure activities which are dementia friendly and are commissioned to meet their changing needs. Refer to Sections 12.				
Green: Most people in the area, who develop or are at risk of developing dementia, have accommodation and day and leisure activities which are dementia friendly and can meet their changing needs. Any accommodation and / or day and leisure activity will be appropriate in terms of: • Have been identified as being 'dementia friendly'. • Have ensured that environments are safe, suitably stimulating, make sense and are predictable. • Have ensured appropriate use of colour in homes and services. • Have ensured appropriate furnishings are provided. • Provide appropriate aids and adaptations in a timely manner. • Provide appropriate wheelchairs, special beds and special seating in a timely manner. • Use appropriate assistive technology.					
Amber: Some people in the area will have access to accommodation and activities that meet these quality standards.					
Red: Few people in the area have access to accommodation and activities that meet these quality standards.					

11. 'Dying in place'					
Standard		**Green** **Amber** **Red**	**Action Required**	**By whom**	**By when**
11.	People who develop dementia are supported to 'die in place', with additional supports provided in a timely manner. Refer to Section 12.				
Green: There are processes in place to ensure that people who develop dementia are supported in ways that help to maintain them in their own home with: • Good advance planning • Additional staff as required including waking night staff • Environmental adaptations as necessary • A system for rapid availability of funding to meet changing needs • Good end of life care If the person needs to move, then the new service should be: • Close to the person's existing home • Within intellectual disabilities services • Allow links to existing day and leisure opportunities to be maintained • A final move					
Amber: Most people will receive care that meets this standard, but there are some gaps for a few people, such that they are moved out of the intellectual disability services.					
Red: Fewer than half of the people who have dementia receive care that meets this standard, or people experience significant delays in providing necessary supports, or people are placed in nursing homes.					

12. Choices and rights of people with intellectual disabilities and dementia					
Standard		**Green Amber Red**	**Action Required**	**By whom**	**By when**
12.	The wishes, choices and rights of the person with intellectual disabilities who develops, or is at risk of developing dementia are respected, and this is evidenced in the care provided. Refer to Section 11.				
Green: Within the identified area, people with intellectual disabilities who develop, or are at risk of developing dementia all have: • A regularly updated Person Centred Plan. • A regularly updated Health Action Plan. • An individualised care plan that is developed with all services that the person utilises, and is coordinated across services. • Accessible reports about their care. • Accessible information about dementia. • Support for their peers with regard to dementia. • Appropriate advocacy to meet their needs.					
Amber: There are some gaps in services so that most, but not all people have access to all these provisions.					
Red: There are significant gaps, such that few people have access to all these provisions.					

13. Support to family carers					
Standard		**Green Amber Red**	**Action Required**	**By whom**	**By when**
13.	Family carers are assisted to understand and support their relative who has dementia. Their needs as carers are met. Refer to Section 18.				
Green: Within the identified area, family carers are assisted to understand and support their relative who has dementia: • All carers of a person with intellectual disabilities and dementia are offered a carer's assessment in line with Local Authority guidance. • Respite care / short breaks are available to those with dementia who are living with a family member. The respite provision is able to provide 'dementia friendly' accommodation and services. • Family carers are offered accessible information including: dementia in people with intellectual disability/Down's Syndrome, thyroid disorder, depression, pain awareness, etc, as relevant to the individual person. • Family carers are provided with support from the local Intellectual Disabilities Community Team as required to manage, for example, challenging behaviour, depression, epilepsy, eating and drinking, aids and adaptations. • Family carers are offered training sessions to increase awareness of dementia and its management in the home setting. • Family carers are consulted about the development of services to people with intellectual disabilities in their area.					
Amber: Carers have access to most of these services and there are only a few gaps in such provision.					
Red: There are significant gaps in the provision for carers.					

14. Capable Workforce					
Standard		**Green** **Amber** **Red**	**Action Required**	**By whom**	**By when**
14.	People who develop, or are at risk of developing dementia, and their families, receive support, advice and care from a capable workforce that is appropriately skilled. Refer to Section 18.				
Green: Within the identified area: • Members of the Intellectual Disabilities Community Team are up to date in their knowledge and skills through continuing professional development opportunities with regard to: the risks of dementia, its early symptoms and progress and the methods of managing it. As a consequence, they can provide evidence-based assessment and advice to individuals and care teams. • A rolling programme of dementia training is provided to the care staff via whole team training in the identified area throughout the year. A log is kept of attendance. Homes caring for someone with dementia and intellectual disabilities are specifically targeted. • Intellectual Disabilities Community Team staff provide training and support to care staff teams in residential, respite and day activity settings concerning the management of any individual with dementia, as required. • There is a workforce development plan that addresses the issues of dementia care.					
Amber: There are some gaps in the workforce development, with some staff not being suitably trained.					
Red: There are significant gaps in the workforce development, with many staff not having the necessary skills to support people who have dementia.					

15. End of Life Care					
Standard		**Green** **Amber** **Red**	**Action Required**	**By whom**	**By when**
15.	People with intellectual disabilities and dementia have End of Life care delivered in line with the national strategy. Refer to Section 16.				
Green: Within the identified area, End of Life care includes all the following elements: • The person with intellectual disabilities and dementia has been involved as fully as possible in decisions and preferences with regard to end of life care. • Carers of the person with intellectual disabilities and dementia have been involved in end of life discussions. • Mental capacity assessment has taken place with regard to specific end of life decisions. • Where possible, the person with intellectual disabilities has been given the opportunity to make Advance Decisions about their care. • Where the person does not have capacity, decisions are made following Best Interests guidance. • Palliative care services are able to meet the needs of people with intellectual disabilities and dementia.					
Amber: There are a few gaps in the provision of a comprehensive end of life care for people with intellectual disabilities, but most of the elements are available.					
Red: There are significant gaps in provision, such that few people receive comprehensive end of life care.					

16. Quality Outcomes					
Standard		**Green Amber Red**	**Action Required**	**By whom**	**By when**
16.	The quality outcomes for people with learning disabilities and dementia are measured regularly to ensure that there is evidence that people are receiving excellent person centred dementia care. Refer to Section 19.				
Green: Within the identified area, • The person with intellectual disabilities and dementia has had their quality outcome measured at least at each stage of dementia • The person with intellectual disabilities and dementia and their staff and family carers have been involved in assessing the person's quality outcome. • The quality outcome measure has been used to identify where improvements in care can be made • The improvements have been put in place within the agreed timescales. • Further reviews have taken place to ensure the quality outcome is maintained especially with the progression across the stages of dementia.					
Amber: There are some gaps in the measurement of the person's quality outcome and the timely improvements needed.					
Red: There are significant gaps in the measurement of the person's quality outcome and the timely improvements needed.					

Appendix 3 – Quality Outcome for Individuals with Dementia (QOMID)

QUALITY OUTCOME MEASURE FOR INDIVIDUALS WITH DEMENTIA (QOMID)

KAREN DODD AND ALICK BUSH (2013) ©

INSTRUCTION BOOKLET

WHAT IS THE QOMID?

The Quality Outcome Measure for Individuals with Dementia (QOMID) has been designed to measure the quality outcomes for any person with dementia. It is easy to use, and in initial analysis, has good internal consistency as a measure of quality outcome.

The QOMID consists of 17 domains which explore the key areas that ensure that the person with dementia is experiencing a good quality experience.

The QOMID is staged for the three main stages of dementia – suspected/ early; mid and late stage. Although the domains are the same for each stage, the description of quality outcomes may change across the stages to reflect the different requirements as dementia progresses.

The QOMID must be used in its entirety, and should not be amended.

The QOMID is available free of charge from https://cms.bps.org.uk/sites/default/files/2022-09/Quality%20outcome%20measure%20for%20individuals%20with%20dementia%20%28QOMID%29.pdf.

The Scoring Sheet can be found at: https://www.bps.org.uk/node/1611

WHEN TO USE THE QOMID

The QOMID should be used sequentially to rate the quality outcome of the person as their dementia progresses. The QOMID should be used as part of a regular review of the person's care to ensure that the person maintains good quality experience through the course of their dementia.

WHO SHOULD COMPLETE THE QOMID?

- The QOMID should be completed by the professional in discussion with relevant people for each stage of dementia.
- It is particularly effective when completed as part of a review of the person's care.
- Wherever possible, and depending on ability, the person with dementia should be asked how they would rate their experience in each domain.
- Additional information for the professional to make an inclusive judgement may come from family, support staff, advocates, care managers or anyone else involved with the person and their support.
- The person completing the QOMID should record the evidence for their decision for each domain.

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HOW TO USE THE QOMID

1. Staging of dementia: The professional completing the QOMID needs to use a combination of results from formal assessments together with their professional judgement to decide which stage of dementia the person is currently experiencing.

Suspected/Early stage Mid stage Late Stage

Early stage dementia is usually characterised by gradual minor changes in the person's abilities or behaviour, especially loss of short term memory. The person may also start to become anxious and agitated. They may experience distress over their failure to manage tasks, and will need reassurance and emotional support. People who fall into Care Cluster 18 (Cognitive Impairment- Low Need) may fall into this group.

Mid stage dementia is characterised by the changes becoming more marked. The person will need more support to help them manage their day-to-day living. They may need frequent reminders or help to eat, wash, dress and use the toilet. They are likely to become increasingly forgetful - particularly of names - and may sometimes repeat the same question or phrase over and over because of the decline in their short-term memory. They will also experience loss of long-term memories resulting in them failing to recognise people or confuse them with others, and for older memories to become more vivid. Some people at this stage become very easily upset, angry or aggressive - perhaps because they are feeling frustrated - or they may lose their confidence and become very clingy. People who fall into Care Clusters 19 (Cognitive Impairment- Moderate Need) or Care Cluster 20 (Cognitive Impairment or Dementia Complicated- High Need may fall into this group.

Late stage dementia is when the person with dementia will need even more help, and will gradually become totally dependent on others for nursing care. Loss of memory may become very pronounced, with the person unable to recognise familiar objects or surroundings or even those closest to them, although there may be sudden flashes of recognition. The person may also become increasingly frail. They may start to shuffle or walk unsteadily, eventually becoming confined to bed or a wheelchair. People who fall into or Care Cluster 21 (Cognitive Impairment or Dementia- High Physical or Engagement) may fall into this group.

Use the column for that stage of dementia and rate each domain using the following rating scale:

1	2	3	4
This is rarely achieved for this person	**This is sometimes achieved for this person**	**This is mostly achieved for this person**	**This is completely and consistently achieved for this person**

For each domain, enter the rating at this current time onto the **Scoring Sheet**. All domains should be completed. If the domain is rated less than 4, specify what needs to happen to improve the person's quality outcome in that area of their life as an action in the **Scoring Sheet**.

Expected scoring: The aim, in supporting the person with dementia, is for them to have an excellent quality outcome throughout the progression of their dementia.

As dementia is a progressive condition, it is vital to ensure that the person's changing needs are recognised and met. This means that as the person moves into each stage of dementia, the quality outcome score for each domain may start at 2 or 3, but as people work together to improve the person's quality outcome, the scores should reach the maximum of 4 in each domain.

Scores may fluctuate during the course of the dementia as support 'catches up' with the person's changing needs. Scores should be entered onto the **Scoring sheet**, putting the evidence for the rating.

A score of 60 – 68 indicates that the person has an excellent quality outcome.

A score of 51 – 59 indicates that the person has a good quality outcome.

A score of 43 – 50 indicates that the person has an adequate quality outcome.

A score of 34 – 42 indicates that the person has a poor quality outcome.

A score of 33 or less indicates that the person has an unacceptable quality outcome.

Forward planning: The QOMID is designed to help the support team and the professionals to work with the person to both prevent deterioration in quality and to forward plan effective care.

For each domain that is scored at less than 4, the support team is asked to specify what needs to be put in place to improve the person's quality outcome for that domain. These actions should be entered into the **Scoring Sheet** and can then be included in the person's support plan.

In addition, by looking at the descriptions for the next stage of dementia, the professional can begin to help the person and their supporters to think about what needs to be put in place to maintain their quality experience.

For further information please contact: Karen Dodd – karendoddconsultancy@gmail.com

Quality Outcome Measure For Individuals With Dementia (QOMID)

KAREN DODD & ALICK BUSH (2013) ©

DOMAIN REFERENCE BOOKLET

AREA	SUSPECTED / EARLY STAGE DEMENTIA	MID STAGE DEMENTIA	LATE STAGE DEMENTIA
1. PERSON CENTRED APPROACHES TO SUPPORT	The person experiences support which is underpinned by planning based on: • the person's own wishes, • their capacity (maximising their decision making wherever possible), • their needs and history as shown in their individualised support plan which includes ○ their person centred plan, ○ health care plan, ○ communication passport, ○ life story book, ○ advanced directives, and ○ end of life planning.	The person experiences support which is underpinned by planning based on: • the person's own wishes, • their capacity (maximising their decision making wherever possible), • their needs and history as shown in their individualised support plan which includes ○ their person centred plan, ○ health care plan, ○ communication passport, ○ life story book, ○ advanced directives, and ○ end of life planning.	The person experiences support which is underpinned by planning based on: • the person's own wishes, • their capacity (maximising their decision making wherever possible), • their needs and history as shown in their individualised support plan which includes ○ their person centred plan, ○ health care plan, ○ communication passport, ○ life story book, ○ advanced directives, and ○ end of life planning.
2. POSITIVE RISK TAKING	The person is supported to take appropriate risks that enhance their opportunities to live an independent, fulfilled life.	The person is supported to take appropriate risks that enhance their opportunities to live an independent, fulfilled life.	The person is supported by people who take positive action to ensure that the person still has a range of fulfilling life experiences.

AREA	SUSPECTED / EARLY STAGE DEMENTIA	MID STAGE DEMENTIA	LATE STAGE DEMENTIA
3. RESPECT FOR HUMAN RIGHTS	The person's human rights are fully respected by ensuring that there is full compliance with: • Prescribed medication is in line with NICE guidelines • Mental Capacity Act- choice and decision making. The person is supported to make as many decisions for themselves as is possible • Best Interest Decisions that are made on behalf of the person are fully documented • Absence of inappropriate restrictions If the person tends to wander, this is managed through respectful and positive approaches that do not impact on their human rights.	The person's human rights are fully respected by ensuring that there is full compliance with: • Prescribed medication is in line with NICE guidelines • Mental Capacity Act- choice and decision making. The person is supported to make as many decisions for themselves as is possible • Best Interest Decisions that are made on behalf of the person are fully documented • Absence of inappropriate restrictions If there is a need to deprive somebody of their liberty, the appropriate Deprivation of Liberty Safeguards are in place.	The person's human rights are fully respected by ensuring that there is full compliance with: • Prescribed medication is in line with NICE guidelines • Mental Capacity Act- choice and decision making. The person is supported to make as many decisions for themselves as is possible • Best Interest Decisions that are made on behalf of the person are fully documented • Absence of inappropriate restrictions If there is a need to deprive somebody of their liberty, the appropriate Deprivation of Liberty Safeguards are in place.
4. CONSISTENCY OF APPROACH	The person experiences consistency of approach in all settings e.g. • They are supported by familiar people • Family /Staff fully understand the content of their support plan • New staff are properly introduced to the person before they start working with them • The use of unfamiliar or agency staff is minimised and staff are well briefed about the person before they start to support them.	The person experiences consistency of approach in all settings e.g. • They are supported by familiar people • Family /Staff fully understand the content of their support plan • New staff are properly introduced to the person before they start working with them • The use of unfamiliar or agency staff is minimised and staff are well briefed about the person before they start to support them. • They are not moved unnecessarily because of funding issues (e.g. need for waking night staff).	The person experiences consistency of approach in all settings e.g. • They are supported by familiar people • Family /Staff fully understand the content of their support plan • New staff are properly introduced to the person before they start working with them • The use of unfamiliar or agency staff is minimised and staff are well briefed about the person before they start to support them. • They are not moved unnecessarily because of funding issues (e.g. need for waking night staff).

AREA	SUSPECTED / EARLY STAGE DEMENTIA	MID STAGE DEMENTIA	LATE STAGE DEMENTIA
5. INTERACTION WITH OTHERS	The person experiences calm and constructive interaction with family, staff and friends, who adapt the amount of language used and use symbols and pictures as required to ensure the person experiences positive interactions.	The person experiences calm and constructive interaction with family, staff and friends, with no confrontation; no time pressures; and validation of roll back memories. The person experiences positive interactions and is always approached from the front to prevent surprise and panic.	The person experiences calm and constructive interaction with family, staff and friends, with protected 1:1 time each waking hour to ensure that the person experiences positive interactions.
6. EMOTIONAL REASSURANCE TO COPE WITH THE CHANGES	The person receives explanations about their dementia and reassurance about the effects of the disease as appropriate to their wishes and level of ability.	The person is reassured about the changes they are experiencing through both verbal and non verbal interaction.	The person is reassured about their condition by the way people interact both verbally and through appropriate touch.
7. ORIENTATION	The person is oriented to time and place through approaches that are appropriate to their level of ability. Their support plan describes routines that are likely to be important to the person as the dementia progresses. There is evidence that the team has made plans to ensure that any future changes that are envisaged for the person are properly considered and take account of possible effect on the person's orientation.	The person is able to understand their daily routine through the use of appropriate cues and aids e.g. daily picture timetable, picture menus, picture staff rotas. There is evidence that the team has made plans to ensure that any future changes that are envisaged for the person are properly considered and take account of possible effect on the person's orientation.	The person feels safe in having a consistent and familiar routine.
8. DAILY LIVING	The person is able to complete personal care and daily living activities as much as they are able, but without pressure. The person's abilities and additional assistance required to help maintain independence are recognised, and the person is supported appropriately e.g. having increased prompting.	The person is able to complete parts of personal care and daily living tasks that they can do and are assisted as necessary so they do not fail. Their support plan details the additional assistance required to help maintain as much independence as possible in a failure free manner.	The person experiences care that is dignified and respectful of them as a person for all their personal care and daily living activities.

AREA	SUSPECTED / EARLY STAGE DEMENTIA	MID STAGE DEMENTIA	LATE STAGE DEMENTIA
9. CARRYING OUT PREFERRED ACTIVITIES	The person continues to access and enjoy activities which build upon on their lifelong interests and preferences and are appropriate to their level of ability and dementia. Activities are adapted to meet their changing needs.	The person continues to access and enjoy activities which build upon their lifelong interests and preferences and are appropriate to their level of ability and dementia. Activities are adapted to take account of their attention span and memory and ensure that the person is not stressed or experiences failure.	The person continues to access and enjoy activities appropriate to their level of ability and dementia. The person has opportunities to interact with people / objects which give them enjoyment and in ways that take full account of their preferences and attention span.
10. FLEXIBILITY OF SUPPORT	The person continues to attend familiar social, leisure, work, respite and recreational activities in their local community, with adjustments made as appropriate to meet their needs.	The person continues to enjoy familiar social, leisure, work, respite and recreational activities in their local community through flexible supports e.g. short days, flexible transport, 1:1 support following the person.	The person continues to access and enjoy the community as much as their dementia allows and as agreed in their support plan.
11. ENVIRONMENT	The person lives and spends their time in environments that are familiar to them and can find their way around easily with depth perception problems minimised. e.g. flooring colour is consistent.	The person lives and spends their time in environments that are familiar to them and have all the necessary aids/adaptations to help them find their way around and meet their needs, and minimises risks of falls. e.g. red toilet doors, red toilet seats, colour contrasts, good signage, handrails, chairs at right height.	The person lives and spends their time in environments that are familiar to them and have all the necessary adaptations to meet their needs. e.g. hoists, adapted bath / shower, special bed, appropriate wheelchair and armchair, changing facilities.

AREA	SUSPECTED / EARLY STAGE DEMENTIA	MID STAGE DEMENTIA	LATE STAGE DEMENTIA
12. BEHAVIOUR	Behavioural issues are minimised by ensuring that the person experiences support that: • Understands the context of their behaviour • responds with compassion and • avoids confrontation. If the person needs support from services because of their behaviour this is underpinned by: • a comprehensive assessment of the person, their care and the environment, • a formulation that enables carers or staff to understand the likely reasons for the behaviour, • a proactive support plan that includes triggers to be avoided, • reactive strategies that are non-restrictive and the effectiveness of the approach is reviewed regularly.	Behavioural issues are minimised by ensuring that the person experiences support that: • Understands the context of their behaviour • responds with compassion and • avoids confrontation. If the person needs support from services because of their behaviour this is underpinned by: • a comprehensive assessment of the person, their care and the environment, • a formulation that enables carers or staff to understand the likely reasons for the behaviour, • a proactive support plan that includes triggers to be avoided, • reactive strategies that are non-restrictive and the effectiveness of the approach is reviewed regularly.	Behavioural issues are minimised by ensuring that the person experiences support that: • Understands the context of their behaviour • responds with compassion and • avoids confrontation. If the person needs support from services because of their behaviour this is underpinned by: • a comprehensive assessment of the person, their care and the environment, • a formulation that enables carers or staff to understand the likely reasons for the behaviour, • a proactive support plan that includes triggers to be avoided, • reactive strategies that are non-restrictive and the effectiveness of the approach is reviewed regularly.

AREA	SUSPECTED / EARLY STAGE DEMENTIA	MID STAGE DEMENTIA	LATE STAGE DEMENTIA
13. HEALTH	The person's physical and mental health needs are met promptly and appropriately including attention to: • Pain recognition and management • Thyroid function • Vision • Hearing • Blood pressure • Diabetes • Mental wellbeing Medication is prescribed appropriately and reviewed regularly. The person experiences care with regard to Vitamin D in line with DH guidance.	The person's physical and mental health needs are met promptly and appropriately including attention to: • Pain recognition and management • Thyroid function • Vision • Hearing • Blood pressure • Diabetes • Mental wellbeing Medication is prescribed appropriately and reviewed regularly. The person experiences care with regard to Vitamin D in line with DH guidance.	The person's physical and mental health needs are met promptly and appropriately including attention to: • Pain recognition and management • Thyroid function • Vision • Hearing • Blood pressure • Diabetes • Mental wellbeing Medication is prescribed appropriately and reviewed regularly. The person has: • No pressure sores • No aspiration • No urinary tract infections The person experiences care with regard to Vitamin D in line with DH guidance.
14. SUPPORT FROM WELL COORDINATED AGENCIES	The person's needs are met by people from providers in primary care, secondary care, social services and voluntary sector who have a good understanding of the needs of people with dementia, and who work well together with the person and their families.	The person's needs are met by people from providers in primary care, secondary care, social services and voluntary sector who have a good understanding of the needs of people with dementia, and who work well together with the person and their families. Where necessary good links are made with neurology services re management of epilepsy.	The person's needs are met by people from providers in primary care, secondary care, social services and voluntary sector who have a good understanding of the needs of people with dementia, and who work well together with the person and their families. Good links are made with local palliative care services.

AREA	SUSPECTED / EARLY STAGE DEMENTIA	MID STAGE DEMENTIA	LATE STAGE DEMENTIA
15. NUTRITION	The person enjoys a good and appetising diet and adequate hydration. The person maintains an appropriate weight which is monitored through regular weight checks.	The person enjoys a good and appetising diet and adequate hydration as appropriate to their needs over each 24 hour period. The person maintains an appropriate weight which is monitored through regular weight checks. Any swallowing difficulties are identified and support plans take these into full account.	The person enjoys a good and appetising diet and adequate hydration as appropriate to their needs over each 24 hour period which also prevents dysphagia and aspiration. There is a full assessment of all eating and swallowing problems by an appropriate clinician. Any needs are well documented, a support plan is in place and staff are trained to deliver it safely. The person maintains an appropriate weight which is monitored through regular weight checks.
16. MOBILITY	The person maintains good mobility. They access regular exercise that is appropriate to their needs and interests.	The person is able to mobilise safely and has appropriate aids and adaptations in place. They access regular exercise that is appropriate to their needs and interests. Risk assessments are in place to prevent falls.	The person is supported to be moved appropriately. They access regular exercise that is appropriate to their needs and interests. Risk assessments are in place to prevent falls.
17. CONTINENCE	The person maintains their baseline level of continence.	The person maintains their baseline level of continence through environmental changes e.g. clear signage for toilets; regular prompting to use the toilet; and attention to relevant health issues where possible. Continence products are only used when the person needs them.	The person experiences dignified management of incontinence through the use of appropriate aids and continence products.

Appendix 4 – Leaflet for Commissioners of Services for People with Intellectual Disabilities and dementia

1. THE SPECIFIC ISSUES

The life-expectancy of people with mild intellectual disabilities now approaches that in the general population of a similar socio-economic status, but the life–expectancy of people with more severe levels of intellectual disabilities remains reduced compared to the general population. Given these improvements, the overall population with intellectual disabilities is steadily increasing and it has been predicted that the proportion of people with intellectual disabilities over 65 years of age will have doubled by 2020, with over a third of all people with intellectual disabilities being over 50 years of age by that time. This is also true for the population of people with Down's syndrome.

There is an increase in the prevalence rates of clinically diagnosed dementia with increasing age that starts when people with Down's syndrome are in their 30s and steadily increases in prevalence into the 60s. It has been calculated that nearly 70% of older adults with Down's syndrome are likely to develop dementia symptoms should they all live to age 70.

FIGURE 1: COMPARISON OF DEMENTIA PREVALENCE RATES BY AGE

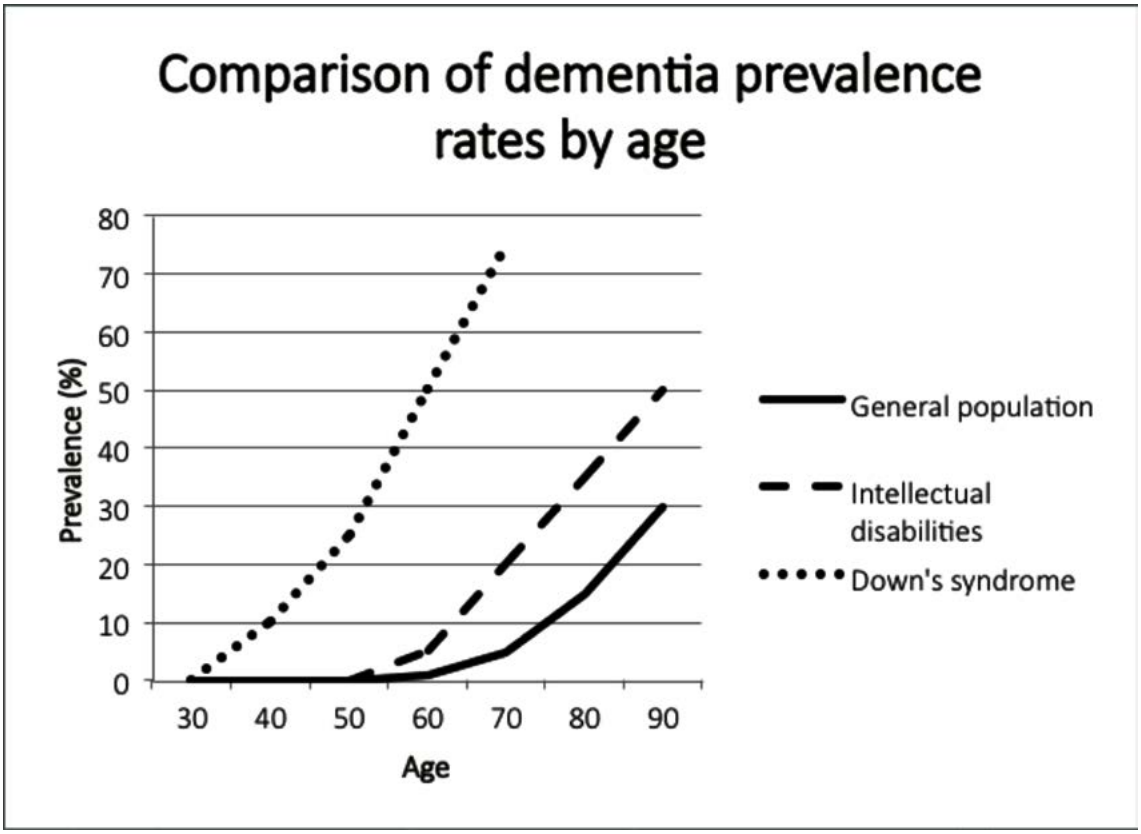

Figure 1 summarises the age-related prevalence rates of dementia in people with Down's syndrome, those with intellectual disabilities without Down's syndrome, and in the general population. The exact rates have to be considered with caution but the trend represented in this

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figure is now increasingly accepted. The early presentation and course of dementia is now well established for people with Down's syndrome. For those with intellectual disabilities but without Down's syndrome, age-related prevalence rates are brought forward to a small degree compared to the general population but not to the same extent as for people with Down's syndrome. This latter group would appear to have a uniquely early risk for developing dementia, almost invariably of the Alzheimer's-type. For the former group the full range of causes of dementia is observed.

2. WHAT SHOULD HAPPEN

Commissioners of health services need to be clear about the care pathway for the assessment, diagnosis, interventions and support for people with intellectual disabilities who develop dementia from primary care, through to appropriate secondary care services, and on to palliative care services. In practice, good quality care will involve active partnership-working between intellectual disability services, older people's services, primary and secondary health care, palliative care and social care. These areas should develop an integrated dementia strategy for the care of people with intellectual disabilities and dementia. This should involve the development of an integrated care pathway involving all relevant agencies. Specialist health professionals e.g. speech and language therapists, physiotherapists, occupational therapists, dietitians, community intellectual disabilities nurses are all essential partners in providing excellence in care.

Commissioners of social care need to recognise that dementia is by definition a deteriorating condition, and that peoples' needs will increase over time, and therefore increased and timely funding will be needed to ensure safe practice. This will inevitably involve the funding of waking night staff as the dementia progresses. Best practice is that people with intellectual disabilities should receive their residential care within the intellectual disabilities arena rather than in generic services for people with dementia, as the quality of the services gives people the best opportunities for a good quality of life for both their intellectual disabilities and their dementia. There will need to be efficient processes and understanding in place to ensure that Continuing Healthcare Assessments are undertaken promptly and funding agreed as needed.

Staff involved in assessment, diagnosis, interventions and support need to be trained in dementia care and be able to offer both holistic and specialist assessments and a range of interventions aimed at meeting the needs of people with intellectual disabilities and dementia. Care managers have an essential role to play in ensuring that services are actively monitored to ensure that they are responsive to the changing needs of the person. People with intellectual disabilities and dementia should have access to regular reviews (monthly - six monthly depending on the rate of deterioration) by an identified care manager. End of Life care needs to be planned in advance, using the same principles and services available to the general population. Good partnership-working with palliative care services is essential, both to support the person and the carers.

3. WHAT ARE THE ELEMENTS OF AN EXCELLENT SERVICE?

Commissioners will want to ensure that there is:

- Demographics are known including having a database of all adults with intellectual disabilities which includes identification of people with Down's syndrome and those in out of area placements.
- A multi-agency dementia strategy.
- A multi-agency care pathway for assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia.

- A multi-disciplinary approach to assessment and diagnosis and support.
- Prompt access to assessment and diagnostic services including baseline assessment for people with Down's syndrome around the age of 30.
- Person-centred dementia care.
- Effective care management and review system.
- Prompt access to the full range of medical, psychological, therapeutic and social interventions.
- All living and day service environments are dementia friendly.
- The person is supported to remain in their familiar home with additional supports provided in a timely manner.
- Support is available to family carers and service providers.
- There is a capable workforce able to deliver excellence in dementia care.
- End of Life care follows the requirements of the National End of Life Strategy.

4. WHAT SHOULD THE COMMISSIONERS EXPECT AS OUTCOMES OF AN EXCELLENT SERVICE?

- Increase in prompt differential diagnosis of the person's difficulties.
- Increase in other conditions being treated promptly.
- Increase in accurate diagnosis of dementia.
- Reduction in behavioural difficulties.
- Increase in quality of life indicators for the person.
- Reduction in moves to other placements.
- Reduction in the need for emergency one-to-one cover, as a result of planned increases in support as the dementia progresses to enable people to continue to access preferred activities and for personal care.
- Reduction in out of area placements.
- Increased carer support and satisfaction.
- Reduction in staff stress.

5. POTENTIAL RISKS IF SERVICES ARE NOT AVAILABLE/ NOT EFFECTIVE

- Increased costs of one-to-one, new in area or out of area placements.
- More complaints.
- Potential safeguarding issues.
- Increase in behaviours leading to abuse or harm to self and others.
- Carer breakdown.

6. FURTHER INFORMATION

Alzheimer's Society
Devon House, 58 St Katharine's Way, London E1W 1LB
Tel: 0300 222 11 22
www.alzheimers.co.uk

Alzheimer's Scotland
160 Dundee St, Edinburgh, EH11 1DQ
Tel: 0131 243 1453
www.alzscot.org

Down's Syndrome Association
Langdon Down Centre, 2a Langdon Park, Teddington, Middlesex, TW11 9PS
Tel: 0333 1212 300
www.downs-syndrome.org.uk

Scottish Down's Syndrome Association
158/160 Balgreen Road, Edinburgh EH11 3AU
Tel: 0131 313 4225
www.dsscotland.org.uk

Appendix 5: Quality Outcome (QOMID) Checklist

Early stage

Domain	Descriptor	What does this mean in practice?	What do we need to do to ensure this is fully met?

1. Person centred approaches to support	The person experiences support which is underpinned by planning based on:
	• the person's own wishes,
	• their capacity (maximising their decision making wherever possible),
	• their needs and history as shown in their individualised support plan which includes
	  ○ their person centred plan,
	  ○ health care plan,
	  ○ communication passport,
	  ○ life story book,
	  ○ advanced directives, and end of life planning.
		• How is the person at making decisions? – how often are they encouraged to make these?
		• Is support being provided in line with their wishes?
		• Which decisions do they still have capacity to make? Which do you need to have a best interests discussion?
		• When were their key documents last updated or at least reviewed? (these should be done every year)
		• Have all these documents been completed with the person?	

2. Positive Risk Taking	The person is supported to take appropriate risks that enhance their opportunities to live an independent, fulfilled life.	• Is the person being engaged as much as possible? • Have you continued to help the person access any activities they are interested in etc with the right support? • Are you supporting the person to do as much as they can for themselves?	

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3. Respect for Human Rights	The person's human rights are fully respected by ensuring that there is full compliance with: • Prescribed medication is in line with NICE guidelines • Mental Capacity Act- choice and decision making. The person is supported to make as many decisions for themselves as is possible • Best Interest Decisions that are made on behalf of the person are fully documented • Absence of inappropriate restrictions If the person tends to wander, this is managed through respectful and positive approaches that do not impact on their human rights.	• Has the person had all relevant Mental Capacity Assessments? Are they up to date with changing needs? • Does there need to be a DoLS in place for the person? – all restrictions to person (e.g. lock on front door, medication locked away and given to person by staff) should have a DoLS document in place – • Have any best interest decisions been made for the person? – these should always be the least restrictive options and are usually discussed at 'Best interest meetings' with carers, family and anyone involved in their care • Are the best interest decisions documented?	
4. Consistency of approach	The person experiences consistency of approach in all settings e.g. • They are supported by familiar people • Family /Staff fully understand the content of their support plan • New staff are properly introduced to the person before they start working with them • The use of unfamiliar or agency staff is minimised and staff are	• What is the staff turnover like? • Are there always permanent staff on shift? • How are new staff are introduced to the person? How do they understand how to support the person? • Are all staff aware of the intricacies of how the person prefers to be supported? For	

	well briefed about the person before they start to support them.	example, when getting dressed, putting on socks first. • Are the person's family involved in the care? Do they know what's in the person's support plans? • How is the communication between the home and day centre? - Do you have a communication book with them?	
5. Interactions with others	The person experiences calm and constructive interaction with family, staff and friends, who adapt the amount of language used and use symbols and pictures as required to ensure the person experiences positive interactions	• Does the person have any close friendships in the home? • What do the other people in the house think of the person? How is this made positive? • How often does the person interact with others? • How is the person encouraged to interact with others? E.g. through activities • Are there opportunities to interact with others outside of the home? I.e. day opportunities, leisure activities or community groups. • Is the person's culture / religion celebrated within the home?	
6. Emotional reassurance to cope with the changes	The person receives explanations about their dementia and reassurance about the effects of the disease as appropriate to their wishes and level of ability.	• How do staff explain to the person about the impact of their dementia?	

		• How do staff reassure the person about the changes that are happening? • How do you recognise if the person is distressed or upset? • How do you reassure the person?	
7. Orientation	The person is oriented to time and place through approaches that are appropriate to their level of ability. Their support plan describes routines that are likely to be important to the person as the dementia progresses. There is evidence that the team has made plans to ensure that any future changes that are envisaged for the person are properly considered and take account of possible effect on the person's orientation.	• Has their support plan described routines that are important to the person? • Is the person supported to know where they are and what time it is? • Do staff and family think about the impact of orientation issues when they access new places? • Do staff prepare people for any change in places they visit?	
8. Daily living	The person is able to complete personal care and daily living activities as much as they are able, but without pressure. The person's abilities and additional assistance required to help maintain independence are recognised, and the person is supported appropriately e.g. having increased prompting.	• How independent is the person at self-care skills? • Which skills can the person still do for themselves? • Which skills do they need support with? • At times when they are supported, is this appropriate to their level of need/not too much?	

9. Carrying out preferred activities	The person continues to access and enjoy activities which build upon on their lifelong interests and preferences and are appropriate to their level of ability and dementia. Activities are adapted to meet their changing needs.	• Is the person's preferred activities known by all who support them? • How are these incorporated into a daily routine? • Do they need adaptation to help the person continue to enjoy them?	
10. Flexibility of support	The person continues to attend familiar social, leisure, work, respite and recreational activities in their local community, with adjustments made as appropriate to meet their needs.	• Is the person going out everyday into the community/getting fresh air? • Are activities/days out in the community adjusted to meet their current needs?	
11. Environment	The person lives and spends their time in environments that are familiar to them and can find their way around easily with depth perception problems minimised. e.g. flooring colour is consistent.	• Has the staff team considered the impact of the physical environment on the person? • Has the team implemented the changes suggested in the Environments part of this workbook?	
12. Behaviour	Behavioural issues are minimised by ensuring that the person experiences support that: • Understands the context of their behaviour • responds with compassion and • avoids confrontation.	• Does the person have any known pre-existing behaviours? • How are these behaviours shown by the person/what do they do? • Are these clearly documented in their plan so that all staff know what to look out for?	

	If the person needs support from services because of their behaviour this is underpinned by: • a comprehensive assessment of the person, their care and the environment, • a formulation that enables carers or staff to understand the likely reasons for the behaviour, • a proactive support plan that includes triggers to be avoided, • reactive strategies that are non-restrictive and the effectiveness of the approach is reviewed regularly.	• Are all staff consistently following this plan? • Do all staff know the triggers for these behaviours? • How are the person's behaviours managed? • Is the person showing any new distress behaviours since being diagnosed with dementia? • How are these being understood by the person and their staff team?	
13. Health	The person experiences good physical and mental wellbeing, with their health needs met promptly and appropriately including attention to: • Pain recognition and management • Thyroid function • Vision • Hearing • Blood pressure • Diabetes • Mental wellbeing Medication is prescribed appropriately and reviewed regularly. The person experiences care with regard to Vitamin D in line with DH guidance.	• Has the person had their annual health check? • Have they had an annual medication review? • Can the person tell staff when they are in pain or feeling poorly? • Do staff clearly know how the person expresses pain? • Do staff understand that people with dementia may still develop other illnesses that are nothing to do with the dementia? • Does the person get daily exposure to sunlight in line with DH guidance? • Does the person take Vitamin D supplements?	

		• Is the person showing any difficulties with eating and/or drinking?	
14. Support from well co-ordinated agencies	The person's needs are met by people from providers in primary care, secondary care, social services and voluntary sector who have a good understanding of the needs of people with dementia, and who work well together with the person and their families.	• Are the person's family involved in their care? • Does the person have a named social worker / care manager? • Do they have, as a minimum, an annual review? • Are you getting ongoing support and review from the local CTPLD? • Are you getting support from the Alzheimer's society or any other voluntary organisations?	
15. Nutrition	The person enjoys a good and appetising diet and adequate hydration. The person maintains an appropriate weight which is monitored through regular weight checks.	• Does the person have a healthy diet? • How is the person's weight? – how often is this checked and where is it recorded?	
16. Mobility	The person maintains good mobility. They access regular exercise that is appropriate to their needs and interests.	• Does the person maintain their mobility? • Are they accessing regular exercise in line with their brain health plan?	
17. Continence	The person maintains their baseline level of continence.	• Is the person supported to maintain their continence and	

		access the toilet when they need it?	

Mid Stage

Domain	Descriptor	What does this mean in practice?	What do we need to do to ensure this is fully met?

1. Person centred approaches to support	The person experiences support which is underpinned by planning based on:
	• the person's own wishes,
	• their capacity (maximising their decision making wherever possible),
	• their needs and history as shown in their individualised support plan which includes
	  ○ their person centred plan,
	  ○ health care plan,
	  ○ communication passport,
	  ○ life story book,
	  ○ advanced directives, and end of life planning.
		• How is the person at making decisions as abilities change? – how often are they encouraged to make these?
		• Is support being provided in line with their wishes?
		• Which decisions do they still have capacity to make? Which do you need to have a best interests discussion?
		• When were their key documents last updated or at least reviewed? (these should be done every year)
		• Have all these documents been completed with the person?	

2. Positive Risk Taking	The person is supported to take appropriate risks that enhance their opportunities to live an independent, fulfilled life.	• Is the person being engaged as much as possible, even if they cannot do a whole task or activity? • Have you continued to help the person access any activities they	

		are interested in etc with the right support? • Are you supporting the person to do as much as they can for themselves? • If something has been tried and not been successful – has this been documented and alternatives considered? • Is the person supported to participate in a previously enjoyed activity regardless of the weather etc?	
3. Respect for Human Rights	The person's human rights are fully respected by ensuring that there is full compliance with: • Prescribed medication is in line with NICE guidelines • Mental Capacity Act- choice and decision making. The person is supported to make as many decisions for themselves as is possible • Best Interest Decisions that are made on behalf of the person are fully documented • Absence of inappropriate restrictions If there is a need to deprive somebody of their liberty, the	• Has the person had all relevant Mental Capacity Assessments? Are they up to date with changing needs? • Does there now need to be a DoLS in place for the person? – all restrictions to person (e.g. lock on front door, medication locked away and given to person by staff) should have a DoLS document in place. • Have any best interest decisions been made for the person? – these should always be the least restrictive options and are usually discussed at 'Best interest meetings' with carers, family and anyone involved in their care • Are the best interest decisions documented?	

	appropriate Deprivation of Liberty Safeguards are in place.	• If the person has epilepsy or needs equipment or manual handling to move them around, have all the staff had updated training to do this safely?	
4. Consistency of approach	The person experiences consistency of approach in all settings e.g. • They are supported by familiar people • Family /Staff fully understand the content of their support plan • New staff are properly introduced to the person before they start working with them • The use of unfamiliar or agency staff is minimised and staff are well briefed about the person before they start to support them. • They are not moved unnecessarily because of funding issues (e.g. need for waking night staff)	• What is the staff turnover like? • Are there always permanent staff on shift? • How are new staff are introduced to the person? How do they understand how to support the person? • Are the person's family involved in the care? Do they know what's in the person's support plans? • How is the communication between the home and day centre? - Do you have a communication book with them? • Has moving the person been discussed? Is this in the best interests of the person? Is it about need for extra funding for staff?	
5. Interactions with others	The person experiences calm and constructive interaction with family, staff and friends, with no confrontation; no time pressures; and validation of roll back memories. The person experiences positive interactions and is always approached	• How do other residents and staff interact with the person? • Do staff ensure that the person has no confrontation from others? • Are people given the time they need for interaction and not hurried?	

	from the front to prevent surprise and panic.	• Do staff validate what people think even if it is a memory from the past? • How is the person encouraged to interact with others? E.g. through activities • Is the person's culture / religion celebrated within the home?	
6. Emotional reassurance to cope with the changes	The person is reassured about the changes they are experiencing through both verbal and non verbal interaction.	• How do staff explain to the person about the impact of their increasing dementia? Have you used any of the Easy Read resources to support this understanding? • How do staff reassure the person about the changes that are happening? • How can you recognise if the person is distressed or upset? – is this clearly documented in their person centred plan? • How do staff manage the person when they distressed about their dementia? – is this clearly documented in their plan? – is this consistent between staff?	
7. Orientation	The person is able to understand their daily routine through the use of appropriate cues and aids e.g. daily picture timetable, picture menus, picture staff rotas.	• How do staff support the person to be less confused in getting around the home? • Does the person have a picture timetable for each day/week? • Does the home have a picture menu timetable that the person can see/access easily?	

	There is evidence that the team has made plans to ensure that any future changes that are envisaged for the person are properly considered and take account of possible effect on the person's orientation	• Does the home have a picture staff rota that is changed each day so that the person knows who to expect on shift and who to go to if there are any problems? • Does the home have staff who knows Makaton or sign language that may help the person communicate if non-verbal? • Has the staff made any plans for the future about how to better meet the person's needs as they progress through dementia? • Has the home got clear picture signage around the house to aid orientation? These must all be at appropriate eye level for the person.	
8. Daily living	The person is able to complete parts of personal care and daily living tasks that they can do and are assisted as necessary so they do not fail. Their support plan details the additional assistance required to help maintain as much independence as possible in a failure free manner.	• Which skills can the person still do for themselves? • Which skills do they need support with? • At times when they are supported, is this appropriate to their level of need/not too much? • Are people supported so that they don't fail in doing a task?	
9. Carrying out preferred activities	The person continues to access and enjoy activities which build upon their lifelong interests and preferences and are appropriate to their level of ability	• Is the person's preferred activities adapted to take into account their attention span by all who support them?	

	and dementia. Activities are adapted to take account of their attention span and memory and ensure that the person is not stressed or experiences failure.	• How are these incorporated into a daily routine? • Do staff implement failure free activities with the person?	
10. Flexibility of support	The person continues to enjoy familiar social, leisure, work, respite and recreational activities in their local community through flexible supports e.g. short days, flexible transport, 1:1 support following the person.	• Is the person going out everyday into the community/getting fresh air? • Are activities/days out in the community adjusted to meet their current needs? • If the person / house has its own car, is there always a driver on shift? • Does the person have 1:1 support when out in the community?	
11. Environment	The person lives and spends their time in environments that are familiar to them and have all the necessary aids/adaptations to help them find their way around and meet their needs, and minimises risks of falls. e.g. red toilet doors, red toilet seats, colour contrasts, good signage, handrails, chairs at right height.	• Has the staff team considered the impact of the physical environment on the changing needs of the person? • Has the team implemented the changes suggested in the Environments part of this workbook? • Are all adaptations in place?	
12. Behaviour	Behavioural issues are minimised by ensuring that the person experiences support that:	• Does the person have any known pre-existing behaviours?	

	• Understands the context of their behaviour • responds with compassion and • avoids confrontation. If the person needs support from services because of their behaviour this is underpinned by: • a comprehensive assessment of the person, their care and the environment, • a formulation that enables carers or staff to understand the likely reasons for the behaviour, • a proactive support plan that includes triggers to be avoided, • reactive strategies that are non-restrictive and the effectiveness of the approach is reviewed regularly.	• How are these behaviours shown by the person/what do they do? • Are these clearly documented in their plan so that all staff know what to look out for? • Do all staff know the triggers for these behaviours? • How are the person's behaviours managed? • Is the person showing any new distress behaviours since being diagnosed with dementia? • How are these being understood by the person and their staff team?	
13. Health	The person experiences good physical and mental wellbeing, with their health needs met promptly and appropriately including attention to: • Pain recognition and management • Thyroid function • Vision • Hearing • Blood pressure • Diabetes • Mental wellbeing	• Has the person had their annual health check? • Have they had an annual medication review? • Can the person tell staff when they are in pain or feeling poorly? • Do staff clearly know how the person expresses pain? • Do staff understand that people with dementia may still develop other illnesses that are nothing to do with the dementia?	

	Medication is prescribed appropriately and reviewed regularly. The person experiences care with regard to Vitamin D in line with DH guidance.	• Does the person get daily exposure to sunlight in line with DH guidance? • Does the person take Vitamin D supplements?	
14. Support from well co-ordinated agencies	The person's needs are met by people from providers in primary care, secondary care, social services and voluntary sector who have a good understanding of the needs of people with dementia, and who work well together with the person and their families. Where necessary good links are made with neurology services re management of epilepsy.	• Are the person's family involved in their care? • Does the person have a named social worker / care manager? • Do they have, as a minimum, an annual review? • Are you getting ongoing support and review from the local CTPLD? • Are you getting support from the Alzheimer's society or any other voluntary organisations? • If the person has epilepsy, are you in regular contact with neurology?	
15. Nutrition	The person enjoys a good and appetising diet and adequate hydration as appropriate to their needs over each 24 hour period. The person maintains an appropriate weight which is monitored through regular weight checks. Any swallowing difficulties are identified and support plans take these into full account	• Does the person have a healthy diet? • How is the person's weight? – how often is this checked and where is it recorded? • How is the person's ability to eat? – do they eat independently? How much support do they need? Do they have any swallowing/choking difficulties? Is f this information documented in their person-centred plan?	

		• Is the person's food and fluid intake monitored? – are there charts that are regularly recorded and reviewed?	
16. Mobility	The person is able to mobilise safely and has appropriate aids and adaptations in place. They access regular exercise that is appropriate to their needs and interests. Risk assessments are in place to prevent falls.	• Does the person maintain their mobility? • Are they accessing regular exercise in line with their brain health plan? • Are their mobility needs clearly documented in their person centred plan? • If they do need support, is all the necessary equipment/support in place? • How often is the person encouraged to move around? • Has the person had any falls? Is there a risk assessment in place for this?	
17. Continence	The person maintains their baseline level of continence through environmental changes e.g. clear signage for toilets; regular prompting to use the toilet; and attention to relevant health issues where possible. Continence products are only used when the person needs them.	• Is the person supported to maintain their continence and access the toilet when they need it? • Is there clear picture signage for the toilet/bathroom – this should be at eye level and in bold so the person can clearly see it • Is the person encouraged to go to the toilet at regular times of the day? • Is the person put in pads even if not incontinent? This should not	

		happen as the person will not wet themselves deliberately and may lead to the person 'hanging on' and developing a urinary infection. • How often is the person incontinent? Is this documented in their support plan? – the frequency should be documented in a daily chart/log • Do all staff manage with issues of incontinence in the same way? • Is the home in contact with the continence service?	

Late Stage

Domain	Descriptor	What does this mean in practice?	What do we need to do to ensure this is fully met?

1. Person centred approaches to support	The person experiences support which is underpinned by planning based on:
	• the person's own wishes,
	• their capacity (maximising their decision making wherever possible),
	• their needs and history as shown in their individualised support plan which includes
	  ○ their person centred plan,
	  ○ health care plan,
	  ○ communication passport,
	  ○ life story book,
	  ○ advanced directives, and end of life planning.
	  ○
		• Is support being provided in line with their wishes?
		• Which decisions do they still have capacity to make? Which do you need to have a best interests discussion?
		• When were their key documents last updated or at least reviewed? (these should be done every year)	

2. Positive Risk Taking	The person is supported by people who take positive action to ensure that the person still has a range of fulfilling life experiences.	• Is the person being engaged as much as possible, even if they cannot take part in an activity? • Have you continued to engage the person with the right support? • If something has been tried and not been successful – has this been documented and alternatives considered? • Is the person supported to participate in a previously enjoyed	

		activity regardless of the weather etc?	
3. Respect for Human Rights	The person's human rights are fully respected by ensuring that there is full compliance with: • Prescribed medication is in line with NICE guidelines • Mental Capacity Act- choice and decision making. The person is supported to make as many decisions for themselves as is possible • Best Interest Decisions that are made on behalf of the person are fully documented • Absence of inappropriate restrictions If there is a need to deprive somebody of their liberty, the appropriate Deprivation of Liberty Safeguards are in place.	• Has the person had all relevant Mental Capacity Assessments? Are they up to date with changing needs? • Is a DoLS in place for the person? – all restrictions to person (e.g. lock on front door, medication locked away and given to person by staff) should have a DoLS document in place. • How are best interest decisions being made for the person? – these should always be the least restrictive options and are usually discussed at 'Best interest meetings' with carers, family and anyone involved in their care • Are the best interest decisions documented? • Have staff had appropriate training to support the person e.g. manual handing, dysphagia and safe eating and drinking, epilepsy etc.	
4. Consistency of approach	The person experiences consistency of approach in all settings e.g. • They are supported by familiar people • Family /Staff fully understand the content of their support plan	• What is the staff turnover like? • Are there always permanent staff on shift? • How are new staff are introduced to the person? How do they understand how to support the person?	

	• New staff are properly introduced to the person before they start working with them • The use of unfamiliar or agency staff is minimised and staff are well briefed about the person before they start to support them. • They are not moved unnecessarily because of funding issues (e.g. need for waking night staff)	• Are the person's family involved in the care? Do they know what's in the person's support plans? • How is the communication between the home and day centre? - Do you have a communication book with them? • Has moving the person been discussed? Is this in the best interests of the person? Is it about need for extra funding for staff?	
5. Interactions with others	The person experiences calm and constructive interaction with family, staff and friends, with protected 1:1 time each waking hour to ensure that the person experiences positive interactions.	• How do other residents and staff interact with the person? • Do staff ensure that the person has no confrontation from others? • Are people given the time they need for interaction and not hurried? • Do the staff have protected time to spend with the person so that they receive positive interactions? • Do staff validate what people think even if it is a memory from the past? • How is the person encouraged to interact with others? • Is the person's culture / religion celebrated within the home?	
6. Emotional reassurance to	The person is reassured about their condition by the way people interact	• How do staff reassure the person about the changes that are happening?	

cope with the changes	both verbally and through appropriate touch.	• How can you recognise if the person is distressed or upset? – is this clearly documented in their person centred plan? • How do you reassure the person? • How do staff manage the person when they distressed about their dementia? – is this clearly documented in their plan? – is this consistent between staff?	
7. Orientation	The person feels safe in having a consistent and familiar routine.	• How do staff support the person to by being consistent in their approach? • How do staff ensure that there is a familiar routine for the person that makes them feel safe?	
8. Daily living	The person experiences care that is dignified and respectful of them as a person for all their personal care and daily living activities.	• Is all care provided in a dignified and respectful manner – including talking to the person about what staff are doing?	
9. Carrying out preferred activities	The person continues to access and enjoy activities appropriate to their level of ability and dementia. The person has opportunities to interact with people / objects which give them enjoyment and in ways that take full account of their preferences and attention span.	• Is the person's preferred activities adapted to take into account their attention span by all who support them? • How are these incorporated into a daily routine? • Do staff implement appropriate late stage engagement ideas with the person?	

10. Flexibility of support	The person continues to access and enjoy the community as much as their dementia allows and as agreed in their support plan.	• Is the person going out as much as possible into the community/getting fresh air? • Are activities appropriate to the person's abilities and concentration span? • Are activities in the community adjusted to meet their current needs? • If the person / house has its own car, is there always a driver on shift? • Does the person have 1:1 support when out in the community?	
11. Environment	The person lives and spends their time in environments that are familiar to them and have all the necessary adaptations to meet their needs. e.g. hoists, adapted bath / shower, special bed, appropriate wheelchair and armchair, changing facilities.	• Has the staff team considered the impact of the physical environment on the changing needs of the person? • Has the team implemented the changes suggested in the Environments part of this workbook? • Are all adaptations in place for supporting the person in late stage?	
12. Behaviour	Behavioural issues are minimised by ensuring that the person experiences support that: • Understands the context of their behaviour • responds with compassion and	• Is the person showing any new distress behaviours since their dementia has progressed? • How are these being understood by the person and their staff team?	

	• avoids confrontation. If the person needs support from services because of their behaviour this is underpinned by: • a comprehensive assessment of the person, their care and the environment, 2. a formulation that enables carers or staff to understand the likely reasons for the behaviour, 3. a proactive support plan that includes triggers to be avoided, 4. reactive strategies that are non-restrictive and the effectiveness of the approach is reviewed regularly.	• How is the person's distress being managed?	
13. Health	The person experiences good physical and mental wellbeing, with their health needs met promptly and appropriately including attention to: • Pain recognition and management • Thyroid function • Vision • Hearing • Blood pressure • Diabetes • Mental wellbeing Medication is prescribed appropriately and reviewed regularly.	• Has the person had their annual health check? • Have they had an annual medication review? • Can the person tell staff when they are in pain or feeling poorly? • Do staff clearly know how the person expresses pain? • Do staff understand that people with dementia may still develop other illnesses that are nothing to do with the dementia? • Does the person get daily exposure to sunlight in line with DH guidance?	

	The person has: • No pressure sores • No aspiration • No urinary tract infections The person experiences care with regard to Vitamin D in line with DH guidance.	• Does the person take Vitamin D supplements? • Are staff aware of the signs of a urinary tract infection and take appropriate action? • Are staff aware of how to prevent pressure sores? • Are staff aware of the risk of dysphagia and aspiration?	
14. Support from well co-ordinated agencies	The person's needs are met by people from providers in primary care, secondary care, social services and voluntary sector who have a good understanding of the needs of people with dementia, and who work well together with the person and their families. Good links are made with local palliative care services.	• Are the person's family involved in their care? • Does the person have a named social worker / care manager? • Do they have, as a minimum, an annual review? • Are you getting ongoing support and review from the local CTPLD? • Are you getting support from the Alzheimer's society or any other voluntary organisations? • If the person has epilepsy, are you in regular contact with neurology? • Have you made links with the local palliative care service?	
15. Nutrition	The person enjoys a good and appetising diet and adequate hydration as appropriate to their needs over each 24 hour period which also prevents dysphagia and aspiration. There is a full assessment of all eating and swallowing problems	• Do they have any swallowing/choking difficulties? • Has the person had a full assessment of their eating and swallowing problems? • Is a support plan in place?	

	by an appropriate clinician. Any needs are well documented, a support plan is in place and staff are trained to deliver it safely. The person maintains an appropriate weight which is monitored through regular weight checks.	• Are staff trained to meet the person's eating and drinking needs? • Is the person's food and fluid intake monitored? – are there charts that are regularly recorded and reviewed? • How is the person's weight? – how often is this checked and where is it recorded?	
16. Mobility	The person is supported to be moved appropriately. They access regular exercise that is appropriate to their needs and interests. Risk assessments are in place to prevent falls.	• Are their mobility needs clearly documented in their person centred plan? • Is all the necessary equipment/support in place? • Have staff been trained to use all equipment safely? • Is their mobility and manual handling needs reviewed regularly? • Has the person had any falls? Is there a risk assessment in place for this?	
17. Continence	The person experiences dignified management of incontinence through the use of appropriate aids and continence products.	• How often is the person incontinent? Is this documented in their support plan? – the frequency should be documented in a daily chart/log • Do all staff manage with issues of incontinence in the same way?	

		• Is the home in contact with the continence service? • Are their continence needs regularly reviewed?	

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