



GUIDANCE

# Responding to HIV care challenges presented by Covid-19

There have been multiple aspects to the Covid-19 pandemic, and in combination this formed a disruptive and challenging environment requiring the rapid adjustment of services to the changing psychological needs of both people living with HIV and healthcare teams. This paper aims to describe the potential psychological impacts of Covid-19 for people living with HIV, on their receipt of healthcare and on the services which deliver that care. Information was gathered from experts by experience and healthcare professionals working within HIV services to compile a document which acknowledges multifaceted effects of the pandemic and considers ways in which we might harness learning and develop services in accordance with highlighted and changing needs.

Alongside the rest of the population, people living with HIV have been coping with changes to their lifestyles and relationships, in particular:

The threat of serious or fatal illness has resulted in a state of heightened vigilance and awareness of others, perhaps particularly for BAME who are understood to be at additional risk.

The isolating effects of lockdown have created changes to the boundaries of social and intimate relationships.

Many people already living with a virus such as HIV may have previously developed many of the psychological skills and resilience needed to cope with such changes. In fact, they have much to teach others and may be seen as valuable consultants to changing services. Those who are more vulnerable and lack these skills are likely to feel more challenged by the changes to the healthcare and support services on which they rely. For these people particular attention will need to be paid to:

The psychological impact of changes in access to healthcare which can be experienced as distressing and potentially re-traumatising, particularly for people living with HIV who have complex needs.

Changes to HIV service delivery may result in additional stress and role-related challenges for healthcare professionals.

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# IMPLICATIONS FOR HIV CARE

People living with HIV may already experience considerable psychological distress due to the high incidence of pre-existing stressors such as stigma, marginalisation, trauma and/or domestic violence. Cultural prejudices against a positive diagnosis may also create the additional need to overcome feelings of shame and/or exclusion. Facing the Covid-19 virus and lockdown conditions may have added to the stresses, in particular:

Feelings of helplessness due to the possibility of facing another life-threatening illness particularly for those with an increased risk of severe illness due to comorbidities such as diabetes, COPD, and hypertension (all more common for people living with HIV). This is exacerbated by other issues such as mental health difficulties, addiction, or by belonging to already vulnerable and/or marginalised groups (e.g. BAME).

# Increased anxiety due to:

- Risks to confidentiality around diagnosis for those in shared accommodation, due to living
  in closer proximity and lack of access to a private space. Explanations are particularly
  difficult for those who are vulnerable and who need to take more stringent precautions
  regarding social distancing/self-isolation.
- Fears of stigma relating to sharing diagnosis with other care systems (e.g. for medication delivery or assistance with shopping and other supplies).
- Difficulties in or worries about accessing medication, including concerns about others accessing antiretroviral therapy for Covid-19.
- Difficulties in accessing supportive social communities which provided a safe space to develop intimate relationships, as only online support is available from many community organisations.
- Uncertainty regarding ongoing Covid-19 pandemic and fear of future loss of employment and social networks (e.g. community groups no longer running, restaurants and bars closing).

Reduced motivation to self-manage due to loss of health care routine (e.g. no outpatient appointments or regular clinics, reduced medical monitoring and loss of contact with the healthcare team).

Feelings of abandonment in response to service changes or withdrawal, particularly for those with pre-existing vulnerabilities (e.g. stemming from a historical trauma in relationships). For some, already living in isolation, healthcare contacts may be their only social support network.

Increased feelings of worthlessness and self-doubt leading to a withdrawal from healthcare support (i.e. not wanting to bother healthcare staff at this difficult time).

Heightened emotional distress and risk of self harm/suicide due to an increased number of triggers for trauma memories (e.g. feelings of vulnerability, neglect, uncertainty, danger), and perhaps specifically retraumatising for long-term survivors who lived through the HIV/ AIDS pandemic.

Exacerbation of issues and risks in existing intimate relationships, such as interpersonal stress and domestic violence

An increase in loneliness and shame due to the desire to access intimate relationships and issues in sexual/intimate relationships.

The very real pressures of losing income through employment (e.g. many people living with HIV on zero hours contracts) and other socio-economic impacts of the Covid crisis, and the uncertainty/lack of control as there is no clear idea of how or when it will end.

# IMPLICATIONS FOR ONWARD TRANSMISSION

These additional stresses have serious Implications for the onward transmission of the HIV virus and present a concurrent challenge to health service teams due to:

People losing 'Undetectable = Untransmittable' status (U=U) due to existing or situational adherence issues.

Service pre-occupation with physical and practical issues, which may leave psychological issues missed.

Healthcare staff being less able to monitor those with higher health risks (e.g. undocumented migrants, sex workers, people who are homeless, those working in front line services).

Healthcare staff being less able to monitor signs of stress in service users and therefore not as able to manage risks.

### SUGGESTED ADAPTATIONS - HARNESSING THE LEARNING

There are risks associated with failing to recognise the changing needs of people living with HIV (e.g. the potential that some people may adopt previous survival strategies and become detached, defensive and/or engage in high risk sexual behaviour). However, there is also evidence that many are reducing sexual encounters.

### WHAT TO OFFER PEOPLE LIVING WITH HIV:

Ensure all people within the HIV are notified and kept up-to-date with service changes and plans for care delivery.

# Identify people under the care of the HIV services with complex needs and offer...

- offer open discussions regarding sharing of HIV status;
- offer individual risk assessments (both proactive and responsive);
- offer structured, proactive check-in appointments using phone or video calls;
- consider attachment theory informed care delivery;

- provide written or electronic confirmation of changes to therapeutic goals and ensure narrative of ongoing engagement; and
- utilise opportunities (e.g. re-engagement due to Covid-19 fears) to enhance relationships and trust.

Support and empower people living with HIV to develop confidence and abilities to self-manage their condition by advising strategies such as accessing online support, webinars, information from national bodies (e.g. BHIVA, NHIVNA, UK-CAB and local and national community organisations), engaging with trusted friends and providing information regarding relevant service access (e.g. sexual health testing, pre-exposure prophylaxis).

**Re-orientate services to become more trauma sensitive** and aware of potential trigger situations by:

- ensuring trauma-related training and information is available for healthcare staff so that
  they are able to acknowledge, normalise and validate signs of trauma in people under the
  care of the HIV services; and
- developing service specific information (e.g. leaflets paper/electronic) naming the impact
  of trauma, encouraging continued service engagement and containing relevant signposting
  for practical and emotional support.

Ensure that service delivery changes support the psychological needs of all people under the HIV services by ensuring that healthcare staff are fully trained in attachment understanding and awareness so that services provide proactive, structured and 'attachment aware' care.

Consider the digital divide and digital poverty particularly for certain groups who have minimal funds for digital access/top up or limited access to Wi-F (e.g. people from deprived populations suffering from structural inequalities, people who are homeless, rural communities, sex workers). Implement creative approaches to contact, such as bringing people into clinic for face-to-face sessions where possible, liaison with GP or community services. Flexibility around DNA policy may also be required.

# WHAT TO OFFER HEALTHCARE TEAMS:

As a result of Covid-19 related changes, healthcare staff may feel overwhelmed, highly stressed or guilty due to being unable to fulfil their usual duties, not doing as much or being redeployed into different roles. There may also be fewer staff for peer support, which may have a negative impact on wellbeing.

### Continuous input from psychology in the form of:

- Support to make sense of the interplay between Covid-19 and pre-existing issues/trauma.
- Consultation, and reflective practice spaces.
- Education and training around trauma-focused approaches to care.
- Help for staff consider issues around managing telephone contacts
   (e.g. difficulties ending conversations when people are lonely and isolated).

Acknowledge the impact of uncertainty, stresses and the need for psychological first aid within teams. Seek and support access to professional networks for support and local/national wellbeing support systems on offer.

Encourage teams to access professional training in video and phone consultations. Working remotely is new to many clinicians and people under the care of HIV services.

Remind teams of important issues such as confidentiality when using new technology and refer to local and other helpful policies (see <u>Working from Home: Healthy sustainable working during the Covid-19 pandemic and beyond</u>).

Participate in the development of organisational structures and policies that promote reflective practices and a proactive culture of support for staff.

**Assist in the development of monitoring systems and responses** to staff experiencing burnout, distress or heightened anxiety.

**Work toward effective team reintegration.** Optimise on learning with a view to keeping 'what works' and utilise relational frameworks to support teams to (re)connect, understand their experiences and share thoughts regarding service improvement.



St Andrews House, 48 Princess Road East, Leicester LE1 7DR, UK

6 0116 254 9568 ♀ www.bps.org.uk ☐ info@bps.org.uk