Growing Older with HIV: Navigating an uncharted territory

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Introduction

- 50+ is a very diverse group with different needs and experiences
- Many people are growing older with HIV with very few issues
- However, some people are struggling with a number of challenges
Health and Wellbeing

- Multiple conditions = multiple appointments, repeating medical history
  
  “It just gets so confusing – there are so many appointments. I have to go to four different hospitals... before I have remembered the correct time but gone to the wrong hospital”

- Managing both physical and mental health can be problematic

- Women concerned about all aspects of growing older with HIV

- Uncertainty about the future

  “I also fear what illnesses lie ahead... you’re getting older and there’s no way around that...but wondering how HIV plays out”

- People want information to help them manage their health

  “Just someone telling you the dos and don’ts, what you need to worry about, where to find information, that can be hugely powerful, makes a real difference”
Connecting with others

High levels of loneliness and social isolation experienced
Social contact, being with other people over 50 and making friends were ranked highly as benefits that people sought from attending our events.

“I really look forward to coming to this group because I get lonely and miserable. Here I see people who speak the same language”

Stigma and fear of discrimination still problematic
"I love it here. It is like my second home. Here I can be me, I can laugh and chat and meet friends. As soon as I step outside, I have to be serious and hide"
Managing finances

- People are very anxious about changes to the welfare benefit system, such as the move from DLA to PIP
  
  “It was a massive help getting support with filling in my form. When you are fighting several major illnesses losing your benefits or risk of losing them does cause anxiety”

- People are worried about being deemed fit to work when they have been unemployed for many years

- The assessment process is very stressful for some people
  
  “The assessment is awful, so degrading - they try to trick you to make you give something away that would show you are pretending. Why would you pretend? I don’t want to be like this”
Final thoughts

- There is huge diversity in the experiences of the over 50s living with HIV.
- Many people will need little support as they grow older with HIV.
- However, for others who experience more complex health and care needs, poverty and poor emotional wellbeing, additional support may be needed.
- Many support needs are not unique to people living with HIV. However, living with HIV may add an extra level of need beyond the ‘standard’ experiences of ageing.
- People draw on their own resilience and experience, support from peers, and services offered by HIV clinics and organisations to help them negotiate the challenges of growing older with HIV.
- Our research suggests that the older a person living with HIV gets the happier they feel, the better their wellbeing and the lower their levels of HIV self-stigma.
Any Questions?
Contact and Useful Links

- Contact clive.blowes@tht.org.uk or 020 7812 1778
- Uncharted Territory research findings and info booklet - http://www.tht.org.uk/unchartedterritory