

QUALITY OF LIFE: REDISCOVERING WHAT MATTERS

A ViiV Healthcare and
NAPWHA livestream

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INVOLVEMENT IN CARE AND REDUCING STIGMA KEY TO IMPROVING QUALITY OF LIFE FOR PEOPLE WITH HIV

A strong relationship with their physician and being more involved in treatment planning are key aspects that help contribute to improved wellbeing for people living with HIV.

While the story of advances in antiretroviral treatment is a positive one, stigma and discrimination are still being experienced by people living with HIV and this negatively impacts their quality of life.

These were some of the main themes to emerge in a Livestream moderated by broadcaster Jenny Brockie, where panellists agreed that improving the **quality of life** for those affected **should be a key focus of our efforts to reduce the impact of HIV in Australia.**

IMPORTANCE OF RELATIONSHIPS WITH HEALTH PROFESSIONALS

Brent Allan, Senior Advisor to the Australasian Society for HIV Medicine, says research shows a person with HIV's 'connectedness' with healthcare professionals is one of the biggest contributors to improved quality of life¹.

Most important is the choice of physician. "Quality of the relationship with the physician is key. Finding the right person who can work with you is critical."

Sarah Feagan, Vice President of the National Association for People with HIV in Australia, reinforces the importance of strong relationships and regular and ongoing contact with clinicians and health care professionals.

"Of course, quality of life starts with really good treatment. It's those small things about explaining to people why it's important to access healthcare and why treatments matter.

You want to make sure you have the right treatment and your side-effects are minimised."

Normalising these relationships with health professionals is crucial because "at the end of the day they become lifelong relationships."

Professor Jenny Hoy, Director of HIV Medicine at The Alfred in Melbourne, emphasised the effectiveness of today's treatments and the importance of patients complying with treatment regimens.

"If somebody takes treatment for HIV, they achieve an undetectable viral load. There is no further damage to their immune system and there is no further risk of any HIV associated conditions and people will live longer with treatment."

Professor Hoy says being able to offer Australians more effective treatments has meant that over 90 per cent of people with HIV now have an undetectable viral load.



INCREASING COMORBIDITIES AS THE HIV POPULATION AGES

One aspect of treatment for HIV that is seeing an increased focus, particularly from clinicians, is ageing of the HIV population.

Professor Hoy says that with more effective treatments people are living longer. More than half the population of people with HIV are now over the age of 50².

"Ageing with HIV, although that's now considered a chronic manageable disease, is also associated with conditions like high blood pressure, diabetes, heart attacks, strokes and cancer.

"If you look at a group of people with HIV and another group without HIV of the same age, the group with HIV has double the number of comorbidities.

"So as health care providers, we have concentrated on ensuring ongoing treatment for HIV with effective treatments that have minimal side-effects, monitoring that the treatment is working, but also screening and managing these age-associated conditions."

IT'S STILL THE STIGMA THAT 'HOLDS US BACK'

Stigma continues to be the most disabling factor for people living with HIV, regardless of how effective treatments are, says Brent Allan.

"It's the stigma that holds us back. Honestly, the general public is still living in 1984 with the Grim Reaper."

"There is fear that so many people with HIV live with day to day. Fear of coming out as HIV positive, fear of what might happen to them if they come out, fear of someone taking violent action against them, things like emotional violence, physical violence, threats and intimidation."

"All of these things happen today, in Australia, to people living with HIV and these are the things that are disabling our quality of life."



UNDETECTABLE = UNTRANSMISSIBLE (U=U)

Brent says there is hope, however. Current treatments result in the HIV viral load being undetectable for many patients, which means it is also untransmissible. "If you have an undetectable viral load, you cannot pass on HIV."

"This is diminishing that sense of fear as a negative influence in such a profound way. It is allowing people with HIV to feel like 'I am no longer a walking threat to anyone'. It is allowing people who would otherwise be afraid of people with HIV to say 'I have nothing to be afraid of.'"

While the U=U message is a positive one for Australia, few outside the clinical and patient community are aware of it, or understand it, limiting its potential to change community attitudes.

Sarah Feagan says there is a big gap in health messaging and HIV in Australia compared with other countries.

"We're running round and we're open saying U=U and it's great. We can have great lives and be ourselves and we're not a risk anymore. We're not a danger to society. But how do you spread the message saying it's ok to have condomless sex with people who have HIV that is undetectable?"

These are health messages that are hard to get across to a society that already has preconceived ideas about what a HIV positive person is."

"Quality of life for me means I can live free of stigma. I can own who I am and I can acknowledge I live with HIV and that's ok."

According to Sarah, COVID-19 has had a massive detrimental effect on social isolation, further undermining people's quality of life. Sections of the community have been isolated without family and friends to call on, something that needs to change.

"This is why peer connection is so vital. We know that people who get connected to a peer quickly after a diagnosis start treatment sooner and have generally better outcomes."

These peer connections really help people get educated and get that health literacy which is so important."





MEASURING QUALITY OF LIFE

Professor Hoy says that apart from clinical issues like HIV viral load, its effect on the immune system or complications of HIV, treatment and ageing e.g. high blood pressure, clinicians need to be aware of other concerns that are paramount to patients and that impact on their quality of life, as part of patient-centred care.

At The Alfred, patients will be asked to fill out a questionnaire in advance of an appointment, which means clinicians can talk about a broader range of issues with the patient and try to help them.

The questionnaires, developed using a tool called PozQol³, will be submitted through the patient's portal and into their electronic medical record. The responses to the 13 question scale are used to calculate a quality-of-life score.

"Quality of life is something that we will be assessing on a regular basis in routine HIV care."

Professor Hoy also acknowledges the importance of social connectedness. "As health providers, we can also help in that step towards engaging with peer support and the peer organisations that are so important."

She says she has seen many patients who initially baulk at the idea of peer support. Convincing them takes time, but once they have engaged they come back and say: "Why didn't I do that at the beginning."

So what would the ideal future be for people living with HIV? Brent Allan's vision is one we can all strive for:

**"If I had a magic wand,
I would wave it and I
would wish everyone who
was HIV positive could
live openly, bravely and
courageously tomorrow."**

THE QUALITY OF LIFE FOR PEOPLE WITH HIV LIVESTREAM WAS CONVENED BY ViiV HEALTHCARE AUSTRALIA AND THE NATIONAL ASSOCIATION FOR PEOPLE WITH HIV IN AUSTRALIA (NAPWHA) ON DECEMBER 2, 2021 TO MARK WORLD AIDS DAY.

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