

poslink

The Newsletter of **Living Positive Victoria**

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Let's grow old together

HIV & Ageing

Note from the editor

A special thank you to the Poslink Team and our guest editor Neale Gerlach, for your time and dedication in the planning, editing and production of this edition of Poslink entitled *HIV & Ageing: Let's grow old together*.

We have tried to provide a wide scope on the issues of ageing well with HIV. This is a topic that has been discussed widely on both national and international platforms, with topics such as stigma, isolation, aged care, rapid ageing, and long term effects of treatments, all up for discussion. It's also encouraging to see the intergenerational support following through, with long term advocates sharing their experiences and the younger generation affected by HIV, advocating for the rights of the older generation, ensuring that no one is left behind and all positive voices are heard.

I am sure you will enjoy reading our feature articles which include, *Let's talk Ageing* written by David Menadue, who was honoured with the Victorian Senior of the Year Award in October.

Neale Gerlach shares his opinion on the *Changing attitudes towards older age*, Naomi Schegloff provides an update on the Graying of AIDS project, *Stories from a Graying Pandemic: A participatory documentary installation at AIDS 2014* and Vic Perri shares his personal story of living with HIV since 1988.

As always, please contact the Poslink editors at poslink@livingpositivevictoria.org.au if you would like to suggest some content, offer feedback or get involved.

We hope you enjoy this edition of Poslink and find the feature articles useful in planning for your future and for those around you affected by HIV.

Shannen Myers

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FRONT COVER: Images from the Graying of AIDS installation at AIDS 2014.

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Neale Gerlach - Treasurer

Since joining the Board in October 2013, I have been most excited to get to know a diverse range of community members across the generations, and speak about our needs and interests.

In my working life, I have spent 25 years in the aged care sector advocating for high quality care for residents living in aged care services. I have seen many changes over that time, with more recognition now being given to person-centred care with a strong emphasis on services acknowledging that each person is unique with different values, cultural expression, preferences and life experiences.

The aged care service system is also giving attention to the older people of diverse sexual orientation, sex or gender identity, by recognising that many older lesbian, gay, bi-sexual, transgender or intersex people have lived a large part of their lives with stigma, discrimination, criminalisation, family rejection and social isolation. It is with 'special' aged care funding that Living Positive Victoria's Senior Voices project is focusing on the lived experiences of people living with HIV to assist and support aged care services to better meet our needs.

During the year, I have participated in the inaugural HIV and Ageing forum held at the Alfred Hospital and the first National LGBTI Ageing and Aged Care Conference held in October which brought together a broad range of community stakeholders and service providers to promote inclusive practice in aged care.

The Board of Living Positive Victoria has recently endorsed a scoping study to verify that the organisation's practice and programs represent and are responsive to the diversity of interests of all our members and demonstrate inclusive practice. I join together with all the other Directors and staff of Living Positive Victoria in our commitment to ensure that no-one is left behind, regardless of age, gender, sexual orientation, gender identity, income and cultural background.

Christabel Millar - Director

As a young woman who joined the Board of Living Positive Victoria in October 2014, I am proud to be able to represent a minority of people living with HIV and champion the lesser faces of HIV in Victoria. Attending the recent AIDS 2014 conference, I was privileged to meet and work with the most dynamic

engaging young people of all genders and sexual orientation from all circumstances around the world. I am most eager to continue this enthusiasm on the Board so that all voices including young people and women are heard, and peer empowered services are available to all.

There can be a misconception that young people living with HIV can feel 'bullet proof' and believe that by taking a pill all will be fine. However learning in your 20s that you will live with something so intensely stigmatising, something that you must not pass on, and live with for hopefully 50 to 60 years (that is much longer than living without it) will certainly require physical and mental resilience through all the stages of life.

While I am keen to raise the profile of younger people living with HIV, and strengthening our collective voice, I am also eager to engage in further efforts to inform and educate the wider community and promote services that encourage future health planning, regardless of age or life experiences. I look forward to working together to expand intergenerational and intergender solidarity and development opportunities.

The age span of current Directors on the Living Positive Victoria Board is from 24 to 60 years old, with an average age around 40.

Let's talk Ageing

David Menadue

We all know that HIV affects people differently. Some people who have lived with HIV for 20 or 30 years can have experienced relatively few symptoms or illness while others have experienced multiple chronic conditions and consider themselves very lucky to still be alive. This can be true for people relatively newly-diagnosed too; some people respond quickly to HIV treatments while others find getting on top of the virus that much more difficult.

Whether you have been recently diagnosed or had HIV for a long time though, you probably have given some thought to what might be down the track. With this talk about some positive people experiencing ageing conditions more often and possibly earlier than the rest of the population, you may wonder how the issue might affect you.

Here are some views on the subject from a range of people - some in their 50s and older and one in her 20s. They show some different perspectives but some common concerns as well.

Bernie, 56

“When I’m asked about whether I have experienced ageing conditions related to HIV, I can never be sure how much can be attributed to the virus, medications or normal ageing. An ID specialist once said to me that my internal body organs were like those of an 80 year-old. While I didn’t enjoy hearing it, I know she was right as daily pain, aches, kidney, liver and lipid issues all confront me as a result of living long-term with HIV.

“I have never really had a healthy

life since my CD4 counts became very low in the mid-90s and I developed my first AIDS-defining illness. I came close to losing my life several times and consider myself lucky to still be here. But my health over the last three to four years has improved markedly as good virological control from improved treatments has made a big difference.

“However I never seem to be able to go for periods without something having to be investigated, treated or managed. I take a huge number of pills for the side-effects of either HIV or

medications themselves which gets me down sometimes. I sometimes wonder what I’m doing this all for. But then I realise that even though I live with these health challenges, I have a loving partner, family and friends who make it all worthwhile. I look back over the years and realise that yes, HIV has damaged me, but in many ways it has re-directed my life into rewarding areas I wouldn’t have sought if I’d remained HIV-negative.”

Bernie has strong views about the need for extra aged care services for HIV-positive people as they

age. “I think some of us will need care in the home earlier than the rest of the population. Everybody would wish that they can remain as independent as possible, in their own home. I hope to remain in my home with my partner for years to come but many positive people live alone and will need significant assistance if their health takes a turn for the worse.” “An education program needs to take place to train care providers on our needs, issues and care requirements. Issues such as homophobia, stigma and discrimination need to be included in that so that people can feel they are respected and not stressed by their care providers.”

“I would love to see a GLBTIQ ageing facility opened which was affordable for people on a Disability Support Pension. While I think it is also important that gay men with HIV are accepted into mainstream services, I saw a very isolated gay man in an aged care facility when I was visiting my mum several years ago. He was sitting on his own in the corner and didn’t respond to anyone. However when I went over and gave him a hug, he completely changed. From that day onwards I would always visit him on my trips there and the staff were appreciative. He just needed someone who understood him and could communicate with him. Maybe this care might happen better in specialised LGBTI facilities.”

Wayne, 55

Wayne has lived with HIV for 20 years and went through a very rough patch when he was

diagnosed with HIV whilst living in Thailand a number of years ago. He couldn’t get regular HIV treatments or care there and it took some time after he moved back here to get on top of his health.

“For all that, I haven’t given that much thought to HIV and ageing,” he said. “The last five years have seen my health improve greatly. But I do need regular monitoring for what I suppose you can call ageing-related conditions. My doctor asked me to have a bone mineral density scan which showed I had some bone depletion in the lower back. I now have to take daily calcium and Vitamin D tablets.”

“I am also on Lipitor to reduce my cholesterol which is high because of my HIV medications. I imagine the long-term effects of some of my medications will affect my kidneys and other body organs. I’m not sure what can be directly attributed to HIV, but I do notice my energy levels are not quite as good as they used to be and my short-term memory is not as sharp.”

“I do worry about what type of care I would receive if I was very debilitated in the future. As a heterosexual man living with HIV, I wouldn’t fit into a gay facility and would expect a general aged care service to look after me. I can see potential issues in such facilities if people want to keep their status private. I wonder too if there will be enough funding to allow us to receive the care we need, particularly if some of us age more quickly and don’t fit into current aged care criteria.”

Christabel, 26

Surprisingly perhaps for someone so young, Christabel has thought a lot about HIV and ageing. “I think it can be a misconception that young people feel ‘bullet-proof’ and that we will just take a few pills and we’ll be fine and live a long time. I can’t begin to comprehend being diagnosed with a condition that has no medicine to treat it, as occurred with the older generation of people with HIV. I am on the other side of the coin with great treatments but I have had to learn, in my early 20s, to live with something so intensely stigmatising, something that you must not pass on and that permanently politicises you for probably the best part of 50 or 60 years (fingers crossed!).”

“I’m not sure what to expect in terms of my future health and information about earlier ageing is not easy to access. There is a lot of discussion about positive women having children but not about ageing, menopause and how you look after those around you as you get older.”

“Having aged care services that are properly informed about HIV will be incredibly important. Despite people with HIV living full and busy lives, breaking down stigma, they may find that if they need aged care services, people who are younger than them do not understand the complexities of living with the virus. Good planning for the future needs of our population is essential as is the need for people to be able to develop supportive relationships, including with medical professionals, as we get older.”

David, 62 years

My own story is not dissimilar to Bernie's. As I have had a period living with the virus where there were no treatments and then ineffective ones in the early 90s my immune system was already damaged severely by several AIDS-defining illnesses, when the HAART drugs arrived. I didn't expect the road ahead to be easy and I figured that the damage to my internal organs would be with me for all time. That the inflammation that goes with HIV would be worse for someone who has been inadequately treated- and so it has been. I developed diabetes 15 years ago (likely to be caused by protease inhibitors), arthritis 10 years ago (leading to several orthopaedic operations) and a Non-Hodgkin's Lymphoma last year.

I accept that at 62 years of age, other people in the population are developing similar health problems but I have no doubt that HIV and its treatments have played a major role in my conditions.

Accepting what life throws at you is a part of learning to accept the ageing process. Bouncing back or being resilient is an incredibly important part of being able to survive it. Some will need a bit of help with counselling or even antidepressants to cope and make the adjustments required. Staying engaged with friends and activities that you enjoy, as well as a bit of exercise, has to be an essential part of maintaining as healthy a life as you can. Knowing that plans are being made for better in-home care

services and well-trained nursing home staff to look after people with HIV as they age, would also be a great relief for me and my positive friends.

Recent Ageing Research

Recent research from the John Hopkins Bloomberg School of Public Health in the US suggests that, while people with HIV have an increased risk of heart attacks, kidney failure and cancers unrelated to AIDS, they were not getting these conditions significantly earlier than the rest of the population.

For example, the study found that the incidence of kidney failure in HIV-positive adults was, on average, six months younger than the group without HIV.

This news might reassure younger people with HIV about their future health prospects. The researcher's acknowledge though that further research is needed to understand the whole story. Despite this research, I believe there is no

doubt that people living with HIV who have lived a long time with the virus, and who took inferior or no treatments in the early days of HIV have a greater risk of co-morbidities, possibly sooner than others. I see it in my positive friends in their 50s, 60s and 70s. I have to believe what I see with my own eyes and what I have experienced in my own life.



MARY'S SON IS TAKING HER MONEY

If you or an older person you know are experiencing elder abuse, call the Seniors Rights Victoria Helpline: **1300 368 821**

Elder abuse is any act which causes harm to an older person carried out by someone they know and trust, such as a family member or friend.

Elder abuse can be physical, social, financial, psychological or sexual and/or involve neglect or other mistreatment.

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Seniors Rights Victoria

1485995

SENIOR VOICES PROJECT LEADING THE WAY IN HIV CARE

Donald Harris - Senior Voices Officer

Living Positive Victoria's Senior Voices Project provides an education and capacity development service to the community and aged care service sector across Victoria. A team of older (50+) people living with HIV (PLHIV) speak to address the issues of HIV and ageing and co-morbidities, by involving PLHIV from diverse LGBTI backgrounds in the response against perceived stereotypes, stigma and discrimination facing PLHIV in aged care services. The project provides training of older HIV positive people to become public speakers and provides social and educational networks for older people living with HIV.

People with HIV are living longer and may need to access services in the aged care sector. For this reason we as a community need to make sure these services are welcoming, inclusive and respectful to everyone.

Aged care facilities and workers may need to challenge their own beliefs and attitudes toward such issues as sex and sexuality (including same sex relationships, transgender and intersex people), fears of and lack of knowledge of HIV and AIDS in order to provide best possible care for people with HIV. By 2015 it is estimated that people over the age of 65 will represent a quarter of the Australian population. In Victoria, the population of people living with HIV over the age of 55 years is estimated to have increased from almost 3 percent in 1985 to over 25 percent in 2010. It is projected there will be a further increase to over 44 percent by 2020.

The Senior Voices Project is funded by the Department of Social Services and supports the Federal Government's commitment to the anti-discrimination legislation contained in the



National LGBTI Ageing and Aged Care Strategy and the Federal Department of Health and Ageing's report Living Longer, Living Better.

With the overwhelming support from key stakeholders in the HIV and aged care sector across the country, we are looking forward to the Senior Voices Project encouraging older PLHIV to speak about what it means to age well with HIV.

If you would like to become a speaker for the Senior Voices Project, and help break down stigma and discrimination by having your story heard, or for more information please contact Donald Harris, Senior Voices Project Officer on 03 9863 8733 or senior.voices@livingpositivevictoria.org.au

Resources: ASHM successfully launches Aged Care Workers guide

In July this year, the Australasian Society for HIV Medicine (ASHM) published a resource on HIV and ageing for aged care workers. “ASHM’s mission is to support the HIV, viral hepatitis and sexual health workforce,” said Karen Seager, the Senior Project Officer responsible for coordinating the resource.

“We have an ageing population that is seeking aged care services generally, and thanks to advances in treatment, HIV is now a manageable chronic condition so many people living with HIV are also beginning to seek aged care.”

“Everybody has concerns when they are going into aged care, but there are special concerns affecting those who are HIV-positive,” said Karen. “There is fear of stigma and discrimination as well as concern that aged care workers won’t understand what they should, or should not, be doing when delivering their services.”

ASHM develops educational material for all levels of the medical workforce in HIV, viral hepatitis and sexual health and saw that the time was right to include aged care workers in their suite of educational materials. “We looked at the aged care workforce and aged care

workers far outnumber the medical workforce. This group may not have access to information about HIV that doctors and nurses can get, but they are expected to provide services to people living with HIV,” said Karen.

“A clear message that this was needed came from the aged care sector and the affected community.” After examining the workforce, including demographics, and service-delivery situations, ASHM contacted the national peak groups in aged care to seek support for a survey through its partnerships. “We had a fantastic response,” says Karen.

“We also discovered that although one in five had previously worked with a HIV-positive person, 68 per cent had never had any HIV-related training.”

Survey responses came from across Australia. They included all levels of the workforce, from management to part-time and full-time aged care workers and volunteers. One third were in regional areas, five percent in remote.

The research found that the top areas people wanted to know about were the special needs of older adults with HIV infection how the HIV virus affects the ageing process and duty of care and legal responsibilities.



Aged Care Workers and HIV and Ageing

“We also discovered that although one in five respondents had previously worked with an HIV-positive person, 68 percent had never had any HIV-related training.”

The survey also asked respondents what type of resource they would prefer. Many mentioned that, alongside a hard copy, a resource that could be reviewed online would make it easier as many did not receive pay or leave to do education or training.

A large number of respondents volunteered to be part of a working group to coordinate the development of the booklet. The working group was comprised of aged care workers, as well as representatives from affected community groups. The group agreed the content areas and helped the drafting process by determining whether sections were applicable and appropriate to the workforce.

“The resource was developed and finalised within three months, thanks to the enthusiasm and engagement of the group.”

Contents include:

- *HIV facts*
- *HIV lifecycle*
- *Treatment and antiretroviral medication*
- *Prevention, infection-control, and standard precautions*
- *First aid for needle-stick injury and other blood exposures*
- *HIV and ageing*
- *Medical management*
- *Stigma and discrimination*
- *Legal rights and responsibilities*

The booklet also addresses some of the fears around HIV and aged care from a user’s perspective through

real-life quotes and anecdotes. *HIV, Ageing & Aged Care Workers* is one of ASHM’s most downloaded resources and popular booklet requests.

Free copies of the booklet can be ordered at:
ashm.org.au/publications or downloaded as a PDF.

Changing attitudes towards older age

*An opinion
piece by
Neale
Gerlach*

Significantly more people across the world are now living well beyond 60, due in part to advances in the healthcare and treatments available; so much so that the United Nations has described this trend as 'unprecedented, unparalleled, persistent and profound' in the way it is changing societies.

Similarly the treatments for HIV that have been available since the mid-1990s have equally had a significant and profound impact, and for many there is the ability to achieve and maintain high levels of health and live into older age. So whatever we make of our lives as we get older, most of us want to continue to be valued for our abilities and our capacity to engage with and contribute to our community.

While there are many opportunities and benefits in an increased life expectancy, there has been much debate about the implications associated with a steadily ageing population, particularly to meet an increased demand for health and aged care. In a recent speech about the economics of aged care given by Senator Mitch Fifield, the Federal Assistant Minister for Social Services

with responsibilities for ageing and disability, the Minister spoke about how ageing is being redefined and outlined key changes about ageing in Australia.

With baby boomers and following generations getting older, people over 65 will increase from 3.3 million people in 2013 to 4.6 million over the next 20 years. This represents a rise in the proportion of older people from 14 per cent to 17 per cent of the total population by 2033.



Another key change in this time will be the characteristics of the older population, with a greater diversity in values, attitudes and expectations. Grouping all people 65 and over into one category spans an age range of almost 40 years – a bit similar

to lumping Generation Y and Baby Boomers into one category. At the risk of presenting a stereotype, consider a 90 year old growing up during the depression and World War II having had their early lives shaped by rationing and economic deprivation, which instilled a strong work ethic within a time of conservative values and rigid cultural norms. Someone who has recently turned 90 is Doris Day, who was born in 1924 (or 1922). Doris became one of America's most popular singers and actresses in the 1950s and 1960s

with her wholesome 'girl-next-door' charm. In the past 30 years however Doris has slipped away from public view, so at her birthday celebrations in April, she is seen as a silver haired woman who has lived and aged gracefully. Her signature song *Que Sera Sera* (Whatever Will Be, Will Be) is about acceptance of unchangeable situations,

and could be seen as a song that symbolises her generation.

By contrast, a 65 year old has grown up in the post-war boom era during a time when television spread news about radical and subversive events that led to significant social and



political upheavals. The civil rights and counterculture movements that emerged in the 1960s and 1970s lead to the relaxation of social taboos and greater individual freedoms.

Rock, pop, soul, reggae and blues were the music of the times. The Rolling Stones #1 hit of 1965 (I Can't Get No) *Satisfaction* expresses the frustration, protest, sexual tension and commercialism of the times. Nearly 50 years on and the Rolling Stones continue to be seen as 'sex and drugs and rock n roll' rebels who are still working after they have turned 70. A review in the Sydney Morning Herald on November 6 asks how can elderly gentleman sound so cool, sexy, loud and nasty?

The Rolling Stones may be considered by some as ageing disgracefully, by wanting to continue to live their life the way they always have. They are however, an example of a new generation who are redefining ageing. So as a community there is a need to recognise and respond to the values and expectations of the baby boomers as they hit older age. They will be more informed than previous generations, have a greater diversity of lived experiences and will expect to exercise personal choice in the same way that they have expressed their individual freedoms throughout their life.

These older people will therefore be seeking health and aged care services that offer them choice and control, and increasingly we are seeing more 'consumer directed services', being made available through Government funded home care schemes for older people, as well as the national disability insurance scheme for people with a disability under 65.

Older age is not about 'them' – it is about all of us!

These services are being operated on the basis that every service user has different needs, preferences and aspirations, and is able to exercise choice and control in the way that the funding is used.

Similarly, hospitals and health care services are adopting 'consumer-centred care' which is respectful of, and responsive to, the preferences, needs and values of service users. There is also a focus on partnering with their consumers/service users, their carers and other advocates to actively participate in the service improvements activities.

This includes making information available to consumers and cares about the overall health service's performance and supporting user feedback.

With all these consumer orientated changes occurring within the health and aged care service system, it would seem that we are on track to have our needs recognised and respected by services, if and when we require them. If only it was that simple – even if the best health and aged care services were available to us, does this provide us with any real comfort about getting older?

Ageing is a natural part of life for everyone. While I

could promote the benefits that come with being older and the rewards of having more life skills that offer wisdom, happiness and feelings of freedom, turning 65 or any age beyond is commonly seen to be confronting and a time when significant changes to one's life are expected to occur.

A survey conducted by the Australian Psychological Society found common challenges faced by older people include maintaining health and fitness, continuing with activities and social networks, financial security, feelings of loss and increased reliance on others.

Ways that are recommended to age well include maintaining a positive attitude, staying socially connected, engaging in physical activity, eating a healthy diet, keeping the brain active, remaining occupied and living with purpose, having regular medical checkups and being resilient. All sounds pretty standard convention wisdom and similar to the ways of staying well with HIV.

I consider there is something deeper to positive ageing, which is common to living positively with HIV, and that is the need to challenge negative assumptions and value the lived experience of an individual. There are many assumptions about older people, both positive and negative, that are accepted and considered to represent all older people. Unfortunately the stereotypes associated with older people tend to be more predominant, such as - older age is a state of miserable decline and older people are ugly; they are not interested in sex and just want to be left alone; they do not remember what it is to be young; they are unable to learn and they are all sick and a burden to our economy and health care system.

Such attitudes portray all older people as the same and negate the diversity of individual attributes and experiences. Older people are just as diverse a group as younger people, all of them with different needs and wants, interests and aspirations. We all need positive images and balanced narratives to challenge ageist assumptions and bring about the changes necessary to create and sustain the kind of future we want – for ourselves and those we care about.

In studies that explore what older people value in their final years, personal contact and meaningful relationships are key values expressed. These reflect that connecting with others is a fundamental human need, whatever our age or need for support. Personal contact with people that you don't usually associate with is also considered to be an effective way to promote understanding and reduce stereotypes and prejudices.

Finally as I have been writing this article I have been reflecting on whether *Que Sera Sera* has any meaning for us as we live our lives with HIV. It is what it is...and maybe we can come to accept it and even embrace the unchangeability of it.

In my research for this article I was reminded of Doris Day's trilogy of movies with Rock Hudson and their close personal friendship. In 1985 HIV/AIDS was given a global spotlight when Rock's final public appearance was with Day on her TV show *Doris Day's Best Friends*. Check out: *Doris Day on Rock Hudson (Movie Promo) Star of the Month* at tcm.com, and *Headline News on Doris Day and Rock Hudson 1985* at dailymotion.com

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Stories from a Graying Pandemic: A participatory documentary installation at AIDS 2014

Naomi Schegloff

Jennifer from Zimbabwe worked to save future generations from AIDS, never saving for a retirement she didn't expect to see. Garry in Australia is juggling a hard-won career, an older partner, and his own mild cognitive impairment. In the United States, Lorena feels 'low' because she is HIV-positive, a trans woman, foreign-born, a former sex-worker, and now, 'old'. When his long-term relationship ended in his late 50s, Michael from New Zealand wanted to see if he still 'had it'. Now this great-grandfather is one of many older adults around the globe who has been newly diagnosed HIV-positive in their 50s and 60s.

Around the world, older adults are living with HIV and AIDS. Some are long-term survivors ageing with the virus while others became HIV+ later in life; their faces and stories are rarely represented in media depictions of this pandemic. *Stories from a Graying Pandemic*, a series of formal portraits and oral history interviews, is part of a larger multiplatform documentary project called *The Graying of AIDS* that is drawing attention to this growing population.

The Graying of AIDS is a U.S. based collaboration between photo journalist Katja Heinemann and health educator Naomi Schegloff. Since 2006, we have produced

media for both popular and specialty media outlets, presented at photography and public health professional meetings and conferences, created multi-media arts installations, and collaborated with others across a broad range of disciplines.

Our idea for the stories from a *Graying Pandemic* series was simple; create a temporary portrait studio and interview station at the 2012 International AIDS Conference in Washington, DC, and invite older HIV positive adults to sit for a formal portrait and take part in a brief oral history interview. With support from NYC community-based organisational partners like ACRIA and Iris House, and international positive people's network GNP+, our original installation walls gradually filled with portraits and quotes as more and more people got involved, creating an evolving collective portrait of the ageing pandemic that initially included 50 portraits. We expanded the series earlier this year at AIDS 2014 in Melbourne. To date, we've worked with almost 100 participants representing 17 countries and four indigenous nations.

At both conferences we set up in the 'Global Village', a homebase for community groups and activists and the only conference area that is always free and open to the



Susan, age 62 / Melbourne / Australia

“I saw all of my gay boyfriends going on protease inhibitors, and they were having projectile vomiting, projectile diarrhea. And I was really afraid of the drugs.

Eventually, I only had 50 CD4, my viral load was 4 million, my hair was falling out, I couldn't really walk very far. And I took the antiretroviral meds, and within two weeks these toxic drugs, were miracle workers. I just was - I survived.

I'm now a grey-haired woman, and I never believed I would have this quality of life at this part of my life. So, I've really embraced my toxic drugs and thank them very much for my life.”

public, allowing the local community to explore and participate. In addition to the pop-up photo studio and interview station, flip charts were set up inviting everyone, no matter their age or HIV status, to ask one question of older adults living with HIV/AIDS around the world (questions could also be submitted through social media). Some of these questions were integrated into participant interviews; all were posted on the walls of the exhibit. People aged 50 and older who are living with HIV could be

photographed and interviewed for the series or, if they preferred to remain anonymous, could answer people's questions in writing on the exhibition walls.

It's our hope that this growing archive of portraits and interviews: **preserves** a wealth of challenging and beautiful stories from an earlier time in the history of the pandemic while providing a collective “snapshot” of a pivotal moment in this demographic shift; **honours** and celebrates the strength and

resilience of this diverse global community while increasing awareness about HIV and ageing; **inspires** honest conversations about quality sexual health, HIV/AIDS, and other health services for older adults in communities around the world; and **serves** as a valuable educational and advocacy tool for all those working to support higher quality, more sensitive and inclusive health and human services, as well as policy and funding priorities that include those aging with HIV today and in the years to come.

Stephen, age 59 / Kampala / Uganda

“Being a doctor also makes it a bit tricky, because I know that as I grow older my immune system is going to grow older. Then the other thing is, I've been on drugs for now coming to 15 years. We don't know some of the long-term side-effects, what will happen to me if these drugs, for example, damage my kidneys, my liver, my bones.

Then also the issue of ageing itself. I have my father who is now 86, my mother is 84, and I notice they are often depressed. I sometimes find my mother crying, and I ask her why, she says she doesn't know, she just doesn't feel well. Then the issue of forgetfulness. As I grow older, I have seen my mother also - and even my father-in-law, he's 100 and now doesn't remember anything - he didn't remember my wife's name.”



Throughout the project, participants have shared stories that speak to universal ageing-related themes that have nothing to do with HIV, like the deep satisfaction that comes from working in their communities, their evolving thoughts on companionship and sex as they get older, the profound joy they experience spending time with their children and grandchildren, their shifting relationships with their bodies, and the disconnect between the way they see themselves and the way others see them. They've also told us about challenges that are unique to people aging with HIV, like the stigma they face not only in the world at large, because they are 'getting old' and living with HIV, but also within the HIV-community itself, because they are not 'living well'.

We are still working to transcribe and edit all of the beautiful work we created with participants in July, but look forward to sharing a wealth of new portraits and short interview excerpts from the Melbourne conference in honor of the coming World AIDS Day on December 1, 2014 (with longer interview excerpts to come in the coming months).

We hope you'll visit our on-line exhibition at agrayingpandemic.tumblr.com to explore these wonderful new portraits and stories at that time, and 'Like' us on Facebook and follow us on Twitter to learn more about the project as it continues to evolve.

Michael, age 62 / Auckland / New Zealand

"I was diagnosed in September 2010. I've only had it four years. Couldn't have been much earlier than that. 'Cause I was in a relationship, and then after that relationship finished I got promiscuous, and thought to see if I still had it at my age. "



Ella, age 'nearly 50' / Selangor / Malaysia

"In year 2003 I already need to be on medications, but at that particle of time, that we need to pay about 1,000 ringget Malaysia, and my salary is less than 1,000. So... I, I stop seeing the doctor because the doctor says, "You need to be on medication." I rather, you know, feed my children."



Educating & informing the community about the realities of living with HIV

This is an edited extract from a presentation by Max Niggel - Speakers Bureau Co-ordinator at Living Positive Victoria, from the National LGBTI Ageing and Aged Care Conference held in Melbourne October 2014

I have been the PSB Coordinator for 15 years and have seen dramatic changes in that time - especially in survival rates and the efficacy of treatments with far fewer side effects. The Bureau was formed in 1990 amidst the hysteria about HIV and AIDS by PLHIV who wanted to put a human face to the epidemic and challenge HIV mythology, stigma and discrimination. Some of our speakers have been with us for over 20 years. As they have aged they have been able to discuss their fears about ageing and the possibility of engagement with aged care services. Our speakers are encountering the reality of living longer when many thought they would be dead and the challenges that ageing brings (both visible and invisible).

It is the experiences of our speaker's voices in the community that make a difference in changing people's attitudes and stereotyping of ageing - gay HIV positive men in particular. It is often our heterosexual male and female speakers who most successfully challenge this stereotyping. They normalise HIV as a now chronic health condition and reinforce the notion that we should all expect dignity in treatment and care with the respect enshrined in all Health Promotion Charters and the Victorian Charter of Human Rights. Social and scientific research is crucial for our speakers to provide evidence of about their fears of ageing, of entering aged care

services and being discriminated against and stigmatised again when they have been open about their sexuality and HIV status.

We are very fortunate to have some of the best social and scientific research right here in Melbourne and that research allows our speakers to reinforce their personal narratives. We now know from the research that many HIV positive people will have longer, almost normal lifespans. However we seem to be prone to some co-morbidities earlier than most of the population. Of most concern is the research that shows underlying inflammation in our organs and vascular system continues to create a range of problems for us.

How will the aged care system manage our multiple conditions? With all of the research are governments and health departments really ready for an influx of HIV positive clients into aged care services?

We need to rapidly adapt to the ageing HIV population with what will be complex clinical challenges.

HIV Disclosure

The majority of 8000 HIV positive Victorians keep their HIV status confidential - Why? Stigma and Discrimination drives this fear of disclosure of HIV status - driven by the fear of people's reactions - family, friends, work colleagues and

health professionals.

It is mostly a fear of the unknown about HIV that perpetrates people's reactions even after three decades of HIV thereby creating a vicious cycle.

Our speakers describe how disclosure lifts a huge burden, is empowering and creates inclusiveness in the LGBTI and the broader community. They are role models for other HIV positive people, for health and treatment literacy, for engagement and support in their own care and for health management. Do all aged care and residential services staff need to know our status?

The simple answer is no. Medical and some health professionals need to know but most other residential care staff do not need to know - I pose the question do all staff need to know about other clients medical conditions such as diabetes? Simply put the HIV positive client is the only one who can agree to release that information.

Challenges may also arise when a carer or client does not want home help or carers coming into their home for personal care because they fear disclosing their HIV status. Some aged care services are more LGBTI and HIV aware and therefore more proactive in identifying the needs of older HIV positive people or LGBTI clients.

Sex and HIV Positive Seniors

It is still assumed that older people do not continue to be sexually active in later life. The often overlooked fact that people aged 50 years and older exhibit many of the risk behaviours also found among younger people is confronting to many GPs, healthcare professionals and aged care services. GPs and other healthcare professionals are less likely to be asking those over 50 about their sexual behaviour and older people are less likely to be offered a test.

We need to assess whether or not STI and HIV may be a risk factor in clients and we cannot ignore the need for STI screening. In Victoria for the period 2010 – 2013 there were 123 HIV diagnoses in the 50 – 59 age group and 55 in the 60 plus age group. So yes we do have sex, we do contract STIs and HIV.

National and State Policy on a Client Centred Care approach

I want to draw a correlation between the Greater or Meaningful Involvement of PLHIV (GIPA) and those affected HIV and AIDS Principle and client-centred care. It comes down to this – speak with us not for us.

One of the strengths of HIV medicine in Australia is the collaboration and close partnership with key affected communities. This led to a significant shift and has informed the development of person and client centred care – now a key policy implementation area at both Federal and State levels.

These aims of consumer engagement and participation, person-centred care, consumer-directed services are all key principles being promoted by government for all hospital and health care agencies to be integrated into all their programs and services. However as long as clients accessing health care are not educated about health literacy and the power of self-advocacy we will continue to

be frustrated by the old fashioned notion of ‘we know best’ that is perpetrated by some but not all aged care services and staff.

Ageing with HIV – a Personal Experience

This photo below is for a campaign called ENUF – a crowd driven and crowd funded social media campaign that challenges HIV stigma. These photos were exhibited during the AIDS 2014 Conference.

I wanted to challenge the stereotype of HIV and ageing – now aged 61, I want to continue to live my life to the fullest potential. However I would like you to consider the imagine being openly gay and HIV positive for 30 years then having to enter aged-care services and worry about your confidentiality being breached and health care workers who have no knowledge of HIV?

Imagine if health care workers have inherited health belief systems and hostility towards gay men?

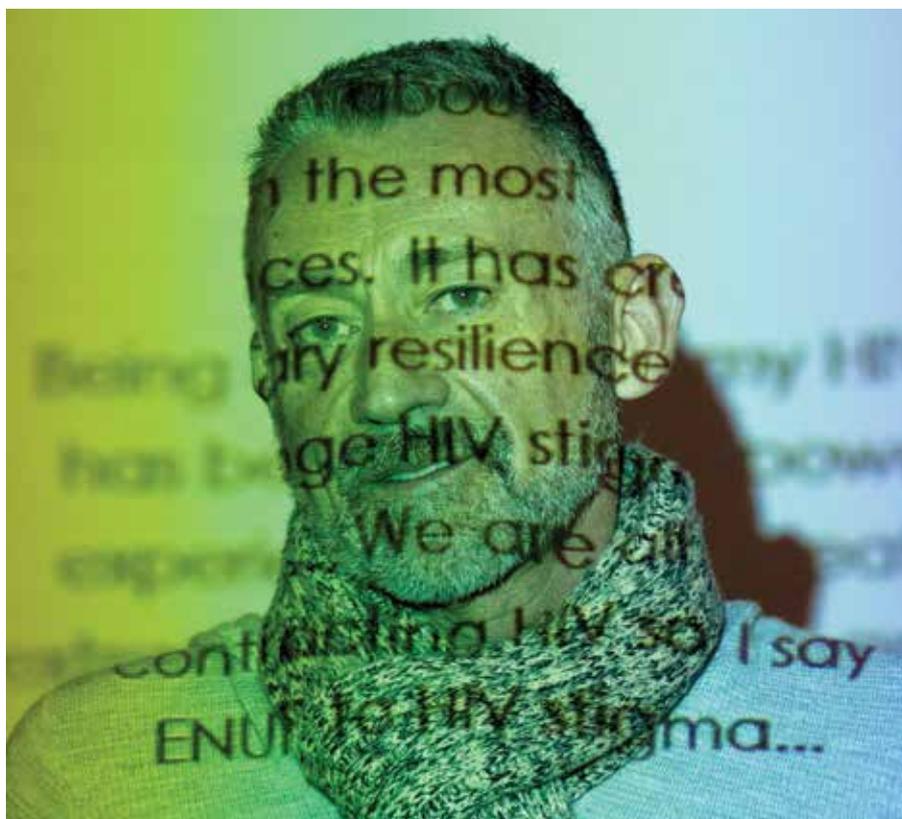
Imagine if they don't understand infection control?

Imagine if they don't understand adherence to HIV treatment?

Imagine being incapacitated with a heart attack or stroke and unable to self-advocate for your care?

Imagine decisions being taken out of your hands by health professionals and to be done according to established policies that do not reflect your needs?

What I would like to leave you with are the key messages of the legitimacy of personal narratives in programs such as the Positive Speakers Bureau contributing towards mutual respect, trust and client centred care – we are all in this together and we can all contribute.



valscafe.org.au

Meeting the needs of LGBTI older people

Historically, the needs of older LGBTI people have received very little attention. Older people are rarely considered as sexual, and the idea that they may be of diverse sexuality or gender has been scarcely considered. In addition, the historical experiences of older lesbian, gay, bisexual, transgender and intersex people have meant they have been invisible.

Many older LGBTI people have had historical experiences far removed from their heterosexual peers. They grew up in a context where their identity was condemned by the major societal institutions of the day. Their sexual orientation or gender identity was considered an abomination by the church, a crime by the state and a sickness or 'madness' by the medical fraternity. This discrimination often extended in to the foundational institution of family, with many older LGBTI people being disowned.

The social context is improving, aided by legislative reforms, increased visibility, and the diminished influence of religion. These major contextual shifts do not however, erase the experiences or the fear felt by many older LGBTI people. For older LGBTI people, having a service provider come in to their home or entering an aged care service can be very difficult, with many believing that they will again be subjected to discrimination.

Since 2009, Val's Cafe has been working to improve the lives of older LGBTI people. With funding from the Commonwealth Department of Social Services, Val's Cafe is supporting the development of LGBTI inclusive aged care services nationally, through research, resource development, capacity building and promoting the work of Val's Cafe.

Membership

Val's Café currently supports over 350 members from the aged sector in ensuring that LGBTI people accessing their services feel safe and valued. Members receive a monthly newsletter, access to resources, professional development and ongoing support and advice. Our comprehensive website provides information and resources to assist service providers to understand the needs of older LGBTI people and the practical steps involved in becoming LGBTI inclusive.

Resources

Our resources are developed through collaborations with LGBTI groups and service providers and provide a platform to profile the voices and experiences of older LGBTI people.

Research

Val's conducts research into LGBTI ageing and the health and wellbeing of older LGBTI people. Given the invisibility of older LGBTI people, research is pivotal to understanding their needs and to the development of evidence based resources and education.

Education

Val's recognises that across the range of formal and informal aged care service there is a broad range of educational needs. In response, Val's has developed targeted education including sessions for HACC and ACAS services. In addition we provide a year-long course that mentors aged care services through the practical strategies involved in becoming LGBTI inclusive.

Collaborate

Working with other organisations in the sector to create a cohesive approach to supporting LGBTI older people in all areas increases the visibility of older LGBTI people.

How you can get involved

Membership to Val's Cafe is fast, simple and free. As a member, you'll gain access to a monthly newsletter with the latest information and sector news, as well as free resources and publications created by Val's Cafe and its community partners.

To become a member, sign up at valscafe.org.au
Complete the Self-assessment and Planning (SAP) Tool
If you are an aged care provider, you can download and complete the Self-Assessment and Planning (SAP) Tool on the Val's Cafe website. The SAP tool can be used when starting out on your LGBTI inclusive practice journey, to monitor your progress or to evaluate outcomes.

Get in touch

If you can't find what you've looking for, get in touch with Val's Cafe, please contact Carolyn Whyte, Coordinator, on 03 9479 8739 or email c.whyte@latrobe.edu.au



Through my eyes

Vic Perri

“It’s a little bit funny, this feeling inside....”

I know Elton wasn’t talking about HIV but that’s how I feel inside my head. It’s a strange, funny feeling but most of all uncertain. I must say I love hearing about other people’s experiences with HIV. Whether reading about it or in groups/workshops. I find it interesting yet sad when I hear insightful stories about the long termers who have lived with HIV and AIDS for many years. The horrible periods of time they endured physically and emotionally prior to combination therapy. The many hospital visits and just waiting to die. Then being brought back to life and going through that ‘Lazarus Effect’.

Then I hear from those who are new with HIV, particularly younger people. Their stories, generally, are different but no less important or powerful. While clinically many are doing really well, they still have to deal with issues such as disclosure and the guilt they feel of ‘how they could have got infected with so much information out there in this day and age’. These stories resonate with a lot of people.

But where is my story? I guess I see myself somewhere in the middle. I was born in 1962. Oh, that makes me 52! I was diagnosed around 1987. I remember feeling very

anxious after being told I had HIV and then filled with fear after being told within a few minutes I probably had a couple of years to live. But I was quite healthy at the time and yet in all the years since have remained so (touch wood). All those years of decent health and not actually needing to go onto treatments until 2004. Only because my CD4 count, while still with in the normal range, was trending the wrong way down. I avoided

protease inhibitors and decided to jump straight onto non-nukes avoiding the potential issue of the associated ‘lipo effect’. Whether the information I had interpreted in my own mind was accurate or not, I had an opinion and I was sticking with it.

All has been well since. Not too bad I guess. Lucky. Yeah I consider myself very lucky actually having

a decent run. But... and it feels like a big but, I’m still uncertain about my future health.

Every time we talk about HIV and ageing and the issues that go with it; decreasing bone density, kidney and liver problems, cardiovascular issues and...ah...there was something else...oh yeah, cognitive issues. So should all that concern me? You bet it does. It’s bad enough thinking about having a natural progression to the grave just like the general population but to have it compounded by

*“It’s a little bit
funny,
this feeling
inside....”*

HIV and it's related issues, seems so unfair. And I'm saying that from a perspective of having a relatively healthy life with HIV. Do I have a right to feel anxious?

These's all this talk of people being diagnosed with HIV these days and providing they go onto treatments soon after and do well, can live a long and healthy life. Nice! But what about me who has had it for more than 20 years and done well but will I continue to do well. The science seems to tell me I will. The science is also being helpful in telling me that with regular exercise, a decent diet, keeping stress to a minimum, doing the best I can in taking my treatments, drinking alcohol in moderation and of course not smoking, yes, I will do well. These are things I can do to optimise the quality

of life I have with HIV for the rest of my days.

I remember asking a very well respected HIV specialist clinician about my situation. He said that even considering the many years of not being on treatment but having done well since, I should be ok. "Ah, can you elaborate on that doc?", I ask. "Well, ok, as in, if you live a fairly healthy lifestyle, you'll do better than if you didn't." So I asked, "as good as someone without HIV?" "Well maybe not but considering you have done well so far, a healthy lifestyle should help." A bit vague but as a person living with HIV and usually wanting answers to many questions we're used to that. So if you are a bit like me, middle aged, long term with HIV but have always been 'fairly' healthy with a

'fairly' healthy lifestyle and doing well on treatments, I think there's a lot to feel good about.

Perhaps there is some uncertainty but I think a bit of hope too. So, I live with uncertainty but hope. Hope that the science including the life saving drugs is as good as it seems and if I follow some steps that, while challenging (exercise!), make sense, I will grow old and feel a little confident that I will probably die of anything but HIV.

Useful information for Seniors

Seniors Information Victoria

A free advisory and information service offered by the Council of the Ageing Victoria on a wide range of issues of interest to seniors including housing options, retirement, new learning opportunities, financial and legal issues, health and well-being, and community services.

P:1300 135 090

W:datascape.com.au/infocomse/cota/search

E:askcota@cotavic.org.au

Seniors Online Victoria

An online community filled with useful information for older people in Victoria

W:seniorsonline.vic.gov.au

Victorian Seniors Card

Register and obtain discounts from businesses across Victoria and public transport nation-wide.

W: seniorsonline.vic.gov.au

P:1300 797 210

E:seniorscard@health.vic.gov.au

My Aged Care

A website and contact centre established by the Australian government to provide information about aged care, for consumers, carers or interested community member navigate the aged care system.

W:myagedcare.gov.au

P:1800 200 422

If you have concerns or a complaint

Aged care complaints scheme

W:dss.gov.au

P:1800 550 552 (a free call from fixed lines; calls from mobiles may be charged)

Age Discrimination Commissioner

W:humanrights.gov.au

P:1300 656 419

Commissioner for Senior Victorians

W: seniorsonline.vic.gov.au

P:03 9096 1052 or 1300 253 942

Disability Services Commissioner

W:odsc.vic.gov.au

P:1800 677 342

Office of the Health Services Commissioner

W: health.vic.gov.au/hsc

P:1800 136 066

Seniors Rights Victoria

W: seniorsrights.org.au

P:1300 368 821

Victorian Equal Opportunity and Human Rights Commission

W: humanrightscommission.vic.gov.au

P:1300 292 153



Supporting people living with HIV-associated neurocognitive disorders (HAND)

Kay Ledgerwood

Alzheimer's Australia Vic launched a toolkit to support an estimated one in five people with HIV who may be affected by treatable conditions of cognitive impairment or dementia at the AIDS 2014 Conference in Melbourne on Thursday 24 July.

The education toolkit developed by Alzheimer's Australia Vic in collaboration with Living Positive Victoria and the Burnet Institute, contains resources to help workers and carers to better support people living with HIV who are experiencing medical conditions known as HIV-associated neurocognitive disorders (HAND). The resources also include information for people living with HIV about this condition, diagnosis and treatment options.

Early diagnosis of HAND and treatment can lead to people regaining cognitive abilities affected by the condition, which may include memory, language, attention, planning and judgement.

Associate Professor Edwina Wright, clinical researcher at the Burnet Institute said, "The aim of the HAND toolkit is to make a difference to the lives of people living with HIV and HAND along with their partners, families and friends".

"In Victoria almost 78,000 people are living with dementia"

The toolkit contains a range of resources that are aimed at increasing an understanding of the cognitive conditions that may affect a person living with HAND and how these conditions impact on a person's ability to care for themselves.

"Ultimately, the toolkit will enable and support workers in achieving better health outcomes for people who are affected by HIV-associated neurocognitive disorders," Professor Wright said.

The HAND toolkit is the first in a series of toolkits known as Dementia and Chronic Conditions Series, funded by the Commonwealth and Victorian Governments under the Home & Community Care (HACC) program.

Dr David Sykes, General Manager Learning and Development at Alzheimer's Australia Vic said acknowledgement, awareness and understanding of HAND is critical in reducing stigma associated with HIV and dementia within the community. "People diagnosed with HIV-associated neurocognitive disorders are at risk of being exposed to stigma in many areas of their life, which often prevents them from reporting their concerns or accessing support services", Dr Sykes said.

Signs of HAND may include forgetfulness, lower productivity at work, difficulty with finances or daily activities such as organising meals, as well as reduced driving ability.

“It’s important to acknowledge that an early diagnosis of HAND and its treatment can lead to regaining abilities affected by the condition. Therefore an awareness and understanding of the signs and symptoms of HAND is vital in helping someone to follow up with any concerns,” Dr Sykes said.

The HAND toolkit is available to view online or download at: fightdementia.org.au/understanding-dementia/dementia-and-chronic-conditions-series-toolkits.aspx

Alzheimer’s Australia Vic are also developing some video resources to accompany this written resource. These resources will be available on the Alzheimer’s Australia Vic YouTube channel from early December 2014. For more information about this toolkit or to request a hardcopy of the resources please contact



Kay Ledgerwood via email: kay.ledgerwood@alzheimers.org.au

In Victoria almost 78,000 people are living with dementia. Alzheimer’s Australia Vic is the charity representing people with all forms of dementia in Victoria. As the peak body, we provide specialised dementia information, education and support services.

Call our National Dementia Helpline on 1800 100 500 or visit fightdementia.org.au/vic

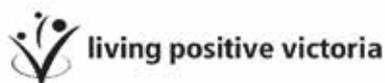
Pictured above: Living Positive Victoria’s President Ian Muchamore at the launch of HAND.



In the Loop is a free workshop for carers, partners, friends and families of people living with HIV (PLHIV).

It is recognised that people who look after, or are close to PLHIV may often feel silenced by the virus and this can make it harder for them to access support for themselves. This therapeutic workshop aims to provide information about support services available in the community and seeks to explore the constraints that carers may experience and how they might overcome these.

The workshop runs twice a year.



For more information about *In the Loop* contact Living Positive Victoria:

TELEPHONE: 9863 8733

EMAIL: intheloop@livingpositivevictoria.org.au
livingpositivevictoria.org.au/programs/in-the-loop

Starting HIV treatment: comparing older patients with younger patients

By Theo Smart - TheBodyPRO.com

The number of people living with HIV aged 50 and older is increasing. It has been estimated that by 2015 more than half of the people living with HIV (in the U.S) will be over the age of 50 and their clinical management may be more complicated. In the days before antiretroviral therapy, the progression of HIV disease had been observed to be much more rapid in older patients and this has remained the case in the era of antiretroviral therapy.

In addition, older patients generally have more health complications and, depending upon the setting, there may also be significant demographic differences between older and younger people living with HIV. Responses to combination antiretroviral therapy in this population may be variable as well. CD4 cell counts are typically lower in older patients, and recuperative abilities may not be as robust. Conversely, older patients may be more settled than younger patients and better able to adhere to treatment. However, many of the differences that have been previously reported in the literature may be specific to the population or demographic groups.

According to a study conducted at Maharaj Nakorn Chiang Mai Hospital in Thailand, there were no apparent differences between older (aged 50 and up) and younger people living with HIV who initiated antiretroviral treatment in terms of CD4 and virologic responses. However, the study, which was presented at ID (Infectious Disease) Week 2014, found differences in blood cholesterol and sugar, but they were “not clinically relevant” according to study authors Romanee Chaiwarith, M.D., M.H.S., and Thanapat Kittipanyaworakun, M.D., of Chiang Mai University. In addition, there was an increased rate of renal and some metabolic complications in the older patients, but some of these differences were pre-existing.

This retrospective study analysed data from patients aged 18 and above, who initiated antiretroviral therapy between January 2005 and December 2012 at the hospital, in order to compare people aged 50 and older living with HIV to those who were younger in terms of virologic and immunologic responses to antiretroviral therapy and adverse effects after antiretroviral

therapy. Another objective was to compare the demographic groups, adverse events and metabolic complications between the age groups.

Baseline Characteristics

Out of 1,073 patients who initiated antiretroviral therapy at the hospital, 312 patients were randomly selected. Among the 312 patients, 209 were younger than 50 and 103 were 50 or older. The median age of the younger arm was 34 and the median age of the older arm was 54.5. The majority of participants were male. There were significant differences in the mode of HIV transmission between the groups: 97.1% of the older group contracted HIV through heterosexual sex, while 18.2% of those in the younger arm contracted HIV through same sex sexual activity.

There were some significant differences in the number of underlying diseases/concurrent conditions in the two groups. In the younger group, 47.3% had no other concurrent diagnoses, compared to 33% in the older arm. Similar proportions had one or two diseases, but the older group more commonly had three or more diseases (13.6% versus 2.5%).

At baseline, the older patients were significantly more likely to already have hypertension, diabetes or dyslipidemia. Other concurrent infections such as hepatitis C, tuberculosis or opportunistic infections were similar between the groups, with the exception of hepatitis B virus infection and cryptococcosis, which were significantly more common among the younger population.

The median CD4 count at antiretroviral therapy initiation was 75 in the younger arm versus 90 in the older arm (the difference was not significant). Around 38% in both arms had CD4 counts below 50.

Initial Antiretroviral Therapy Regimen

The treatment regimens most participants started with were similar with nevirapine (Viramune) and lamivudine (3TC, Epivir) plus either zidovudine (AZT, Retrovir) or stavudine (d4T, Zerit) being the most common regimen. However, there were significantly more patients in the older group on a tenofovir (Viread) containing regimen (16.3% versus 32.0%).

Results After Antiretroviral Therapy Initiation

CD4 Count

There was no significant difference in CD4 responses after antiretroviral therapy initiation between the two groups. The median time to reaching a CD4 count of 350 was 30 months in both arms. With follow-up out to 78 months, the median CD4 counts were up around 450-500 in both arms.

Viral Load

In the subset of patients for whom viral load data were available, the proportion of patients achieving an undetectable viral load at six months was 93.5% in the younger arm and 95.3% in the older arm.

Adverse Events

- There were no significant differences between the rates of lipodystrophy, rash or drug-related liver toxicity.

- There may have been a trend toward more bone marrow suppression in the older arm, but it did not reach statistical significance.

- Rates of renal complications were higher in the older arm (as well as slightly elevated creatinine), but this was likely due to the greater use of tenofovir-containing regimens in this arm: 0.5% versus 5.8% ($P = .006$).

- Metabolic complications were significantly more likely in the older arm, but they had been more common at baseline as well: 19.6% versus 36.9% ($P = .001$).

- Rates of hypertension were similar in both arms, as were rates of diabetes mellitus.

- Dyslipidaemia (an abnormal amount of lipids, e.g. cholesterol and/or fat in the blood) appears to have been the exception. While it was more common at baseline, and increased in both arms, a significantly greater proportion of participants in the older arm developed dyslipidaemia on treatment: 13.4% versus 28.2% ($P = .003$).

Laboratory Findings

In addition to the increased creatinine levels, LDL cholesterol and blood sugar levels were increased in the older arm as well, although the investigators believed that these differences “were not clinically significant.”

Conclusions

There are a number of limitations to this study. First and foremost, the results in the Thai population may not be generalizable to other populations due to differences in weight, diet and lifestyle. In addition, other studies looking at more complex measures of immunologic recovery than simply CD4 counts suggest that there may be important differences between age groups.

However, this study does suggest that differences in mode of transmission, population and underlying diseases may be more important determinants, or at least cofactors, in the development of complications and comorbidities observed in older people living with HIV than the response to antiretroviral therapy itself.

Source:

TheBodyPRO.com - <http://www.thebodypro.com/content/75207/starting-hiv-treatment-responses-compared-in-older.html?ic=700102>

LEGAL REMEDIES FOR GOOD HEALTH

Faith Hawthorne, Lawyer, Justice Connect Seniors Law

“Keep C.A.L.M. in mind”. The four areas of life where legal issues generally arise for older people are Care, Agency, Living and Money. “C.A.L.M” is the mantra of the Justice Connect Seniors Law team when working with health and community professionals to raise awareness of legal issues experienced by older people. The team’s “legal health check” for older people is a screening tool developed to help these professionals identify the increasingly complex and varied legal issues experienced by older people and navigate difficult conversations. These issues can include making arrangements with family and friends for care or help with making decisions through powers of attorney or guardianship and administration orders. Living arrangements with retirement villages and aged care facilities, loans or age discrimination are other issues where older people may require legal assistance.

Older people may also experience mistreatment by family members, friends or other people they trust. This mistreatment, known as “elder abuse”, is generally understood as any act within a relationship of trust which results in harm to an older person. Elder abuse can take various forms including financial, physical, psychological or emotional as well as

neglect. The impact of elder abuse can be life changing, leading to poor physical and mental health outcomes, poverty and homelessness.

Up to five per cent of older people in Australia have experienced some form of abuse or neglect, with up to half being financial abuse. Given the ageing population and the rise of age-related health issues, particularly dementia, elder abuse is likely to become more prevalent.

Moreover, it is very likely these numbers underestimate the reality. Elder abuse is generally under-reported, out of fear, embarrassment or social isolation. Many do not realise independent advice is available, and that the situation can be addressed.

Justice Connect Seniors Law is a free, confidential legal service for older people who cannot afford to pay for a lawyer in relation to these legal issues associated with ageing with a focus on the prevention of, and response to, elder abuse. The ultimate aim

of the Seniors Law service is to help older people age with dignity and respect.

Justice Connect builds on the culture and community of goodwill fostered over many years with lawyers, governments, professional legal associations, community groups and health and community professionals. Through this goodwill, Seniors Law can draw on the capacity and resources of pro bono lawyers to

assist with a broad range of matters, from appearing in VCAT for a guardianship matter to commencing Supreme Court proceedings for a property dispute.

However, lawyers cannot help older people on their own. Seniors Law works with the health and community sector because people experiencing multiple and complex health problems also tend to experience more legal problems and vice versa, with a causal effect in both directions. People with multiple and complex health problems tend to have more interaction with the legal system. Legal problems can also lead to or exacerbate health problems. For example, Seniors Law helped an older person obtain compensation to replace a heater leaking carbon monoxide into her rental property. Resolving the underlying social problem, sub-standard housing, can result in improved health outcomes for clients.





Furthermore, research indicates 30 per cent of people with a legal problem would initially turn to a trusted health professional or welfare adviser about the problem, rather than a lawyer. This figure rises to 80 per cent for legal problems associated with health. It is also likely that the person with the legal problem will present the problem as part of a complex life or social problem, rather than identifying a specific legal issue. Recognising this research, Seniors Law works extensively with health and community professionals to identify legal issues and resolve clients' legal and non-legal problems together. Addressing the underlying social determinants of poor health achieves better legal and health outcomes for clients.

Justice Connect tries to reach older people in many different ways. Pro bono lawyers at Seniors Law provide free legal appointments at hospitals and health centres across Melbourne. Complementing this, Seniors Law delivers training on the "legal health check" to staff at these health facilities. This promotes better access to justice for older people and facilitates referrals from

service providers with whom they already have a relationship of trust. From 2015 Seniors Law will further develop its close connection with the health and community sector by having a lawyer based at cohealth, a community health organisation, in Footscray. The lawyer will work with staff to identify legal issues for older people and provide more convenient legal assistance and referrals.

Seniors Law also recognises there are a significant number of frail, homebound and dependent older people living in the community and residential care, who may not be able to make it to a hospital or health centre. To reach these people, Seniors Law offers a "Lawyer in a bus" service where pro bono lawyers visit aged care facilities to provide free legal advice to residents.

With older people experiencing increasingly complex and varied legal issues, Seniors Law is well placed to draw on the capacity and resources of its pro bono partners, collaborate with health and community professionals and develop innovative ways to reach older people so that they can age with dignity and respect.

For more information, visit the Justice Connect Seniors Law website or call 1800 606 313.

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ADVANCE CARE PLANNING

Helena Cairney

Advance Care Planning Manager, Alfred Health

Advance Care Planning is a process that ensures those people close to you and those caring for you know what is important to you and how you want to be treated if you become unable to make decisions or communicate your wishes.

“I feel very strongly about being in control of my life and didn’t ever want my children to have to make heart breaking decisions (ie. Turning off a life support machine)”

Advance Care Planning is a process that ensures those people close to you and those caring for you know what is important to you and how you want to be treated if you become unable to make decisions or communicate your wishes.

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Who should consider Advance Care Planning?

Anyone can do Advance Care Planning. It is of particular importance if you have a chronic health condition or are regularly admitted to hospital. A good time to do it is when your health is stable.

“My advice to people is to try and get all these things in position before it is too late.”

What are the steps in Advance Care Planning?

Advance Care Planning can include:

A. Appointing a substitute decision maker (Medical Enduring Power of Attorney)

In Victoria you can legally appoint another person to make medical treatment decisions on your behalf if you are ever in the position where you are unable to make or communicate decisions for yourself. This is called the Medical Enduring Power of Attorney.

When selecting someone to be your Medical Enduring Power of Attorney, it is important to choose someone 18 years or older, whom you trust, who knows you well, who is willing to respect your views and values and who will be a good advocate for you.

C. Chat and Communicate

Have a conversation with your family, friends and doctor about your beliefs, values and what quality of life means to you. Most importantly talk to the person who you are appointing as your substitute decision maker. Talk about your preferences for health care and future situations that you would find unacceptable or too burdensome in relation to your healthcare.

“It can be confronting and emotional to have these conversations, but I’m so glad I’ve done it. It feels like a weight has been lifted off my shoulders. Now everyone knows what I want and it will make things easier in the future.”

P • *Put it on Paper*

Advance Care Directive (ACD)

You may choose to record your wishes regarding future medical treatments and lifestyle preferences in an Advance Care Directive. An Advance Care Directive enables you to write down your thoughts about what quality of life means to you and circumstances where you would prefer comfort measures over active medical treatment. It is important to discuss your wishes with your medical enduring power of attorney, family and doctor.

The Advance Care Directive is designed to guide your substitute decision maker, your family and your doctors in making medical treatment decisions if you can no longer do so for yourself.

“As a doctor really value having an Advance Care Plan in front of me because it actually tells me what that persons values and preferences are and what the choices they would have made are particularly if that person is currently confused or has a reduced conscious state.”

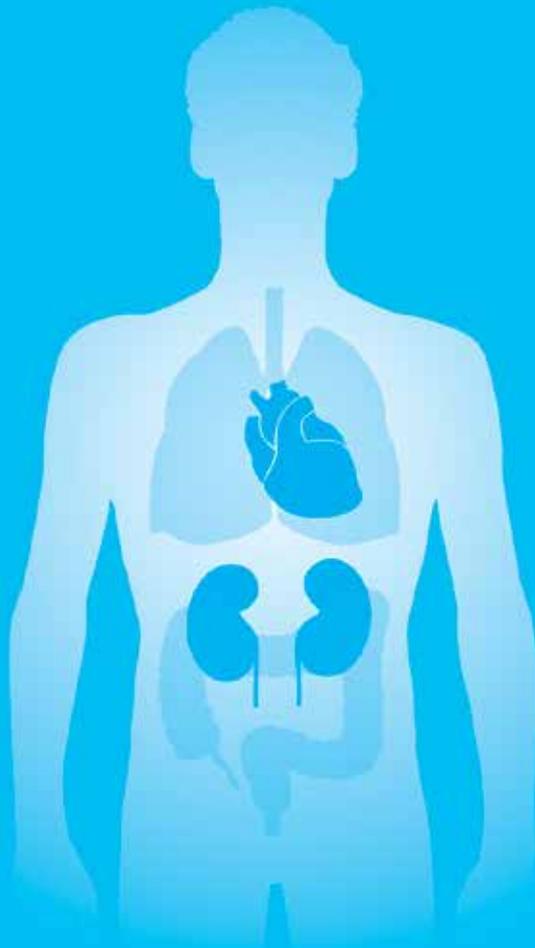
Refusal of Treatment Certificate (RTC)

A refusal of treatment certificate enables you to legally refuse some or all current and future treatments related to a specific illness you have (except palliative care-relief of pain and suffering). You need to talk to your Doctor about your reasons for wanting to refuse treatment and complete the certificate in consultation with them.

Your Advance Care Planning document(s)

It is important to share the documents so that they can be used, if required, for decision making. This may include providing a copy to your substitute decision maker, your family or those close to you, your GP and your local hospital (so that it can be put on your medical record).

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info@livingpositivevictoria.org.au

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PEOPLE LIVING WITH HIV/AIDS VICTORIA
livingpositivevictoria.org.au

You can review or cancel your advance care planning document(s) at any stage in the future particularly if there is a change in your personal or medical circumstances.

How can you get started?

The Alfred Health Advance Care Planning Program is a free service to all patients of Alfred Health or people that live in the cities of Bayside, Glen Eira, Port Phillip and Stonnington. We can post you an information pack to do advance care planning at home or you can make an appointment with our service to assist you with advance care planning.

To contact the Alfred Advance Care Planning Service simply phone 03 9076 6642 or email advancecareplanning@alfred.org.au

For people living in other areas or for further information about Advance Care Planning, refer to the website advancecareplanning.org.au This website will provide blank documents, links to resources and contact details for across Australia.

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Members receive a free subscription to Poslink, an Annual Report and occasional mail/email updates.

For more information, visit livingpositivevictoria.org.au

- Full member** (I am a VIC/TAS resident living with HIV) As a person living with HIV, you are entitled to full voting rights. You must tick the Privacy Information Statement at the bottom of this page.
- Associate member** (I am not living with HIV eg; a partner, family member, carer, healthcare worker).
- Affiliate member** (I am authorised to represent the organisation/business applying for membership).

Note: Applications for membership must be approved by the Living Positive Victoria Board of Directors. Full members may be asked to provide verification of HIV status. The Rules of the Organisation are available online at livingpositivevictoria.org.au or can be requested by contacting 03 9863 8733.

Privacy Information Statement

Living Positive Victoria collects your personal information in accordance with our Privacy Policy (livingpositivevictoria.org.au/about/privacy).

Your details are strictly confidential and only used to add you to our membership database. We will send you information about Living Positive Victoria, our newsletter and email updates.

We store your personal information in hardcopy and or electronically. Access to your information is strictly limited to Living Positive Victoria and will not be shared with any other organisation or individual.

You can access and correct your personal/health information by contacting us on 03 9863 8733 or info@livingpositivevictoria.org.au

- I have read the Privacy Information Statement and consent to my information being collected and stored by Living Positive Victoria.

Please return the completed form to:

Living Positive Victoria

Reply Paid 87634

Southbank VIC 3006

No stamp necessary.

Please tick and complete the following:

New Membership **Update contact details**

Name	
Address	
State	Postcode
Contact Number	
Email	
Date of Birth	Gender
Signature	
Date	

General Correspondence

I/we wish to receive correspondence from Living Positive Victoria about the latest HIV news, information, events and campaigns.

Post/Mail Email Do not wish to receive

Poslink Newsletter

Members can receive Poslink, we produce four copies of Poslink each calendar year.

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ABN 67 049438341

Suite 1, 111 Coventry Street, Southbank VIC 3006

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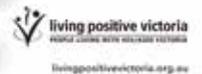


PHOENIX

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