

HOT NEWSLETTER

OCTOBER 2021

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Within the last several years, HIV researchers have turned a focus to not only aging with HIV, but aging with HIV

“Successfully”



AGEING SUCCESSFULLY WITH HIV

We are blessed that our forefathers and foremothers fought for treatments for people living with HIV and not only treatments but created a charter of rights to inform how we want to be treated. Today we live with the benefits of not only living and aging, but finding ways to ensure we have good quality of life. I thank those elders in our community and many who sadly are no longer with us for their fight for our ability to still be here thriving some 40 years later.

Many pre 1997 elders faced what was an expected death sentence and lost many of their lovers, loved ones and friends. It was a time you didn't finish university because, well you were not going to use it. , Losses went beyond living and the many who passed for those who lived they encompassed loss of dreams, plans, opportunities, finances and security but for many it was learning to live with survivor's guilt.

But the landscape is different now. Those who survived the turbulent years of early treatment development are now living futures once unimaginable.



"A lot of us feel more liberated now with the new meds and that we may actually have more of a life left where we can be freer with our decisions."

The First HIV-Positive People to Age



HIV-positive people heading into their 50s, 60s, and 70s and beyond are the first HIV-positive people to do so. While the general population can look at their elders for an understanding of what's to come from old age, there exists no baseline, no framework and no reference points for what the HIV-positive community can expect, and what's possible, in growing older.

Within the last several years, though, HIV researchers have turned a focus to not only aging with HIV, but aging *successfully* with HIV.

Among those growing older with HIV, there are high amounts of comorbidities (arthritis, hepatitis, neuropathy and hypertension, among others) and lasting significant mental health effects from decades of stigma and discrimination. Based on this, living well as an older person with HIV might seem unattainable.

"So, there was this big question: Can you age successfully with HIV? We found that yes [you can]," says Anna, research assistant professor at Emory University's Rollins School of Public Health in Atlanta, whose work is primarily on women aging with HIV.

Once researchers know aging well with HIV is achievable, they can then concentrate on learning about the varied realities of successful aging with HIV and recommend ways to replicate and foster it in public health and clinical settings.

Aging with HIV: A New and Developing Field

Charles Emler has spent his entire career researching HIV and aging, yet he describes it as a "relatively new phenomenon. "We've been looking at aging as a process for hundreds of years, but for this group of people we're barely twenty-five years into it," says Emler, a professor of social work at the University of Washington Tacoma.

Past research generally defined the notion of successfully aging as freedom from disease and disability, which of course completely excludes from the equation those living with HIV and other chronic conditions.

"To suggest that in order to age successfully, one must age in the absence of disease is unrealistic if not ageist, ignoring the diversity that exists in the health of older adults," reads a 2016 paper from a team of researchers including Emler on approaches to successful aging in older adults living with HIV in Ontario, Canada



What Does 'Successful Aging' Mean?

There are many ways to define successful aging. The term was first originated by scholars John Rowe and Robert Kahn in the 1990s. They defined successful aging as freedom from disease and disability, having a high cognitive and physical functioning, and an active engagement with life. While this concept has aided in theory and research, it's also sparked some controversy. For one, achieving all of these is nearly impossible. Aging is a natural process in which we can experience declines.

While there are some things we can control, such as our diet and health behaviors, there are others we can't control. If someone has a disease or disability does it mean they haven't aged well? Of course not. And, it shouldn't define someone. Older persons can still live great lives full of meaning, despite any kind of health decline or limitation.

Successful aging involves much more than the absence of disease. How it's viewed also differs from person to person. It involves maintaining the highest autonomy, well-being, and preservation of one's self and identity as possible, even in the face of limitation or loss.

The following are several ways to define or measure successful aging. Keep in mind that no one measure is better than the other. Think about which of the following resonates or would be most important to you.

- Life expectancy — the number of years that you can expect to live
- Life satisfaction and wellbeing (includes measures of happiness and contentment)
- Mental and psychological health and cognitive function
- Personal growth and learning new things
- Physical health and functioning, independent functioning
- Psychological characteristics and resources, including autonomy, control, independence, adaptability, coping, self-esteem, positive outlook, goals, and sense of self
- Social, community, leisure activities, integration, and participation
- Social networks, support, participation, and activity



What Are Some Real-Life Examples of Successful Aging?

You don't have to be in your eighties and run a marathon to age successfully, nor do you have to live to be past 100. Real-life examples of successful aging could mean many things.

It could mean starting a company later in life. It could mean participating in the senior Olympics and it could also involve overall happiness and enjoying life. When it comes down to it, what matters is quality of life and being able to live with a sense of purpose. Being able to do things for yourself and remaining as independent as possible is another component.

Research shows that most people want to age in their own homes and communities. They want to grow old in their own homes and familiar surroundings, rather than long-term care. Even being able to age in place can be considered successful aging.

What are Strategies for Successful Aging?

There are many ways we can be proactive when it comes to our personal health and aging experience. The following are some tips to help you age as successfully as you can, depending on how you define success.

Maintaining a healthy diet

Maintaining good nutrition is key, no matter your age. Proper nutrition as a person ages is much more significant when it comes to successful aging than people realize.

So as we age, we start thinking more about things like eating enough fruits and vegetables, staying hydrated, and watching cholesterol and blood pressure levels. You may even want to talk to your doctor or a nutritionist about your diet and how you may be able to adapt it to live a healthier and longer life.

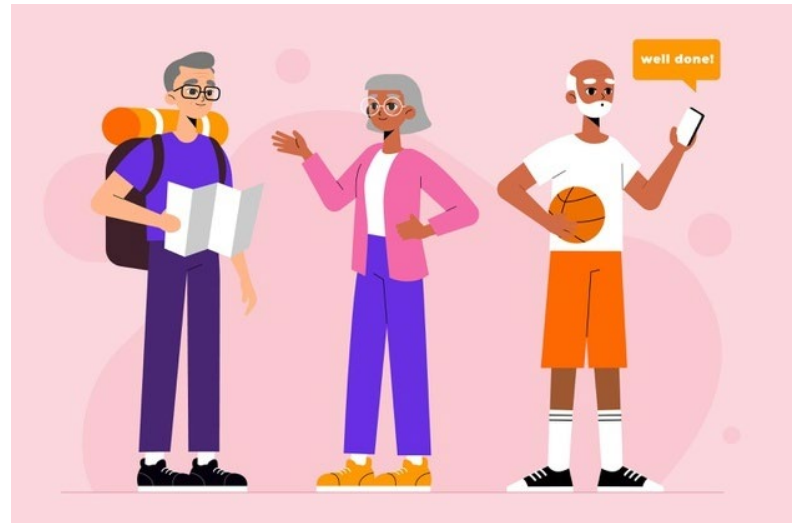
Social engagement and social support

The impact of a person's social network is often overlooked as a part of aging. However, staying active, socially engaged, and living with purpose are all goals that support well-being

Research shows that social engagement has positive impacts on health, well-being, and life satisfaction.

It also protects against feelings of loneliness and social isolation, two conditions accompanied by a significantly increased risk with age.

Increased social engagement may enhance one's confidence and ability to age in place. It could even delay or prevent having to move into a long-term care facility.



Engaging in physical activity

Whether you go to classes at the gym or need to exercise while sitting in a chair, it is important to stay as active as possible and to avoid a sedentary lifestyle. Engaging in physical activity helps one's health and well-being in a number of ways. Due to its anti-depressive relationship with mood, physical activity is an effective treatment for depressive symptoms and is also considered a crucial component of the rehabilitation process for a range of different health conditions.

Research suggests that engaging in even low levels of exercise may serve as a protective factor against depressive symptoms. Other studies have found that engaging in physical activity can help reduce pain, improve physical performance, and may improve or delay disability

Having a community to rely on is important for older adults in order to age with dignity, autonomy, and independence.

Such resources may include a local senior center, a village or naturally occurring retirement community, home health care, and other long-term care options. And, knowing who or where to call when a problem arises is also important. Other community resources could include a local library, a neighborhood association, or a ride service.



Healthy behaviors and coping strategies

Other healthy behaviors and coping strategies can also improve one's aging experience. As many doctors say, it's important to get adequate sleep, and not to drink or smoke in excess. Managing stress is another major component of living a healthy life.

Whether it's meditating, engaging in yoga, seeking gratitude, or talking to a therapist, it's important to address stress.

Similarly, it's important to address physical ailments or limitations as they arise. This means visiting your primary care physician, engaging in as preventative care, and following medication regimens.

Purposeful engagement

Engaging in activities that you are passionate about, that sparks your interest, and creates some sort of meaning are other ways to improve your health, well-being, and aging journey. As is learning new skills or developing new and fulfilling hobbies. Anything that generates feelings of reward or purpose.

This could be volunteering at a local homeless shelter or cooking meals for friends and family. As long as you continue to take part in activities that bring you pleasure.

Resiliency

The longer we live, the more losses we encounter. We will experience the loss of loved ones, the loss of certain capabilities, and may not be as physically able as we once were. While these losses may be discouraging, studies show that the way people adapt to changing circumstances is important.

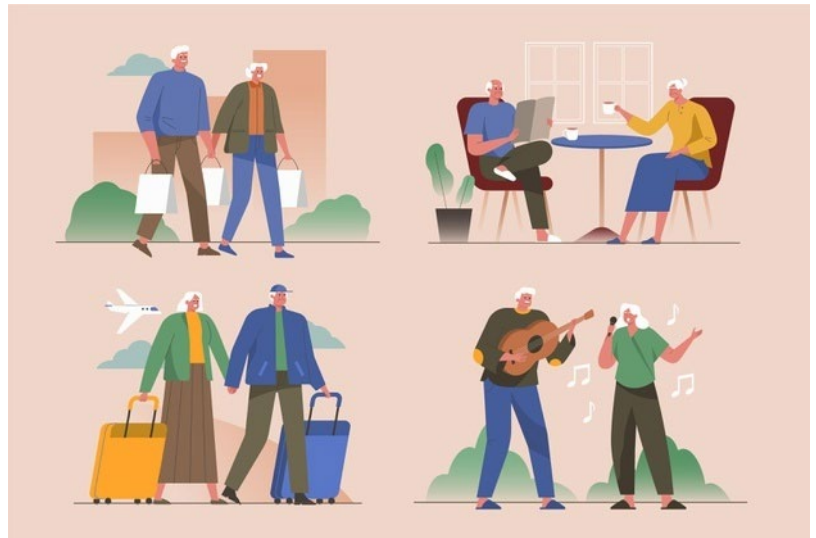
If we respond positively to negative situations and adapt as much as possible we will fare much better than those who gave up. For example, maybe your vision declines and you love to read. Should this stop you from reading books? Quite the contrary you can order books in larger print, listen to audiobooks, or even have someone read to you. All these abilities contribute to our resiliency.

Success is in the Eye of the Beholder

When it comes to successful aging, success much like beauty is in the eye of the beholder. It comes down to aging on your own terms, maintaining autonomy, and quality of life. In planning for your journey through life, start thinking about what you value and how you'd like to spend your golden years.

Are there any changes you can make to achieve those goals? What is currently going well for you may set you on track in years to come. You may want to talk to others about how they view "successful aging," if they think they have achieved it, and about any advice they may have.

So come on lets show others how to AGE SUCCESSFULLY!



Hello all, I'm BESS!

I am 11 month old Labrador who has many humans in my life two of the tall humans are called Mum and Dad by the smaller humans.

How did I get to be so lucky to have so many choices of who to play with, the little humans are so much fun, but they do have so much energy they like to run around with me all day long!

I love the outdoors as you can see I'm ready to GO, GO, GOOOOO!!! What will it be today the beach or nice grassy park?

I dream about balls big and small bouncy balls that I love to chase all the time.

Don't get me started about food, wow so many types I love trying new food.

My family say I'm a clever puppy and my tail wags every time I hear it. My humans say 'Bess is the best thing that happened to us' but guess what I think they are the best thing that happened to me.





Interview with HIV Elder on successfully ageing whilst living with HIV

By Dianne Nyoni

As I eluded earlier on the front page of this newsletter I believe we need to not only pay homage to those elders who are still amongst us, but capture their stories and advice that we may learn from or choose to take-away as tools in our lives.

I am certain many of you would agree often our elders astound me how they have endured so much loss and yet can smile and laugh and be some of the most kind and giving souls you can meet. I think by interviewing in this segment on the topic of the month we can garnish great ideas, laughs and absorb their infectious lives they have created amongst a time of unprecedented change.

I spoke with an Elder I have known for some years and has so many amazing stories of his life that would take years to hear. I see him as a person I want to aspire to when it comes to ageing because he is a man who has defied the odds, and takes charge of his lifestyle which is visible by his toned, tanned physique, glowing skin and a heart for helping others. I hope you enjoy what he shares with us today.

Dianne:

Good morning and thank you for agreeing to share your wisdom with us the people living with HIV on 'Aging Successfully whilst living with HIV'. I hope you don't mind me referring to you as a HIV Elder in our community. I refer to this title with affection for the long term positive who can share on the HIV epidemic from the early 80s and 90s through to today in 2021. I honor your loss and honor your survival, I appreciate your knowledge and applaud you for sharing your many experiences of living with HIV.

Welcome.

If you could share please how long you have been living with HIV and what have been some of your challenges from the beginning until now? Very briefly can you share your *then (pre 90s) and now (post 2000)*:

HIV elder:

I was first diagnosed in late 80s but we came to find out I had it since 78, whilst doing blood test in Uganda. At that time I was working for World Health Organization (WHO) and we did not know what we were dealing with, we were aware there was a strange illness killing people but what it was and how it worked was unknown.

I was working with the Tanzanians and Ugandans relocating orphaned children in order to protect them from being enlisted child soldiers. Working with the mercenary nuns, in order to do this work we needed the protection of the UN soldiers.

It was not until the late 80's I was officially diagnosed only with HIV. I was one of the lucky who was able to control it possibly an elite controller. Even back then I focused on a healthy diet and I believe this helped me not spiral into serious illness. Eating healthy allowed me to focus on what was good for my immune system.

Dianne:

You sound like you have taken the road less traveled and chose helping others from an early age, what a difference you must have made with the nuns for those children. Living with HIV in the early period must have come with some losses can you tell us a bit about that?

Losses

HIV Elder:

I as did many, endured much loss, in that time sadly I lost two partners. Many friends also slipped away, going through that was traumatic especially seeing the Kaposi Sarcoma. I even knew women who passed in the 80s, I feel it's important to mention that as many don't acknowledge this happened, but it is part of our history. I feel as strong need to state women were getting it back then too.

I still worked and no one knew I was HIV positive, remember back then in QLD it was illegal to be a Gay man. I had to sneak down to Sydney to the Albion center to get a HIV test. The wait was agonizing as at that time we had to wait two weeks for the results. Not long after learning my HIV status I then relocated to Sydney to live due to work commitments.

Some-time later my health crashed, I had PCP and was in hospital for 12 months at that time, later my right lung collapsed pneumothorax and they had to do surgery and I was on a machine for a month which has left scaring.

At that time I lost my career, my home, my superannuation/life insurance/finances, I lost my family, my pet dog due to being homeless. It was a time of great loss.

I decided after some time I was going to fight back, I was able to go back to university and did a degree in human behavior. I worked with EPA with my background degree in enviro-mental science but only causally as I could not work full time again. I was housed in a HIV Hospice when that closed I was finally housed."

Dianne:

Thank you for sharing that, what a scary time that sounds like. I am aware many faced stigma how did you navigate that?

Stigma feelings

HIV Elder:

It was a nightmare you were labelled and had to keep our status quiet and private to not get the judgement or discrimination. Trust becomes a big issue.

Dianne:

Many retreated and isolated to survive and still I know some fear anyone especially family finding out today. How do you see stigma today?

HIV Elder:

I think stigma is getting less due to education of the population and that this is also a person virus not a gay virus and equality actions have erased a lot of stigma also. I am an advocate for human rights in my work for UN and my international community work and indigenous work and I am a big advocate for equality for all and how this eradicates all stigmas.

Health

Dianne:

You mentioned before in the 90s I came down with PCP and I was hospitalized for 12 months. Since then looking at the now in last 10 years how has your health been especially as you are aging and living with HIV?

HIV Elder:

I was diagnosed in more recent years with what I call the three bitches Bowel, Breast and Brain Cancer. Yes men get Breast Cancer too!! When I was in breast center getting my mammogram I turned and said to the other women in there as a response to a shocked look why is this guy here, "Hey men get breast cancer too, look on the bright side I'm gonna get some new boobs, which they roared with laughter." With my cancers I made them my best friends, and called them Beryl for Bowel cancer, and my breast cancer Betty, Brain was Lola the show girl and I would tell Lola there's no show today the curtains are closed we got work to do!

HIV I call Vera Virus so I keep things as mind over matter, you control your mind which controls your body. Brain is just a vessel that, answers to the mind but your mind is your emotions are what you feel thoughts are how your feeling and that where you're in control. Your brain is a driving mechanism to walk talk and so on very different from your mind.

Emotional feelings

Dianne:

Emotionally I have heard very raw stories of pre late 90's prior to new meds, was this a difficult time for you to navigate emotionally?

HIV Elder:

I won't sugar coat it I did have feelings of being defeated and felt like swimming out to the ocean or jumping off a cliff at times, I thought I at times was tired of it and what I am living for. I had over-come it with self-talk and seeing a grief counsellor. I started talking to a spiritual guru, and the best piece of advice he ever gave was stop listening to others and believe in yourself. He told me I am stronger than what you think you are and he said you're not depressed you don't have anxiety he said you are like a gold fish in a bowl, he asked me what a goldfish does, I said swim around and around, he said see you wasted your time you still feel the same way. He said it's like constantly thinking or overthinking things.

Dianne:

I know you are a strong model of overcoming these emotions and that is one of the reasons I wanted to share your thoughts on this newsletter, Today you are a source of encouragement to others, and I am sure you have times when you are emotionally down even today but you are so busy helping others I see that is a source of Joy in your life. Thank you for being raw and sharing your learning experiences with us on how you have overcome and learned as you say a lifestyle that helps you age successfully. Pre new medications many faced social feelings that were crippling to people, can you share a little on that?

Social feelings

HIV Elder:

I'm a person who likes my "loneness" I don't call it alone as I love being alone walking in nature and so on. So I guess I coped quiet well. I encouraged others to not talk to people who know you well but rather a professional who can have a non-biased ear. I think we have to put ourselves first take care of our self-first like when an airplane drops down oxygen they always say put mask on child first and ourselves second we must focus on ourselves.

I haven't changed since then, I tend to keep myself more as I age not looking for any drama, you're not old but it's keeping our mind safe from wearing out.

Dianne:

Fear has and still is a big component of crippling people from living full lives, what were your fears before and what are they now?

Fears

HIV Elder:

Loss of life and for many loss of career, finances, purpose and family were a part of our lives but today my fears are people living with HIV will stay stuck in a place of fear.

We have two basic emotions love and fear, and I mean the love of self, love of our pet's kind of love. Focus on love rather than what is basic human behavior to focus on living in fear of the unknown, it hasn't happened, fear is just an emotion that you think could happen but in essence its nothing. I would encourage all who read this to focus on the now, today and living in the moment. Fear has its place but not when it holds you back from living.

Dianne:

Those are some dark times and it seems some of the issues are still issues today but our theme today is more about "How we can age successfully whilst living with HIV?" Many look at ageing successfully as being disease free but the truth is many HIV and non HIV people often do age with co-morbidities. This can still be achieved regardless of health and can even improve health outcomes.

So now we have context around some history can you share your wisdom on how you have overcome and faced challenges whilst focusing on ensuring you feel a sense of control on aging what you deem successfully? I know you have even recently faced a number of serious health issues and yet every-time I speak to you I notice you have a joy

about you, yet I am also aware you are still a community conscious person not only in HIV but volunteering in many causes out-side of HIV.

What are your goals and tips to ensure you age successfully that you would like to share with the readers?

Lifestyle	Being Kind
Mental outlook/focus	Being connected
Helping others	Mindfulness
Gratefulness	Nutrition

HIV Elder:

Being *kind* is important part of who I am because it's positive and very rewarding personally. Being *kind* feels good and gives you the warm fuzzies whether it's helping an elderly person carry their groceries or giving up a seat on the bus. I think a reward is not a monetary thing or materialistic it's an emotional feeling, a feel-good feeling. That heals your mind body and soul.

Being *grateful* is always front of my mind and *listen effectively* to others to give them the space to talk is a way to gain *gratitude* and get a good synopsis of what they share which can be done out for a walk or sit in a park. Listen effectively as many listen and hear but not hear what is said. By seeing how others have difficulties and finding ways to realize you have a lot to be grateful for which is happening whilst you are giving.

By keeping *connected* we don't naval gaze but looking outwardly to look at the bigger picture I tell myself there is no yesterday, no tomorrow, you have today so make the most of it. Make every second count because life can change in a minute. Find things to be grateful for and *connecting* can help not only yourself but others with this.

Talking about fear earlier is another point I think is valuable because living in a state of fear only inhibits you from taking risks and living it can have a negative in your quality of life. Whereas a *positive attitude* will always eliminate negative emotions and thoughts.

Gaining knowledge and understanding of what you are going through is valuable, don't ignore it, but face it and ask, what's going on with me? Why do I feel this way? Stay true to yourself believe in yourself. You are stronger than you think tell yourself you can do it, never give up!

I focus a lot on the importance of nutrition, a *healthy food* program is a lifestyle change as they say you are what you eat. Eating healthy is not completely illuminating but rather try to look for healthy options and this can be done on a budget. I follow the seasons for fruit and vegetables, I eat a lot of baby spinach, stick with rocket and sprouts not lettuce as breaks quickly and forms bacteria quickly so I avoid bacteria forming foods such as lettuce. I try to keep everything in moderation as lifestyle & keep a good balance. Eat lean meats and in moderation and I only grill I don't fry foods. I avoid milks from cows, yogurt are good and mozzarella cheese rather than other cheese as it has less fats in it. Listen to your body it tells you what you want and need.

I'm a big fan of pink ladies as they have a high fiber content and eat two a day. It increase energy and acts as a detox cleans as do lemon a whole lemon and 1 teaspoon of apple-cider vinegar drink blended in my nutrabullet every

morning with 1 tbsp. honey preferable natural or Manuka. This helps keep red blood cells purified, I use whole fruits as you need the fiber as well as juices of these. Try and keep reading labels to avoid unnecessary chemicals. Even if you can't buy organic washing in white vinegar cleanses the toxins from farming. Eating snap frozen veggies is the best way to gain best nutrients and cheaper as less wastage.

Feel confident and don't let others take your confidence away and remove toxic people from your life

Clean living, clean eating and clean body and clean soul equals a clean mind

Use mindfulness nature and living in the moment, environment is important to me we are connected to the land, the water and land. Learn listen to others but more importantly learn to listen to nature especially animals they have a good sense of the world and humans.

Dianne:

My final question is what does resilience mean to you?

HIV Elder:

Resilience is staying strong and believing in yourself, we stronger than we think, resilience means strength mind body and soul.

That comes back to believing in yourself, you can't ignore it recognize it is what it is and let that drive you to be stronger. Yesterday is gone tomorrow is not promised but you can enjoy TODAY as it is here in this moment that counts.

I don't want to be happy I just want to be content which encompasses gratitude and commitment to yourself. Being grateful and living without regrets and even if you face severe obstacles they help you grow and fear is eliminated.

There is a solution to every situation you just got to a situation. You don't have problems you have situations.

Thank you for sharing your rich and encouraging advice and story. So as we can see Living with HIV and Aging can be successful!





Lifeline 13 11 14
Beyond Blue 1300 22 4636
Headspace 1800 650 890
Men's line Australia 1300 789 978
Multicultural Mental Health 1300 726 289
Crisis Care (Counselling, accommodation & food) 9223 1111

Feel free to call these to talk or be referred for emergency assistance

WORD FROM OUR CONSUMER ADVISORY GROUP

“Focus on living and living well, be the yellow umbrella, stand out as you & you can weather any storm just as you.> You got this!”

WE can do this together, STAY SAFE

We acknowledge the traditional custodians
of the land on which we live and work and
pay our respects to the elders past and present.



HOT Consumer Tick