

# HOT NEWSLETTER NOVEMBER 2021

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**International Kindness Day – November 13<sup>th</sup> Why not try making every day this month a day to try a random act of kindness?**

**Happy International Kindness Day from HOT Team & CAG**

## SLEEP AND QUALITY OF LIFE WITH HIV

Sleep is not a topic often associated with HIV and often overlooked but to live a healthy life such an important topic to discuss. Many PLWHIV report difficulties with sleep and quality of sleep so let's explore this topic.

At some point in time, all of us will have had problems falling asleep. For some people living with HIV, other factors can seriously compound sleeping issues. Whether it be the effects of certain HIV drugs or conditions like night sweats that can sometimes occur, the inability to fall asleep can often chip away at a person's general sense of well-being.

Chronic insomnia or hypersomnia can cause numerous health issues if left untreated. So as PLWHIV what can we do to ensure we have a good sleep to live as healthy as we can? What medications may affect our sleep? What are the flow on effects of poor sleep?

Read on to find answers to many of these sleep related questions...

Many report that, even after a full night's sleep, they don't feel refreshed or clear-headed.

“I REMEMBER THE FIRST TIME I TOOK EFAVIRENZ (ART CLASS OF DRUGS) I WOKE SCREAMING AND EVERY DOG IN THE NEIGHBORHOOD WAS HOWLING DUE TO MY BLOOD CURDLING SCREAMS, MY VIVID DREAM OF CREATURES EATING MY BRAIN WAS BEYOND ANYTHING I HAD EVER EXPERIENCED.” ANON PLWHIV

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## WHY DO PLWHIV HAVE ISSUES WITH SLEEP?



### Sleep disorders in People living with HIV

Sleep disorders are more common in people living with HIV (PLWHIV) than in the general population according to a research study in 2019. Sleep complaints were recognized early in the HIV epidemic, the long-term effects of these disturbances are becoming more important now that highly effective anti-retroviral therapy (ART) have transformed the care of HIV into that of a chronic disease.

Sleep disturbances have a significant impact in quality of life and are associated with poorer health outcomes, including increase risk of cardiovascular and metabolic diseases as well as impaired cognition.

In PLWHIV, impaired sleep quality has been also associated with poor medication adherence, and some have hypothesized that given the regulatory role of sleep in the immune function. However, despite a very high prevalence of sleep disturbances in PLWHIV and significant morbidity, sleep disorders remained largely underdiagnosed and undertreated in this population.

It has been said some HIV medications can also sometimes interfere with sleep. While most drugs used to treat HIV are not related to sleep problems, we do know that Efavirenz (ART *anti-retroviral therapy* class of drugs) is associated with insomnia and vivid dreams in a significant number of people on therapy. Many report that, even after a full night's sleep, they don't feel refreshed or clear-headed.

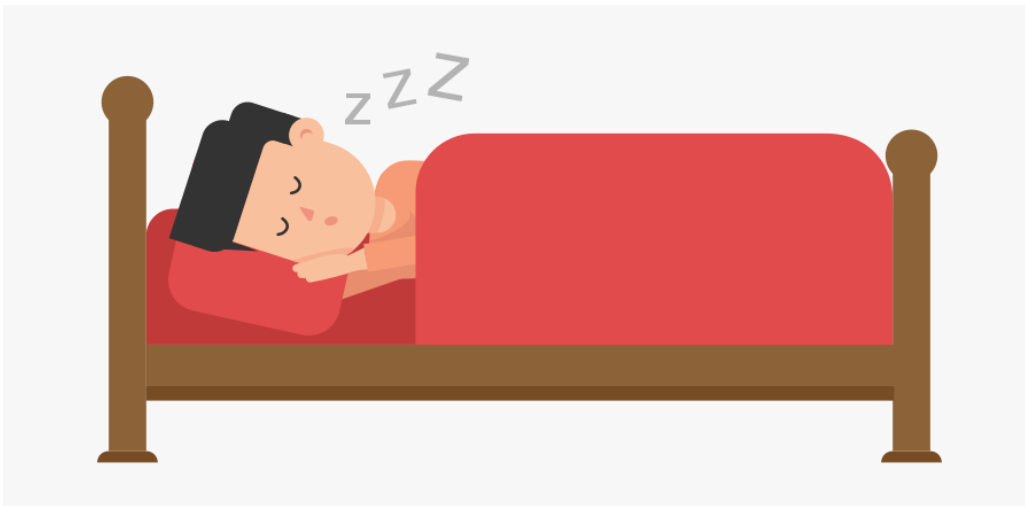
Many view sleep disorders as lack of sleep but it also can include Hypersomnia. Hypersomnia, or excessive sleeping, can be a sleep disorder in PLWHIV, although it may be less uncomfortable for the patient than insomnia. Hypersomnia is usually found in the advanced stage of HIV disease, when it is associated with extreme fatigue.



## Why do we need Sleep?

In PLWHIV, and the general population a recommended 7 - 9 hours' sleep is optimal. As we age that may decrease to 7 - 8 hours. Too much or too little sleep is linked to poor health.

A disruption in the amount or quality of sleep we get takes a toll on mood, energy levels, and concentration. Sleep also plays an important role in the state of our immune system, with chronic insomnia and sleep depletion often correlating to a poorer immune response. When low on sleep people have more negative reactions to stressful situations, and they are more reactive to other people's negative expressions, and less reactive to positive expressions. Sleep deprived people exhibit greater activity in the amygdala part of the brain, indicating stronger negative emotional responses.



A typical night's sleep is comprised of many stages ranging in length from five minutes to a couple of hours. Each stage starts with light sleep, a stage where you can be awakened quite easily. From there, as your brain waves slow and you gradually progress to what is known as REM sleep, your body movement slows and you are able to achieve deep, restful sleep needed to feel fresh and clear-minded.

Prolonged or regular interruptions of these cycles only take away any gains you may make from having a proper, good night's sleep.

## Why sleeping Problems Occur in PLWHIV?

There are numerous reasons people with HIV may have sleep problems. Among them:

- Anxiety is often a natural part of having a serious chronic illness. Fear of the unknown, of infecting others, or of having to disclose your HIV status to others can understandably take its toll on your ability to sleep.
- Depression is characterized by an inability to fall asleep or stay asleep during the night. For people with HIV, negative feelings about their treatment or future can fuel feelings of despair. To make matters worse, some medications used to treat depression can themselves impact your ability to get a good night's rest.



- Financial concerns can keep anyone up at night. The stress associated with the financial impact of the disease can interfere with our ability to sleep well.
- HIV-associated infections can also interfere with sleep patterns as they activate certain proteins that regulate sleep patterns. While it is still unclear to what degrees these proteins can affect us, it does support the early start of antiretroviral therapy in order to reduce the overall burden of untreated infection.
- HIV medications can also sometimes interfere with sleep. While most drugs used to treat HIV are not related to sleep problems, we do know that efavirenz is associated with insomnia and vivid dreams in a significant number of people on therapy. Many report that, even after a full night's sleep, they don't feel refreshed or clear-headed. Most of these effects, however, are known to resolve within one to several weeks of starting the drug.
- HIV-associated symptoms can often profoundly impact one's ability to sleep. These include the sometimes painful sensations of peripheral neuropathy, as well as the damp, clammy nuisance of night sweats.
- Sleep apnea is a condition characterized by periods of absent breathing while sleeping. People with sleep apnea wake themselves choking and gasping for air. While there is no direct link between HIV and sleep apnea, there is some evidence that HIV can cause enlargement of the tonsils and adenoids, particularly in those who are untreated or have advanced disease

# EFFECTS OF SLEEP DEPRIVATION

Impaired heart rate variability  
Risk of heart disease

Severe yawning  
Hallucinations  
Symptoms similar to ADHD

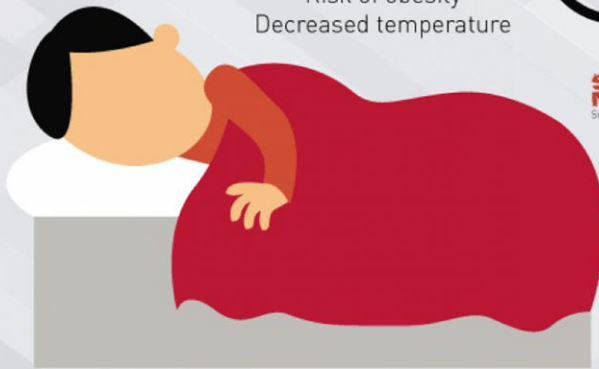
Irritability  
Cognitive impairment  
Memory lapses or loss  
Impaired moral judgement

Increased reaction time  
Decreased accuracy  
Tremors  
Aches

Impaired immune system

Risk of diabetes

Growth suppression  
Risk of obesity  
Decreased temperature



**SURVIVAL MASTERY**  
Source: survival-mastery.com

What are Strategies for Successful Better Sleep?

A healthy body is a well-rested body. If you have difficulty falling asleep or staying asleep, speak with your health provider to help identify or resolve these issues.

Whether it be changing medication, starting antiretroviral therapy, or seeking counseling for emotional or psychological support, the importance of a regular night's sleep can never be understated. In the end, it's not only about staying healthy; it's about maintaining a positive outlook in order to ensure a long and happy life if you are a person living with HIV

- \* Talk to GP to ascertain cause of sleep issues. Do sleep study.
- \* It's a good idea to do a full medication review especially with a pharmacist.
- \* Access Counselling and financial Counselling Support
- \* Talk to your GP about options you can take such as Melatonin.
- \* Keep active and structured during the day.
- \* Exercise and Eat well
- \* Look for sleep apps to help
- \* Work on Mind, body and spirit Health
- \* Meditation and Mindfulness
- \* Find Joy and Gratitude in life

## FEATURED PET OF THE MONTH MEET – “Snowy”



Hi HOT people, my name is Snowy and I was born in 2016.

I'm a proud father of nine Guinea pigs and as you can see I'm a good looking fella, so um yes 'they' cute!

My breed is an Abyssinian Guinea Pig and my human says I'm an extremely affectionate fella.

My favourite food is any vegetables and fruits and the crunchier the better, you can keep the wilted, watery stuff.

My human tells people I'm a well behaved boy. My human mummy loves her cuddles and I love my scratchies so it's a win/win for all.

Don't tell her I told you but I love to seat next to my human especially when she has her breakfast. Snowy yup that's

me loves to get a bit of treat when my human is eating.

My life is full of sunshine and my job is to eat up all the scraps, veggie and fruit that my human give me.

Chewing and giving cuddles is hard work so I like to find a nice cosy warm spot and LOVE to take an afternoon nap.

Thank you for sharing me and I hope other HOT Pets can join me on the newsletter.

Big cuddles and Peace Out Y'all.



*Interview with HIV Elder on living with HIV as an older Woman*

*By Dianne Nyoni*

I will start all interviews with our Elders as 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 many years when I first met I was confused this woman was the same age as my mother, why would an older lady be at a HIV women's group? I made the effort to get to know her and was surprised how isolated and alone this sweet lady was. As we see a lot in our older Australians, this lady was just battling on quietly and I was astounded how invisible yet resilient this lady was in my mind she definitely had defied the odds. I hope you enjoy what she shares with us today.

Dianne:

Good morning and thank you for agreeing to share your wisdom with us the people 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?

HIV elder:

I was first diagnosed in the late nineties, I thought I had the flu and didn't go to the doctor at first but I kept getting sick, so I decided to explore what was wrong. After some time and numerous visits to my GP my doctor noticed I was getting sick often and even after antibiotics wasn't getting well. The Dr asked me this not like you what is going maybe we need to do more test to see why you keep getting sick and she got me to do a blood test. About a week later the Doctor rang me and asked me to come in for an appointment.

At the time I went to go in to see her, I had been having many strange symptoms and was week from being unwell. My symptoms were

that I hallucinating and I was even hearing voices! I found I couldn't eat or even struggled to drink, it was obvious as I was losing a lot of weight. Along with all that I had lumps in my throat it was a



nightmare. Once in with the Doctor she told me I tested positive for HIV and followed by saying "I'm very sad this has happened to you." Little did the Doctor know I felt glad with my diagnosis? I shared this with the Doctor explaining I was glad to be told this because I felt like I was dying and because I was so sick I wanted to die. I had enough of being sick. I was struggling to breath I couldn't get air in my lungs, I was just so tired.

What I realized after was I had PCP and was in late stage HIV which was called AIDS then. I saw a special HIV Dr at the hospital and that started me on medication but it took a long time to start to recover and get strong again.



In the meantime my partner was in hospital with final stage HIV, yes he had AIDS. I had to work all day go visit him then take his washing home do his washing then repeat again to bring his clean clothes, and had to care for him until he passed away which just at the beginning of the year spending Christmas and New year at the hospital. Sitting there wondering why me why me, I

wish there was a hole and I could fall in and disappear.



I struggled to talk because my mind was not 100% with the virus, with grief and being so sick. After he passed I had to pay the full rent and no matter how sick I was I had to go to work to survive. I had a physical job and it took everything I had to do it. My rent was too much for me to retire, I did not know what to do and I was turning seventy with no idea if I would survive. I was alone and my grown children lived out of state and I told no one not anyone about my HIV.

Thank fully I met a person at a HIV support group who took the time to find out about my life and offered advice and put me in touch with a lovely lady from the HOT team. I was put on an aged pension and housed in a facility for older people. I did not need to worry any more about being safe, I could finally rest and focus on healing from my past trauma. I cannot say how grateful I was to this help and I believe it saved my life.

My life is so much better now and HIV is not in my thoughts so much and I'm alive and I'm happy, living healthy other than being locked down in an aged care facility for two years due to COVID. I've made many friends who are also living with HIV and they are beautiful people and I have great support and care from the staff at HOT.



I'm in a walking group that I love, I volunteer on a committee and feel a part of something. One thing that has not changed is my fear of people especially where I live finding out I have HIV and that will never change for me. Even my family don't know and never will. I still have so much anger towards my partner that he lied to me and allowed this to happen to me. From what I understand he had this for many years and never told me and most likely had it when we first met. He had traveled and lived abroad with the Australian Air Force and was based in Malaysia. It was during this time we believe he got HIV.

Dianne:

I'm without words to hear this tragic situation you found yourself in as an older woman not only losing your partner but finding yourself also very sick from what you felt was a shameful illness at the time. I am so sorry you had no one to turn to at this time when you should have been preparing to wind down from work and retire. I understand sharing this must be very hard and brings up memories of a time you would rather

forget so again thank you for sharing your story with us. I am just so glad that you were able to get help with HOT and it changed your life to be much better.

I was going to ask about losses, but you shared so much just now and I don't want to upset you as it is obvious this took a toll. I am aware many faced stigma how did you navigate that?

### **Stigma feelings**

HIV Elder:

I'm terrified of anyone finding out I have HIV, I don't even like to say the word...no it's scary.

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 still frightens me every time I have to tell a new medical professional my status, are they going to judge me, will they treat me differently, I usually am shaking and crying when I go to tell. I had a bad experience with a GP that I used to see for years and years. After being diagnosed this g changed and became very short, rude, and nasty with me. That left me feeling afraid to tell Dr's and dentist. Another time a dentist and when they saw I had HIV on my notes I felt they were being cruel and not caring due to my status, and yes I still have that fear in back of my head always.



### **Health**

Dianne:

You mentioned before in the 90s I came down with PCP and I was hospitalized. 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'm in my late 70's and I feel great, I eat healthy I'm a vegetarian and exercise a lot walking many miles which is very healing I love walking on my own as well as my HIV walking group. The walking group is good to feel connected and

have a good laugh, with friends that I feel safe, comfortable and I can speak openly about my HIV and other things that friends share. I have great supports with friends and services that check in on me. Life is good.

I have had a few health issues, cancer but with treatment all is well now and I can focus on living a great life.

I would say to a newly diagnosed person to don't let HIV control you and live your life and be happy, there are services if you need for help but I'm alive and living healthy look at me and remember it's possible.

### **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 was a mess as I said before I kept asking why me, why me. I spent so much time crying I would just cry, cry, and cry. When it was very bad all I could do was go through the motions of the day and felt like a zombie but in time as my health returned but I was still just living as a zombie for many years alone and stressed and worried for my future. I struggled to pay my rent and feared becoming homeless. I had given up actually and it was a miracle that someone noticed and helped connect me to HOT which took care of all my issues and not having to worry about feeling safe anymore has given me gratitude. Even this last two years of lockdowns I know nothing stays the same so I just wait patiently to be able to enjoy going outside again and getting back to my walking group.

Dianne:

That sounds like a time that was very frightening, I hope you realize that today you are a source of encouragement to others. I am sure you have times when you are emotionally down even today but you are still getting on with it, what keeps you pushing through?

### **Social feelings**

HIV Elder:

I guess as I said before having gratitude for life and knowing things don't always stay the same are my thoughts to keep on top of bad days.

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:

Fear is a normal part of life and there's no secret my biggest fear is anyone finding out I am living with HIV. That hasn't changed but I feel I have people to talk to openly in my walking group and HOT staff that it is now easier to deal with and I don't feel so alone.

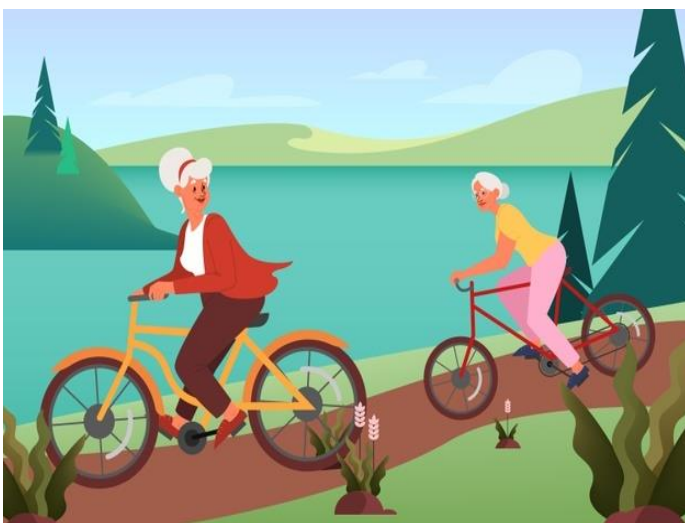
Dianne:

My final question is what does resilience mean to you?

HIV Elder:

What is Resilience, a great question...with HIV everything is in the past, and I've been blessed to get back to a normal life and fully recovered. Walking is a healing thing for me listen to music dancing on my own and laughing as much as I can. Many special gifted people have given me strength to live my life and I'm grateful that they cared to pull me up and help me find security in housing and removed my worries in life.

I would say to the readers, never feel alone reach out if you need help, I did and because of the people at HOT I am safe.



their own experiences of navigating living with HIV.

Dianne Thank you for sharing your rich and encouraging advice and story. I encourage all women to not feel alone and isolated and if you need support many women would love to connect, join the walking group and meet many wonderful people who are going through





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

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## WORD FROM OUR CONSUMER ADVISORY GROUP

“HIV can affect people from all age groups and genders, lets support each other in this life of living with HIV”

WE CAN DO THIS TOGETHER, STAY SAFE

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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**