



| Taking Care of Me |

Taking care of me

“It can be difficult describing me as a person without including HIV or having it define who I am. I like to think I live life independently of it and it doesn’t affect me. However, daily there are constant little reminders, like the pills I take, the snippets I hear in conversations and the reality of the imperfections in how my body functions.

There was a time HIV was constantly on my mind and coping was a daily challenge. It was forever present and defined the direction of my life. Diagnosed in 1994 at the age of 24 and given five years to live, it was a huge STOP sign in my life when I had always felt life consisted of green for go. Being fit, healthy and an athlete I never thought HIV would be a part of my life. How wrong I was.

When diagnosed I was adamant that I would fight this virus with natural therapies and stay off the medication for as long as possible. It turned out to be about three years. Within that time my immune system was almost completely destroyed and I had only five T-cells. I was not unwell but I did lack energy. I was working full-time and found myself needing afternoon naps and plenty of rest. I made the decision to go on medication after much deliberation and I was very scared. Not only was taking HIV medications, to me, like a small defeat it was also finally realising that this was all real. I really was HIV-positive. Fortunately, due to the combination of HIV medication, support from family and friends and a healthy outlook on life, my health improved, as did my vision for the future. Being solution-focused was my main drive to achieving many successes in life. Yes, I have HIV in my body but how can I still achieve my goals?

Having children was something I was originally told was not possible. My daughter and son are healthy, beautiful children and both living examples of following a dream. Many other HIV-positive woman are having children. A gift we had thought was unobtainable.

Health and fitness are still vital parts of my everyday life. Reaching elite levels in adventure racing and travelling internationally to compete has blown my mind. It is something I’d never have thought possible. It has proven the power of having a dream, setting a goal, and then making a plan. In everyday life I hear too many people making excuses why they can’t do things rather than finding a reason to do it. My life with HIV is an example of how to make your own journey through life regardless of the obstacles that can be thrown your way. I amaze my positive and non-positive friends at how much energy I have, but it has a lot to do with will power and determination. And to be honest, I love the way my body feels with all this exercising, strong and fit.

I am now working as a Peer Support Worker. I am surrounded by other HIV-positive people so I have been able to normalise this illness as I can talk about it freely in my home and work life.

Being HIV-positive seems like a gift to me in many ways. It has given me an appreciation of life and how precious it is. I believe that so many people walk through their lives without ever really living it because they believe there are always tomorrows. For me, there may not be a tomorrow or many more tomorrows so I wonder at today and see how special it is. I stop to smell the roses often, and to watch the sunset and to tell those people around me who support me how special and loved they are. This is the positive side of being positive. I will face the negatives when they come my way and hopefully I will face them with grace.”

Treat yourself well - our physical and emotional health go hand in hand

Caring for oneself

Whether we manage to make it a priority or not, most of us are aware of the need to take care of ourselves. Some of us know it is important, but we have become complacent about our health.

“Eating right is a challenge when alone and on a limited budget. Often fatigue causes me to reach for the biscuit barrel rather than have a meal.”

For those of us who are mothers, our children provide us with a reason to care for ourselves so we will be there for them in the long term. At the same time we are often too busy looking after our family to stop and think about our own physical and emotional health and factor it in to our busy lives.

“Being a working mum keeps me so busy, sometimes I forget to take care of myself.”

“I don’t think about me. I only think about my family. I come last on the list.”

Some of us have learnt to treat ourselves well, listen to our bodies, reduce the stress in our lives, have a positive mindset, exercise regularly and have a good diet. We place a high priority on trying to stay relaxed, take our HIV medications and vitamins, and sometimes we give ourselves little treats and indulgences. Some of us have regained a sense of ourselves and are happy and proud of who we are and what we have achieved despite the challenges that HIV brings.

“For a long while I didn’t care if I lived or died. I’m more aware now of taking good care of myself.”

“I still have trouble in the ‘looking after myself’ aspect of this virus. I am trying to do better and look after myself physically which motivates me to go out and socialize, volunteer and stay in contact with those who are invaluable to me.”

“It took me a long time to remember who I am and that I am more than a virus. Having HIV has taught me to live in the here and now, not allowing my chronic condition to define me as a person.”

Looking after ourselves means attending to our state of mind, as well as our body. In fact, so much of living with HIV is about the emotional side of dealing with it. Some of us have nobody to rely on emotionally and have to support ourselves. This is difficult. We find ourselves going around in circles, getting frustrated, feeling hopeless, angry and upset. Sometimes it is difficult to decide what is really important to us.

With time, most of us get a whole lot stronger at dealing with our emotions and we find ways to balance our physical and emotional wellbeing. For some of us music is the ingredient that keeps us calm, for others it is physical activity. Some of us find counselling one of the most valuable services we have access to as HIV-positive people.

“This has been a long journey. The hardest, longest part has been accepting that I have HIV and realising that it is a virus, and not who I am. It’s been hard for me to learn to take care of myself. I love to go swimming. There, all my negativity melts away and all my stress is absorbed by the water. It is difficult to get there regularly because I am always last on the list. The benefits flow especially to me, but not only me, also to my children, partner and work colleagues. Taking the time to do little things that you love, no matter how trivial, can have far reaching benefits.”

“HIV made me reassess what is important to me. I stopped doing things I thought I should or ought to do and tried to do only what I need or want to do for me and my child.”



I am not afraid to ask for help

Support networks

Some of us have no support networks. Some of us live a long way from family, choose not to tell anybody, or have been rejected by people we thought were close to us. HIV is a lonely and difficult journey to make by ourselves. Sometimes we keep things to ourselves to protect our loved ones and family.

Many of us do get support from our family - our partners, our siblings, our parents, our children. When everything gets too much, they are often there for us. This support is essential to get us through the bad times. Most of us also find some support through good friends.

“My husband is my best support network. I don’t know what I would do without my family.”

“Mum passed away earlier this year. The fact that I was standing there was due to her. I’m determined to continue to keep on and not fall in a heap. I’m still here because of her support.”

“I’m lucky to have special people that help me through tough times. I couldn’t get by without them.”

Those of us living with HIV in urban centres have a lot of support available if we need it. Some women feel we still have to fight for equal service delivery. Others ask whether women know what services exist. At times it may be hard to find what we need if we don’t know what we’re looking for, and for women outside the urban areas, getting access to quality services is not easy.

HIV-positive peer support does wonders for our self-worth. Most of us feel we can drop in and connect easily to support groups when needed. Peer support helped so many of us in the early black days, and some of us have made lifelong friends among our peers. Those of us who get support from other women living with HIV find it invaluable.

“The greatest support I get is from my positive peer support group.”

“I really feel grateful for the efforts and pathways women before me trod to make it easier for someone like me, diagnosed ten years after them. I feel like resources and support exist because people in the past fought to make it happen.”

“I love being involved with the positive community. I feel like I belong.”



I have the right to ask questions and the right to say 'no'

HIV medication

Each of us is different in the way we respond to antiretroviral medication, both physically and emotionally. Whereas our reaction to our diagnoses are similar, our reactions to taking HIV medications are very diverse.

Some of us feel we should have started treatment sooner and some of us are not quite ready to start yet. Some women distrust antiretroviral medication and worry about the long-term effects of taking “toxic” drugs each day. This fear is partly a hangover from earlier days when antiretroviral medication was much more potent and difficult to tolerate. Today there are new treatments with less likelihood of side effects and better responses and as a result our life expectancy has been extended enormously.

For some of us, it takes a long time to decide to go on the medication despite the fact that we know it will most likely save our life. Many of us seek out all the information available, talk to our peers and then make informed decisions about the antiretroviral treatment that will suit our lifestyle.

“I went a long time, twelve years, before I had any experience of the health system. When I finally started treatments I would stop and start and stop and start. The health professionals were very patient with me. At some point they asked me why I kept stopping and I said that it was too hard to be reminded every day that I am HIV-positive. I resented it. I realised that I had to change how I saw the pills and started to see them as my magic bombs that would work to do me good.”

Most of us don't like the idea of taking medications for the rest of our lives. It is a double-edged sword, a constant reminder that we have HIV. But also we understand the benefits and recognise that antiretroviral medication is life-saving, so we see it as the lesser of two evils. Many of us have a love-hate relationship with our medications.

“When I commenced treatment I was really angry. I did not want to be reminded every day of my HIV by taking a handful of pills.”

“There are often two contradictory messages: one is trivialising, don't worry they are just tablets, the other is a warning about how serious it is and how you need to be on treatments to live.”

“Some days HIV never crosses my mind, until I have to take those little coloured pills.”



Many of us have been surprised at how well we have responded to antiretroviral treatment and how much it has given us back control over and improved the quality of our lives. Some of us have embraced our antiretroviral treatment because it really has brought us back to a life worth living.

“Now I am on treatments I remember the person I am – it has been like coming back to me!”

“I can recall being terrified of treatments, even though I was dying. My hair had fallen out and I had no energy at all. I had 16 T cells. As I gradually began to take the meds I became aware of myself, as if I had awoken from a five-year sleep. Everything seemed new and fresh. The sky was a clear blue and the grass was a rich green that felt like velvet under my feet. My senses had reawakened and I realised how close I had come to not being there for my kids. Now I treasure every day and relish each moment. Something that I had resisted so strongly for so long was now my lifeline.”

“I was so mentally resistant to starting antiretrovirals and now I love them. They brought me back to a quality of life I never thought possible. I would certainly be dead by now if I had not started them.”

Most women have side effects from taking antiretroviral medication but for the majority of us, the side effects decrease, become part of life, or disappear with time as our bodies adjust to them. Some of us are lucky to have no side effects. A few of us worry that the side effects might cause problems as bad as the virus. Most of us feel so much better now that we are on antiretroviral treatment and we have a future because of it.

“It took me several attempts at different combinations to find the one that worked for me and allowed my immune system to re-establish and didn’t give me terrible side effects. I am lucky, I only take one pill twice a day and I do not seem to have side effects. But I work very hard at making sure my body can cope with the undeniably toxic meds. I exercise five or six times a week, I drink buckets of clean water and I follow a strict diet of good food.”

“My side effects are emotional. I’m still working through them!”



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