“My Journey”

An HIV-positive diagnosis can be the start of a very lonely and frightening journey. As women living with HIV, we face complex challenges to our health and wellbeing. The fear of disclosure and of discrimination often makes forming and maintaining relationships difficult. Because of the stigma associated with HIV, we frequently experience social isolation. Antiretroviral medication is now available to help people with HIV to live long, “normal” lives, and the physical impact of HIV has lessened, but the psycho-social impact remains.

The **“MY JOURNEY”** kit was conceived and written by and for women living with HIV. The kit weaves together, in our own words, the experiences of 32 women living with HIV in Australia. Despite our wide ranging backgrounds and beliefs, it highlights much common ground in our experiences. The Kit is meant as a resource of information, support and comfort for all women living with HIV. It also provides health sector and other allied service workers with an insight into the realities and needs of women living with HIV. Contact details for all major service providers are in the “Resources” booklet.

“MY JOURNEY” is divided into five themes, each focussed around a positive woman’s story, and highlighted by comments and quotes from other women about their experiences of living with HIV. The **“MY JOURNEY”** kit explores: Diagnosis, Disclosure and Discrimination, New Relationships, Taking care of ourselves, and The Future. It also contains a personal journal, a candle and 30 cards with messages we have written to inspire you each day of the month.

Once diagnosed, the beginning of our journey is fraught with fear. HIV can send us to the depths of despair and seems to close off the life that we had hoped to have. It sends us in another direction, along a new path. As we continue our journey, for most of us, the fear is gradually replaced by hope. As we increase our knowledge and understanding of HIV and we listen to the stories of other women who have gone before us, we learn compassion for ourselves. We learn who we can trust to stand next to us, we find a voice to say how we want to be treated and we realise that we are not alone.

The women involved in the creation of **“MY JOURNEY”** invite you to realise you are part of the treasures contained within it. Positive Women Victoria hopes that by sharing our stories and experiences through the **“MY JOURNEY”** kit we can lighten the pathway along your unique journey and help you to navigate the challenges and complexities of living with HIV, reduce the experience of stigma and minimize the personal and social impact of HIV.

Diagnosis

You are not alone.
You are not the only woman living with HIV.
We belong to a family of tens of millions.
Over two thousand of us are living in Australia.

Diagnosis

"I am a proud woman living with HIV.

I grew up in a large loving family in a small country town. I moved to Melbourne in 1985 following the man of my dreams and along with that, a fairy-tale life that most girls have when in love. I gave birth to my son in 1989 and my daughter in 1990. It was during this time signs appeared that my relationship with my partner was under stress but it wasn't until I became sick that the truth came out. In 1994 I was diagnosed HIV-positive. Today, I can reflect on my journey of living with HIV.

My HIV diagnosis brought fear, discrimination and stigma. This mind space did not come from those close to me but from within me. The more I learnt about HIV I found I was more forgiving of myself. Every day was like running a marathon. I was now a single mum struggling to bring up two children, fighting a virus that wanted to take my life and dealing with toxic HIV medication, until finally I was diagnosed with an AIDS-defining illness in 1999. This did not stop me but made me more determined to live.

In 2001, I decided to do public speaking because at the time of my diagnosis I felt very naïve regarding HIV. I thought my life was safe from the risks of catching this virus and yet here I was. It had happened to me. I worried constantly that my children would suffer because of something that was inflicted upon me and yet I felt this incredible need to educate the wider community. Being a mum of two children had a lot to do with this. I found it important to stand up and not be a victim of this virus. I needed to talk - not only about HIV but also issues around safer sex and prevention. I needed to teach communities so that fear does not become stigma and discrimination. This is very important to me. I have found that this has not only helped me, but also my children.

Speaking publicly is a very positive and empowering experience. It has improved my confidence and enabled me to challenge myself and has opened up many opportunities I may never have had.

Today my life is better than I would ever have imagined it could be. My children have grown into well-adjusted supportive and loving young adults. I have also found happiness in a relationship with a very nurturing, good and honest man.

But that's a whole new and different story."

I will not let my HIV diagnosis hold me back - I am more than my virus

The Day that Changed My Life

When we are diagnosed as HIV-positive, we feel overwhelmed by a range of intense emotions. We feel shocked, afraid and isolated. Life as we knew it is changed forever. We suddenly see ourselves as different from the person we were before our diagnosis and our feeling of self-worth is affected as a result. For many of us, the horror of our HIV diagnosis feels unreal and we are in a suspended state of disbelief.

Some of us feel that it is the end of our world. We feel devastated and some of us even consider suicide. We ask ourselves questions that nobody can answer: Why me? Who will love me now? How long do I have to live? What am I going to tell people? What did I do to deserve this? Can I still have children?

Our head swarms with terrible images of poisonous, tainted blood and a slow and painful death. We feel angry, distressed, empty, wrong, confused, finished. We are enveloped by anxiety, fear and secrecy. We imagine we will never again have a partner, children, a future.

"Not knowing, nowhere to turn, very alone, confronting."

"I felt it was the biggest challenge I could ever face. Not only was I being told I had a life-threatening disease, I also knew it carried so much stigma and taboo."

"Octopus...there are no areas its tentacles do not reach!"

"Totally blew my world apart. As time goes by you do adjust somewhat."

Regardless of why we got tested and how prepared we thought we were for the result, regardless of our differences, it takes a long time to regain a sense of self and where we are in this world. For some time we are on "sensory overload": there is too much information and also not enough.

For those of us diagnosed early in the epidemic, HIV meant a death sentence. Since then, antiretroviral medication has stopped what was an inevitable progression from HIV to AIDS and thus death. We now know we can live long and healthy lives with HIV. Yet women diagnosed with HIV today still take on much of the fear and stigma that has been forever associated with HIV.

"Through engaging with the women's group I have learnt to love and hate 'Alvin'. It has helped me to name this wicked child that lives inside my body. Heaven forbid I have 'AIDS'. No, I have 'Alvin' with me. I have accepted 'Alvin' even though I have carefully and decisively not disclosed to most people in my life. How come I am no longer overwhelmed by 'Alvin'? Briefly, occasionally, I still am but I have sought out people to talk to about it - women's groups, psychologists, doctors, internet forums. My partner gets angry and feels his life is wasted because of being positive. I don't think like that. I need to keep stronger for my children, and for myself. It helps to make plans, keep busy and not to give up on yourself. I don't like living with 'Alvin' but it isn't all bad and with support of others, I can cope."

"HIV is different now. We were told that we would only have a few months or years to live. Now newly diagnosed women need to plan to have a long and productive life."

"I didn't know that I had commenced a journey but today I know I have. It changes and evolves. The initial honeymoon or 'horror-moon' period passes."

You can't be stigmatised if you feel good about yourself

Stigma

At some point and to some extent all of us feel a sense of stigma in relation to our HIV diagnosis. Many of us feel we will be treated differently if people know we are HIV-positive. Depending on how we contracted HIV, we feel we will be judged as being better or worse than others: perhaps tainted as a loose woman, a slut, or a junkie. If we have experienced stigma, we try and avoid situations where it may happen again.

"I know many people judge whether I was unfortunate or just irresponsible."

"What I've realised over the years, is that a lot of the stigma is self-perceived. Yes, there still is stigma attached to being HIV-positive, but how much do I want to buy into that?"

At a personal level, we are often our own worst enemy. We take on a great deal of the stigma associated with the virus and internalise it. Sometimes the stigma is much harder to deal with than the physical implications of being HIV-positive. For some of us this self-stigma manifests as overwhelming feelings of shame or irrational feelings of guilt. We can be so cruel and say very hurtful things to ourselves.

"I am filthy, I am dirty, I am damaged, I am dangerous."

Shame and stigma are a big part of trying to cope with HIV and we need to try and work through it. Over time, feelings of stigma do lessen.

"Strong self-esteem is the answer. If you're confident in your love of yourself, stigma can't hurt you."

"It has been lovely taking off that heavy cloak."

It is a personal journey but try to stay connected with other people

Isolation

Most of us experience a sense of extreme isolation after our HIV-positive diagnosis. We move into a dark and difficult place for months or even years. Our internal stigma causes us to pull away and withdraw from people. We feel no one will understand us and nobody will want us. We try to keep it a secret from everyone so we have no one to talk to about it. At times it's all too hard and we disconnect from everyone around us. We feel very lonely, and this in itself eats away at us.

"My aloneness envelops me often. I feel quite isolated in the world."

"Isolation for me is so much a part of the early days of HIV. Sometimes we can choose to isolate because we think we are lesser than we are. That's not the truth. You're not the only positive woman out there. We belong to a family of tens of millions. Even if you feel or think you are alone, we are all out there living the best we can with HIV. Sometimes it is comforting to wrap yourself in the blanket of isolation."

Some of us grow accustomed to the isolation and we seek it out as a place to enjoy time alone to reflect on life choices, without having people telling us what to do.

"My head is the space I retreat to: where I find confidence, memories and the strength to look forward to everyday, the future and living a happy life."

I am brave and resilient

Grief and loss

Each of us faces grief and loss in some way as a result of HIV. We grieve over the loss of the life we believed we were going to lead: the loss of our sexuality; of opportunities to forge new relationships and find a partner or create a family; of the chance to study or to carve out a career and earn money. All of us fear and grieve the potential loss of our health. Some of us have lost our husbands, partners or children to HIV, and some of us have lost friends and colleagues. Sometimes we wonder why we are still here.

"Grief and loss are a part of my life... When you find out you are positive you grieve and believe that you have lost your life and all possibilities that come with it. As I have lived into my second decade I have grieved the positive people that I have loved and lost. I'm amazed at how many funerals I had to go to in such a short space of time. I've lost so much from each and every one who's died and yet gained so much from the lives they have lived."

"I'm still grieving: it's a journey for me, it's not as heavy as it once was but it's with me every day."

I continue to get stronger all the time

Emotional health

Most of us plunge into a downward spiral when we are diagnosed with HIV. Feelings of stigma, isolation and loss can contribute to poor mental health, which impacts on our physical health. Although most of us recognise how important it is to maintain a positive mindset, we often struggle to do so. Some of us lose a sense of who we are and start to question our identity.

"Somewhere between starting treatment and menopause, I lost my identity. I forgot who I was, what I enjoyed, what makes me laugh, cry, be happy or sad. Was it accelerated ageing, early menopause or the whole lot?"

Not all women living with HIV experience depression, but HIV does throw us into a dark void that we would prefer not to visit. For some of us depression was with us before HIV and testing positive certainly compounds the condition. Our emotions are cyclical and we go through highs and lows. Gloom, melancholy or despair can sometimes creep up on us when we least expect it. We learn how to manage it in different ways as best as possible.

"I was so depressed for so long. I had such a low self-image. I learnt a trick to make myself feel better: make an effort, especially when you feel low. Dress up, put on a bit of make-up. It was just like a mask: when I put it on I felt different. This made me feel better about myself. I became a different person."

HIV sends us on a roller coaster of emotions. Overall, our emotional lows decrease with time, but they still sneak up on us periodically. Keeping busy and the passage of time help many of us through the initial challenges that our diagnosis brings. For some of us day-to-day routines are necessary to keep our spirits up; for others it's finding something to look forward to. And for those of us with children, they usually snap us out of our negative mindset eventually. Connecting with other HIV positive women is very valuable and important. Peers allow us to realise that we are not alone. We understand how best to support each other.

"It's getting better through more contacts with other positive people as time goes by."

"No one can comprehend how it feels apart from other HIV-positive women."

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Disclosure & Discrimination

Disclosure & Discrimination

"I am an HIV activist, facilitator, trainer and community-based researcher. I was diagnosed with HIV over twenty years ago and it was the most shattering news I could have faced. In those days I was told that I had a life-threatening condition and I was going to be dead in five to eight years' time. I had a son who was only two years old and I thought that I might not see him finish primary school. Now he's about to finish university so that's rather joyous for me.

Shortly after I was diagnosed, I contacted a peer support group and that was incredibly helpful. I also got some counselling to deal with the diagnosis because my self-esteem was completely gone.

When I was first diagnosed the nurse gave me some good advice. She told me that I didn't need to tell anybody else unless I wanted to. I told my brother straight away and he was great. It took me months before I could tell friends and they were all okay. About a year later I had an accident and a doctor was called to the scene. I was semiconscious in a pool of blood so I said to her: "Before you touch me I just want to let you know that I've got HIV". She backed away and refused to treat me. She just left me there with open wounds. Although I had been terrified about what people might think about me having HIV and terrified about any discrimination my son might face, the only discrimination I have ever faced is from health care workers. Not from people who work in the HIV sector, they are true angels but from people who don't understand HIV. I've been refused treatment by dentists. Once when I was going to have a surgical procedure the doctor asked me as I was going under anaesthetic: "A druggie are we?"

I began to speak out to show the face of HIV. At first I spoke within the health sector to help reduce the stigma we face. I think it's particularly important for people with HIV to speak to young people. People are so afraid to talk to young people about sex because they think they'll go and have sex. But there's good evidence that educating young people about sex before they become sexually active is perhaps the most valuable thing you can do, in terms of their life skills and their future. I look at how and why young people trust their partners. The issue of trust is very difficult, particularly for women because we often don't have the confidence to negotiate safe sex and I think it's very challenging in long-term relationships.

In 1999, my health was going down very quickly and I had almost no immune system left. I started taking antiretroviral medications; they are miracle drugs. Now I embrace my toxic drugs because I was very lucky. I didn't have any side effects and I've led a much fuller life over the decade or more since starting meds than in the decade before that. The drugs enabled me to embrace life again and to realise that HIV is not a death sentence. Providing I take my medication every day, I can lead a long and healthy life with HIV.

My HIV status defined me before I started antiretroviral treatment and before I went public in the media these two things happened about the same time. Curiously, since I've gone public and since I started taking antiretrovirals, my HIV status is no longer so important. Even though I work in HIV all the time, it doesn't define me any longer.

So it seems HIV is just a stage in what appears to be a long, and hopefully even longer, life."

My voice is powerful

Disclosure

Most of us are terrified of disclosing our HIV status to the world. We are afraid that we will be viewed differently to other people. It doesn't matter if we were diagnosed decades ago or months ago, each of us experiences some fear about disclosing our HIV status to others. For many of us, it is the most frightening challenge we face, whether we are disclosing to health care workers, to family members, to potential sexual partners, to our children, to work colleagues or to friends.

Disclosure is not a one-off event but something we continually have to negotiate as we meet people who have no reason to associate a healthy looking woman with HIV. Because we fear the possible consequences of disclosing our status, most of us tend to keep it tightly to ourselves. This adds a huge burden of secrecy to our lives.

Those who mind don't matter and those who matter, don't mind

Friends

A few of us told the world about our HIV shortly after we received our diagnosis and it backfired. We found that some friends were not as trustworthy as we had hoped. We faced negative reactions and we lived to regret disclosing. Some of us have told nobody because we are so afraid of the reaction. Many of us share our status with only a few close, supportive friends or family members.

"Always be honest, it's the best way."

"No way! No. Don't tell. Absolutely Not. Haven't told anyone - afraid of the outcome."

"I had to tell someone at point of diagnosis: my best friend. She was supportive. My next disclosure to a friend I'd trusted rejected me. I have put up a wall, isolated myself, kept the virus secret."

"I have found it easier at times to simply keep my own counsel and my own company. This I am aware isn't healthy."

Several of us feel that HIV has coloured our ability to make friends. With time, most of us learn who our true friends are, who we can trust to share our HIV status, and when to keep quiet.

"Finding out I was HIV-positive at 19 showed me who was just there for the good times."

"My friend cared and wanted to know what was wrong. I told him. He wrapped his arms around me and said you can talk to me."

For each of us who has faced rejection or stigma, others have had good experiences. Most of us who have disclosed to friends have found them supportive.

I am who I am

Family

Disclosing to family members is very hard. We feel guilty that we will disappoint them, cause them pain, wreck their lives. While siblings are often very supportive, sometimes our parents' reactions can be harsh. They act out of anger, blaming and rejecting us. Mostly our parents are very supportive, even if they don't know how to show it.

"I haven't disclosed to anyone other than my son, but his wife wouldn't let me kiss the kids."

"My mother found out I was HIV-positive after twelve years. All she said to me was, 'I know: when you're ready to talk to me about it, I'm here.' It was the best thing she could have said."

I am a good person and deserve to be loved

Partners

We are afraid to tell sexual partners that we have HIV because we fear rejection. We get anxious and lose any confidence we may have had. Most of us would prefer to disclose our status if somebody gets close to us but it feels so difficult at times. Usually we choose to wait until we know the person really well. Sometimes our status is disclosed to partners without our consent. Reactions vary enormously, but some of us have forged new relationships, told our sexual partners that we are HIV-positive and it has all been okay.

"Always a tricky one. Do I tell the person straight out and risk rejection? Do I wait and then hurt them by not being open and honest? I like to get disclosure over with. If someone rejects me 'cause of HIV then I reject them. I have nothing to feel ashamed about. If the person loves you, HIV won't matter."

"My partner at the time wanted to run a mile, but he thought that would not be helping me or him. Still together now after 15 years with three beautiful children."

"After weeks of me convinced that this man would run as far and as fast as he could, he wanted to marry me and have children. He barely reacted at all and still very much wanted to go ahead."

Don't hold back who you are - Be yourself

Children

As mothers, most of us worry greatly about whether or not to tell our children about our HIV status. Most of us have not yet disclosed our status to them. We are afraid that they are too young, not ready, that it will be a heavy burden on them, that it will have negative repercussions, ruin their lives or change the relationship we have with them.

"I don't want to have to do this if I can get out of it."

Many of us don't know how to tell our children. Unless they grow up knowing about our status from a very early age, how to approach disclosure needs careful consideration. Some of us feel we should make sure there is somebody there for them if they need someone to talk to after our disclosure.

"Telling my son was a series of little disclosures, it wasn't easy. I think he worries about my health."

"Confusing. What are appropriate, age-related questions, how to answer?"

"I waited until I could ask people who had been through the same thing, what their experiences had been. I felt sorry for my son that he didn't have the parents I wanted him to have. I told him when he was four because I wanted him to understand that there were reasons why I couldn't do certain things that other parents could. There was a reason why he lived differently. I told him we had a bug in our system that made us feel very tired and we needed more rest and sometimes it made us sick. He's grown up in the HIV community: it's part of his life, as it is mine."

Most of us who disclose to our children find that despite our fear of the consequences, the results are positive.

"Found it easy. Kids are great at understanding, without stress."

"First thing I did was tell my son. He was wonderful. He wanted to kill the man who gave it to me."

"My child grew up knowing I was HIV-positive so I never had the problem of disclosing."

My HIV status is entirely compatible with living an active, productive and fulfilling life

Work

Wherever we don't need to disclose our HIV status we tend not to. Most of us are adamant that we would not disclose in the workplace because it is not necessary. Those of us who work in the HIV sector, on the other hand, have no problem in disclosing our status at work if we choose to, and we feel that it provides us with a strong connection to our community.

"Never told anyone I worked with. Why do they need to know?"

"I'm lucky, everyone knows I have HIV and it's no big deal."

If you feel worse after you leave a health care professional then change that health care worker

Health sector

Within the health sector our HIV status is most likely to be known or disclosed. Most of us have had very good experiences with health care workers, especially within the HIV sector. We have found doctors and nurses who are helpful, compassionate and caring, who understand us, provide us with information, connect us to other services in the community, and give us emotional support.

"Some of them are brilliant, true angels, particularly those I've encountered who work in the sector."

"Doctors helped save my life, but now I know to take responsibility for my own health."

Unfortunately, most of us have also faced HIV-related discrimination at some time, from health care providers who are ignorant, judgmental, arrogant and lacking compassion. Most of us are frequently asked by health care workers: "How did you get it?", perhaps because we are women in a country that has a predominantly gay epidemic. The question makes us feel uncomfortable. We know it is inappropriate and there is never a simple answer because we know a value judgment is attached to the question.

"There are no guilty or innocent victims and if it doesn't matter to me why should it be such an issue for others?"

"I ask the health professional if 'how I got it' is relevant to my care. Otherwise I ignore the question."

We face negative experiences ranging from non-caring attitudes and insults to traumatic episodes. Sometimes we are placed last on surgical theatre lists and sometimes we are refused treatment. Many of us live with ongoing fear of discrimination by health care workers who have no understanding of working with clients who are HIV-positive.

"During my twenty years of living with HIV I have been refused medical services. I have been treated as something that is untouchable. I have had my sexual activities questioned and judged when I have been in a long-term relationship. It has been assumed that I am a drug taker and promiscuous. And yet without the care I receive in Australia by compassionate people I would not have the wellbeing I have today."

"I was fairly newly diagnosed, keeping HIV secret. I had a major tooth extraction and told to rest. I had two school age kids, caring on my own. Around midnight, I ended up in emergency hospital needing six stitches. I was so fearful of them treating me differently. They did. I was made to feel like I deliberately bled. I kept hoping it would stop bleeding, but it would not clot. Alone with my kids, I had no adult or peer I could use as a sounding board. I avoided dentists for a long time until I had overwhelming tooth and gum pain. There's nothing trivial about treatment. It is serious and can rob you of your mental, physical and emotional health."

Our experiences with health care professionals are up and down. Those of us who have faced stigma or discrimination are subsequently fearful and distrustful when we need to utilise health services in the future. When we are unwell, we don't have the resilience to deal with discrimination and advocate for ourselves. We don't have the strength to point out that the concept of standard precautions is simple: treat all clients in the same manner. Discrimination makes us isolate ourselves further so we continue to live with the burden of secrecy. Some of us are able to laugh it off; others feel angry at the discrimination we face.

"I disclose when I feel safe. When I'm sick, the last thing I want to do is deal with people discriminating, judging and assuming. I don't want to educate others when I'm not well."

"In over 15 years of being HIV-positive, I must admit that 50 percent of my interactions with services has been fruitful and productive, due largely to my assertive nature. Sadly, the other 50 percent has been less than successful. Ignorance and fear have always been the underlying issue. My mental health has been left up to me to deal with, which is unacceptable when you think about it. When interactions have been negative, I have generally taken it upon myself to educate and inform."

"Being treated badly by doctors in the past means that I am more guarded now."

Educate yourself, be informed and keep up to date

Pregnancy

Some of us who are pregnant or want to get pregnant face negative attitudes from medical professionals who themselves need to be educated about our right to have children and how we can do so safely and with dignity and respect.

"When I was pregnant with my youngest child, my doctor decided to walk with me to the nurse's station. He stood in the doorway and announced, in a raised voice, 'I need to let you know this woman has HIV'. Not only did all the nurses stop and turn, so did all the patients in the room and those queuing outside. I was only relieved that my eight-year-old who was with me didn't realise what was said. I felt about a quarter inch tall."

"The obstetrician jumped away from me and told me he couldn't treat me. I felt that I was too filthy and unworthy to get medical treatment. When I was in hospital waiting to give birth, one of the nurses didn't look at me or talk to me for her entire shift. When I asked to go to the toilet, she told me to squat on the bed and use a tray (very difficult being heavily pregnant). When I asked for a tissue to wipe myself (I was attached to a baby monitor), she told me to get it myself."

Fortunately not all of us who decide to go ahead with a pregnancy are treated badly. Some of us have been encouraged in our decision and reassured that everyone has the right to choose, regardless of being HIV-positive, whether to have a child or not.

"My doctor was helpful as he told me that it wasn't a death sentence and I would still be able to have a baby. He said, 'You have the right to have a child'. That was very affirming."

"No one should decide for you if you want to have a baby. There are ways to minimise transfer from both dad and mum. My baby is living joyful proof."

Healing begins when someone bears witness - share your story, talk about HIV

Public disclosure

Going public about living with HIV can be a truly frightening experience and also one of the most rewarding. It lifts the burden of secrecy that many of us take on when we are diagnosed. It is a relief that we no longer have to hide that part of ourselves that has had such an impact on our lives.

"Comfortable, confident, part of who I am. I speak with pride."

Some of us who do public talks in settings such as schools, do not do media interviews because we want to protect our children or parents from any possible negative repercussions. Nobody should ever go public about their HIV status unless they want to and have good support, and their housing and livelihood are not threatened by doing so.

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New Relationships

New Relationships

"When I was told I was HIV-positive
I thought for a brief and terrifying moment that my life was over
It was a moment of true devastation.
And then something else kicked in. A faint hope, a glimmer of strength
Part of this strength has been my friends and family.
When I talk to other women who are HIV-positive there are some common threads.
Like the loss of not being able to be a lover, or never being a mother
I really thought that no one would ever love me again: love me, love my virus
Yeah, right
I don't believe in fairy tales, and then you came along.
Fast forward and it's a knight in shining wet weather bike gear riding a CBR 600
I am quietly amazed each morning that I wake up with you
And I am overwhelmed with the love we share
Even with what we deal with
You've helped get over the "I'll never love again"
And you've helped me rediscover me again
Now we're tackling the part about being a mother
But that's a whole other story"

Give of yourself and love others. You will get back more than you give

Partners

We are a very diverse group of women in our attitudes to starting new relationships. For some of us, HIV has shut off our sexuality. We avoid sexual encounters and believe we may never have sex again. We don't want to start a new relationship because we are scared of disclosing our HIV status, consequently we don't put ourselves "out there" like we used to.

"At times I'm not sexual. I feel like an empty shell, nothing to offer."

"I don't feel like a woman very often, only a mother."

For most of us, HIV takes away our femininity - of feeling like a woman - at least for some time after we are diagnosed. Many of us feel that we are no longer attractive and no-one will ever want us again: we feel undesirable, unlovable. Some of us have become embarrassed about what our bodies look like because of weight loss or other changes due to the side effects of the medications.

"I forgot I am still a woman. Sometimes I feel asexual. I don't want to be loved, have sex or feel anything. Other times I crave touch, intimacy and companionship."

"I don't know if I will ever want to have sex again. I think it's a combination of hating the way I look now and feeling desire for someone who desires me unlikely. I need to get the motivation to go out and meet people again and learn to love this body that I have so often thought of as my prison."

Many of us fear rejection when we enter into a new relationship. HIV complicates relationships. We have to spend more energy and effort and thought about how to disclose and when to disclose. We are afraid of not being accepted. We recognise that anybody who does accept us as a sexual partner must be a special person. Some of us stay in unhealthy relationships for years because we fear we can never find another partner, but in hindsight, after the relationship ends, we realise how soul-destroying this is.

"Recently I met two non-positive guys who were okay with sex and the virus. The majority run away, which is hurtful and feels like you have been kicked in the gut."

Most of us feel we will never find another partner but that is just not true. Many of us have developed good, caring relationships with new partners since our diagnosis. We feel loved and supported and we have someone to love and hug.

"My partner is wonderful. I couldn't ask for a better relationship."

"My man makes me feel feminine all the time."

Although many of us live in fear of transmitting HIV to our partners, we realise the importance and need to have open, honest discussion about safer sex and at the same time we may have difficulty negotiating it. Condoms can be frustrating, not conducive to fun sex play, not easy to use, and often can interfere with the mood. Some of us choose not to disclose our status to sexual partners. We are now told that if we take antiretroviral therapy consistently, have an undetectable viral load for at least six months and have no sexually transmitted infections, then we are not sexually infectious[1] and are not likely to transmit HIV sexually, but many of us need more information and greater reassurance about this statement.

"I met a wonderful man who wasn't scared off by disclosure of my positive status and I'm now enjoying my first new relationship since diagnosis. Even though I am determined to ensure that my new partner is not infected, the reality is that HIV impacts his life every day, just as it does mine."

Over time, many of us have reclaimed our femininity and learned to celebrate it.

"HIV took away my femininity for many years. I feel great now and love myself being a woman."

"Important. Love it. Hanging on to it."

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[1] Undetectable viral load and risk of HIV transmission: The 'Swiss statement', AFAO, 2009. http://www.afao.org.au/__data/assets/pdf_file/0004/4594/Dec09_factsheet_swissstatement.pdf

Children

"I was overjoyed at 26 weeks when you kicked me.
Proudly pregnant, eating chilli sauce sandwiches at 2 in the morning,
"Burning Spear" playing out loud.
I loved you already.
I barely remembered taking tablets three times a day with grapefruit juice.
I hate grapefruit juice
Blood test all the time. Everything is great.
You were born at 9:30 in the morning, 3.4 kilograms.
PERFECT
Nanna and your uncle couldn't wait to hold you.
Eight years old. Wow! Years have passed so quickly. You are a young man.
I love you more than all the trees.
Your music is inspired. You are so gentle and brave.
We have travelled. What adventures and stories to tell.
Sometimes I get tired, I snap at you. You say I'm mean. I can't always do the things you want.
I told you I have a virus. It hasn't gone away.
Last month I got sick and couldn't pick you up from school. I slept a lot.
You did your homework in bed with me. You played "Mary had a little lamb" on your violin.
I was scared. This time I wasn't sure. I found strength. Thoughts of you.
I am so proud. You are wise. You know who you are. You keep me real.
No time for dwelling.
I love you more than all the trees.
The doctors said I wouldn't have children. I had you.
PERFECT
The specialist said I might not live. I started living the day you kicked me.
You are my friend for life. Thank you for loving me.
I have a virus.
My secret is HIV"

Some of us who were diagnosed before the advent of triple combination antiretroviral therapy were told that we could never have children and have learned to live with that loss.

"I didn't have any children because I was diagnosed so young and didn't have the information available today. I had a termination and didn't tell the hospital. It's one of the few regrets in my life."

"In many ways my decision not to have children makes me feel like somehow I'm less of a woman and other women have this precious knowledge that I will never have. I have learned to live with my decision and at 40 years old, I was lucky enough to get an 11-year-old stepson, who is my own in my heart and I am his parent of preference."

Many of us have now been assured that we can have children without passing on the virus. We are very thankful for this possibility and many of us have gone on to have children.

"Waiting for my baby's HIV results was excruciating. Thank God she is clear so it was all worth it. I am so glad I had her. She is very precious and a joy to me. I am so busy I hardly think about HIV."

Although raising children is hard work, those of us who have children are grateful that they are part of our lives. Some of us worry too much about the future of our children. We want to be there to see them grow up, find partners and form their own families. For most of us, children provide us with love, fulfilment, hope for the future, inspiration for life. And they keep us grounded.

"The love of my life. My children keep me going and give me unconditional love."

"My kids, they are the air I breathe."

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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 to 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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The Future

The Future

“I am someone’s daughter, someone’s sister, someone’s friend. I could be your neighbour. I am an ordinary woman on an extraordinary journey. My journey is wonderful; it’s tragic, and awesome, the way it shapes my life and touches my soul.

When I was in my early twenties I travelled to Europe. Little did I know the extent of the journey upon which I’d embarked. I got a job in Italy. I loved getting to know the place, the people and their culture. I made some good friends. What amazed me was how many of my new friends who were using heroin. Having no concept of the risks involved, it wasn’t too long before curiosity got the better of me. Three years later, having moved to England to get my act together, I was totally shocked to be diagnosed HIV-positive.

“What’s HIV?” “Doesn’t that have something to do with AIDS?”

Yet on some level I had the feeling that those few words “You’re HIV-positive” would have an enormous impact on my life. I wasn’t wrong. My doctor told me I’d be lucky to have four more years to live. I was twenty-four years old!

In those early days of HIV, before treatments, stigma was rife and the prognosis was grim. As an HIV-positive woman I was a minority within a minority. I lived one day at a time. I fought to survive. I didn’t think about the future, let alone plan for it, yet I never gave up hoping.

In 1996, a breakthrough in treatments brought with it renewed hope. Finally I wasn’t sick all the time. You would think I’d celebrate, and believe me, I did, but how do I support myself through the future I never thought I’d have? For many years, struggling with HIV, I thought I’d never ever be well enough to study again, let alone work. HIV has sent me to the deepest depths of depression, yet it has also given me some of the most wonderful, incredible moments. You can’t enjoy joy without suffering sorrow. Of course the medications have played a pivotal role in my life in that I believe I would have died without them.

The support and love from my family and the incredibly inspiring people living with HIV, with whom I’ve shared peer support, have been what’s kept me alive and forever hopeful. Relationships have been a hard thing and being ill has been a big part of that, because I’ve not been able to get out there. Hope is a beautiful thing.

I recently went back to study, and I am employed as a Peer Support Coordinator. My work brings me into contact with many HIV-positive women from all walks of life, each living productive lives, studying, working, having children, achieving. I’m constantly amazed at the fear that a lot of newly diagnosed women have of people finding out they are living with HIV. They are scared because their experience shows them that people make judgements about them because of their virus and it’s often just not true.

I have now lived with HIV for 24 years. Our futures look bright.”

I focus on thoughts and activities that bring me joy

Facing illness

As antiretroviral medication has improved, we are able to look forward to a much brighter future than ever. The thought of AIDS terrifies all of us, however most of us realise that HIV no longer means we will inevitably get an AIDS-related illness that will ultimately lead to our death. With the assurances of modern medicine and the health system that we have in Australia, it is no longer our most likely outcome.

Nevertheless some of us still fear getting sick and some of us do get sick. For those of us who have lived with the virus since before the advent of antiretroviral medication, looking after ourselves is an ongoing challenge. We worry about finances, losing our independence, what will happen to our family if we become ill, what will happen to our children. Some of us who are without any family support panic about who will look after us if and when we face serious illness.

“Some days my ‘health care’ is too much to deal with. Too many doctors appointments, blood tests, prescriptions, medications, questions and probing, and medical students judging me.”

“My sons worry I will get sick and die like their dad. I have two small boys. I worry I will die and my boys won’t have a mum or a dad to take care of them.”

“I try my best to keep healthy. It affects my whole family when I get sick. As I get older I am not sick very often, but when I am, I am really sick. It’s hard work!”

I will not let HIV stop me leading a full, normal life

Work

A few of us are unable to work because of our poor health, however most of us are leading very full lives that include paid work. Work keeps many of us in touch with other people and provides a healthy balance to our lives. Some of us who thought there would be no better future have returned to work. Many of us are now considering doing further study. Those of us working within the HIV sector find it a relief that we don’t have to hide our status and we feel we are making a difference.

“Love working, love to study. Keeps my sanity, keeps me healthy.”

“Got to enjoy work or I don’t do it.”

“When I volunteered for a peer support organisation, light came into the darkness. I was not alone. I could put all my pain to use. I could test out all my fears about living with HIV with others. All of a sudden I felt normal. I belonged.”

Travel with condoms and travel insurance

Travel

Travel is a big part of life for some of us and we look forward to doing a lot more of it. Some women are frustrated that certain countries do not allow people to take medications into the country without disclosing their HIV status or they worry about confusion over medication and time zones. Overall for those who have travel in our veins, HIV is not going to stop us and travel is something many of us continue to work and plan towards.

I plan to have a long and productive life

Growing old

Some of us don't ever want to think about getting old. It is a scary prospect. And certainly most of us don't want to think about getting to the end of our lives. As we grow older, some of us feel the toll that HIV has taken on our bodies. Some of us are surprised we got here at all. Most of us are happy that we now have the possibility of growing old.

The end of life is no longer something we think about in the same way we did when we were diagnosed as HIV-positive. Some of us accept that we will die one day, and that between now and then, we are going to live life to the fullest, enjoy it and take most things in our stride. We realise that it is now likely that we will live to a ripe old age. Some of us have made preparations. We have our networks in place, we have peace of mind and we have at last overcome our fears.

"I'm not going to die from HIV. I'm going to die of 'misadventure' and I don't mean by taking my life."

"I've lived a lot longer than I ever expected. I've come to terms with my own mortality. I no longer fear death. I am at peace with my maker and will be dancing for joy when we meet."

"I am happy I can say this - I didn't think I'd live past HIV but lately I am seeing what getting old involves."

"Looking forward to growing old and wise with grace."

I have a bright future

A changing future

Our attitudes to the future reflect our diversity as a group of women. Many of us never thought we would have a future and now we have to plan for one. We lived one day at a time for so long it became our survival strategy. We learned to live in the here and now. Although we know our health prospects are much improved, some of us never think about the future and some of us are still fearful of it.

"I just live in the moment and embrace each day."

"My lifestyle choices are governed by the virus. At the point of diagnosis I was told five years was all I had. I can only plan five years ahead. Over twenty years on, I am still here."

"I lived for a long time one day at a time. If I had been able to plan my future, it would have been very different. I have learned never to lose hope and faith and that life can be good again, even if I didn't plan it that way."

Most of us are very optimistic about what the future will bring. We recognise that our average life expectancy has been greatly extended with antiretroviral medication. We can enjoy a much brighter future than we could ever have imagined when we were diagnosed. Many of us now have a more positive perspective on life and look forward to enjoying what lies ahead. For some of us this means raising our children and growing old with our loved ones. We are very thankful for being given the opportunity to do so. We begin to see a future where HIV is no longer at the forefront of our lives, no longer an all consuming obsession, but simply another chapter in our long and unique journey through life.

"I do have a future - my kids, my partner, my hope, my friends."

"Being a mother was an amazing part of my journey but being a grandma has given me back my identity."

"I'm feeling optimistic about a happy future. I'm much stronger now than eight years ago."

"All I wanted to do was exactly what I had planned and hoped to do with my life - go to university, get a job, fall in love and be surrounded by family and friends. I am living the life I've always wanted. I never really steered off track.“

My story is a treasure of hope

Hope

Our journey with HIV has many ups and downs but right now life is much better than ever seemed possible at the time we were diagnosed. Today, HIV is a chronic, manageable condition and living a full, long life is not only common, it is expected. Women living with HIV are working, caring for families, studying and travelling. Our futures are bright, exciting and unpredictable. There is life after HIV and it can be long, healthy and fulfilling.

"I'm proud of myself - I've beaten everything that's put before me."

"Eighteen months on, I am finding my inner strength. I have come a long way."

"I think the key to my longevity is my attitude to my virus, it gets no respect and the fact that I won't buy into 'being a sick person'."

"The future is good. I have a long life to live with my beautiful children."

"HIV has opened doors that I never thought possible. I've stood on stage at Federation Square, me on the 'big screen', addressed the Health Minister, travelled overseas to the World AIDS Conference and faced fears that I thought would overwhelm me. HIV has challenged me and made me realise that I am stronger than I ever imagined."

"My message is very much hope. It's not just around HIV. It's around life in general and the challenges that we face. Stay determined, stay hopeful."

"Living with HIV united in my life for 25 years, there have been many stages to my journey. The most important lesson I have learnt is what matters is that I treat people the way I need to be treated."

"You are never alone. You are not the only positive woman out there. We belong to a family of tens of millions; over two thousand of us are living in Australia. Even if you feel or think you are alone, we are all out there living the best we can with HIV."

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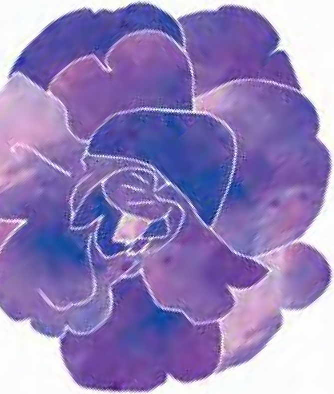


I am beautiful

My voice is powerful

I focus on thoughts and activities
that bring me joy

I treat people the way I like to be treated

My courage is inspiring

I have a voice as to how I respond to any adversity

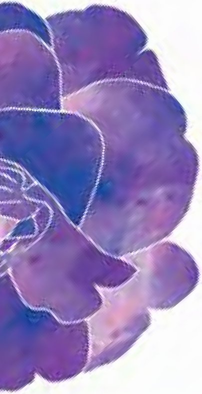
It's my body, my life, my choice

I focus on solutions, not problems

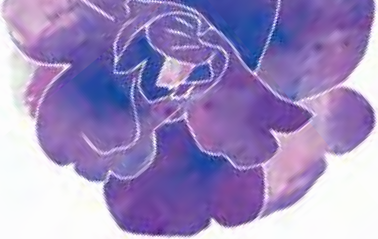
In adversity my beauty shines through

I am a good person and
I deserve to be loved

I am kind to myself and treat myself with respect

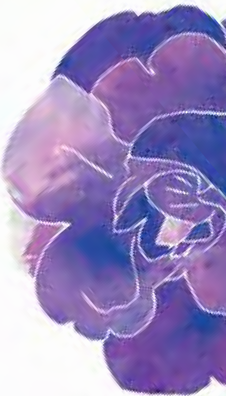


I have choices, the right to ask questions, and the right to say ‘no’



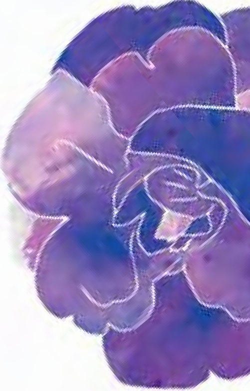
Caring for myself is an ongoing journey

I alone have to do it but I
don't have to do it alone



I have hope

I plan to have a long and productive life



My story is a treasure of hope

I will not let HIV stop me leading a full, normal life

Just because I am not being heard doesn't mean I have to be silent

I embrace each day

I am who I am -
if people don't like that,
bad luck

I have a bright future

I am not afraid to ask for help

Those who mind don't matter and those who matter, don't mind

My HIV-positive status is entirely compatible with living an active, productive and fulfilling life

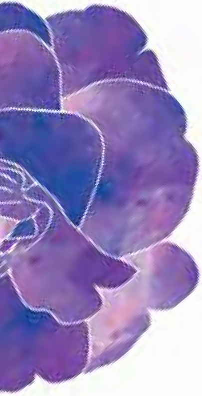
I will not allow myself to stress about the little things

I will not let my HIV diagnosis hold me back – I am more than my virus

I have the right to enjoy what life has to offer

I continue to get stronger all the time

I am brave and resilient



Don’t hold back who you are
- be yourself

Stand up, be strong, don't hide

Live every day in the moment and
don't stress about the little things

It is okay to be angry or blame others but don't get lost in negative emotions

Don’t whinge - get involved and change things - it can be life affirming

Speaking, not hiding, gives us strength

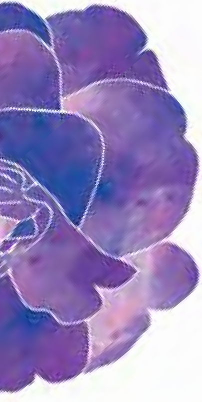
You always have a voice – use it

Strive to be forgiving and let go of anger because it eats away at you

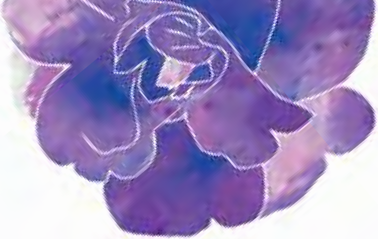
Remember to be flexible and adaptable –
some days there just has to be a Plan B

Give of yourself and love others, and you will get back more than you give out

Not every illness and every issue is going to be related to HIV

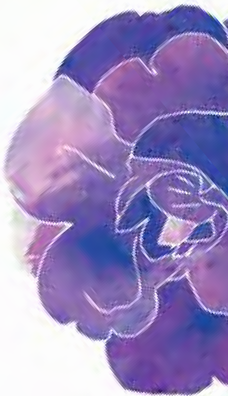


If you feel worse when you leave a health care professional then change that health care worker



Ask plenty of questions, listen to people's advice and then make up your own mind

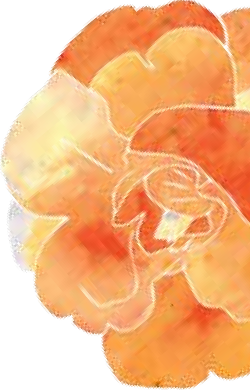
Take someone with you when you go to the doctor – we all need an advocate and when we are unwell we can't do it for ourselves



Educate yourself,
be informed and keep up to date

Maintain HIV-positive friends, listen to the stories of others and see what fits for you

Respect the experiences of positive women, take what works for you, and define your own story



Healing begins when someone bears witness - share your story, talk about HIV

It is a personal journey but try and stay connected with other people

Try and find laughter,
music and sunshine in
each day and celebrate
and enjoy life

You can't be stigmatised if you feel good about and love yourself

Reach out to services and utilise what suits you

Talk to a counsellor, a professional you feel comfortable with, every now and then

Health professionals are people and they sometimes make mistakes - have realistic expectations

Good 'self care' promotes your overall health and wellbeing

Treat yourself well - make sure your mental and emotional health are good - they go hand in hand

Keep your body healthy - exercise any way that elevates your heart rate for thirty minutes, three times a week, and rest when you need to

Don’t be afraid of starting meds -
ARVs can save your life

Schedule starting meds around other commitments - take time off if you can

Travel with condoms and travel insurance