



| 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.”





PositiveWomen

Support and advocacy for women living with HIV

Suite 1, 111 Coventry Street, Southbank VIC 3006

Tel: (03) 9863 8747

<http://www.positivewomen.org.au>