

# My Life as a Positive Women

*Chris's Story*

I am a mother, a daughter, a sister, an aunt, and a friend in an ever-growing network of people. I used to be a wife, but now am widowed, and apart from raising a teenage boy on my own, battle the day to day struggles to function as a positive woman.

I was diagnosed HIV positive 11 years ago, and, after losing my husband to his fight with AIDS nearly 5 years ago, have re-located from interstate to be closer to my family for both emotional and practical support.

For the moment I am in what I would call 'good health', but each day can be somewhat of a struggle. Today has been one of the better days; although waking with a headache and fighting the constant waves of nausea from treatments tends to be the norm, rather than the exception. I tend to tire easily and don't always feel enthused or energetic to be terribly active, but for the most part, I am coping.

Every day is a new start - I can no sooner predict how I will feel tomorrow, than guess next weeks Lotto numbers, but I take each day as it comes. In the past 5 years since my husbands' passing, although I miss him dreadfully, I have somehow managed to move on with my life - learning to listen to my inner voice, and to look after me. Admittedly it hasn't been easy, but the future is beginning to look brighter. I am still quite able to get around, the treatments have allowed me to keep my counts constant, and have even given me the chance to plan some sort of a future for me and my son. We are in the lead up to our first overseas trip - something that I would not have contemplated a few years ago, although I'm still quite nervous of stepping off Australian shores!

As a positive woman, I've had to go through the processes of declaring my status to cover myself, should something happen while I'm away. I've always been a forthright person, but still get nervous having to disclose my status after so long. I also happen to live out in the country, rather than the city, so have found the need to be quite particular about my status. Sometimes I think it would be good to be absorbed into the anonymity of city life, but so far I've not felt the need to hide myself away. I visit the city often- attending support groups and talking to other positive women, and find solace in the ability to be able to do that.

# Standing on Shifting Sands

## *Katherine's Story*

I am a woman of forty something years and a mother to my 15 year old daughter and 21 year old son, a long time partner to their dad and a daughter to my separated parents. I am also HIV positive and was diagnosed way back in 1987 and given a two year death sentence. When I asked the medical doctors if I was the only HIV positive woman in all of Australia there were no available answers.

Now that I have disclosed this intimate information about my personal life please do not judge or discriminate against my family or me.

In spite of HIV/AIDS existing in Australia for 20 plus years there is still a level of ignorance and discrimination within our society. If the messages are working then why do we have rises in HIV/AIDS infection rates in most Australian States?

After my initial HIV diagnosis I experienced a range of emotions from shock to fear then confusion, guilt, denial and many painful memories as I felt my whole life was being tipped upside down. Our son was just 4 years old and I had always planned to have a big family. Instead I was making hard decisions about an abortion, as I was also pregnant at the time of my diagnosis. My partner was also tested and his results came back HIV positive also. I assumed since we used heroin and shared syringes that this was the most likely way we contracted HIV. This was way before Needle Exchange Programs were funded and fortunately the Australian Government developed a pro-active and innovative approach which reduced the HIV epidemic within this population group.

My survival strategy was 'one day at a time', along with my continued drug use that helped me to cope and numb those painful and difficult emotions or so I thought.

In 1989 my daughter was born by elected caesarean with no breast-feeding allowed. The medical profession all assumed she would be HIV positive and gave me no hope otherwise. We had a long and painful two-year wait for her final diagnosis and I felt I was living in a



nightmare. Fortunately today the process is much shorter and the risks of mother to child transmission in Australia are greatly reduced.

I never planned our future as a family as I never thought we had one. When we recently celebrated my son's 21<sup>st</sup> Birthday I experienced a high level of emotional sorrow and joy along with grief about how often those real emotions had been denied.

For me it was the opportunity to link and meet other HIV positive women that made a big difference to my engagement with life and gave me the inner strength and the courage to find my voice and take a stand.

For far too long now HIV positive women have been invisible and the opportunity to increase and strengthen our support networks is vital.

I believe there is always a sense of hope as we continue to dispel the myths about HIV positive women in society and invite others to share us in this journey.

## Kate's Story

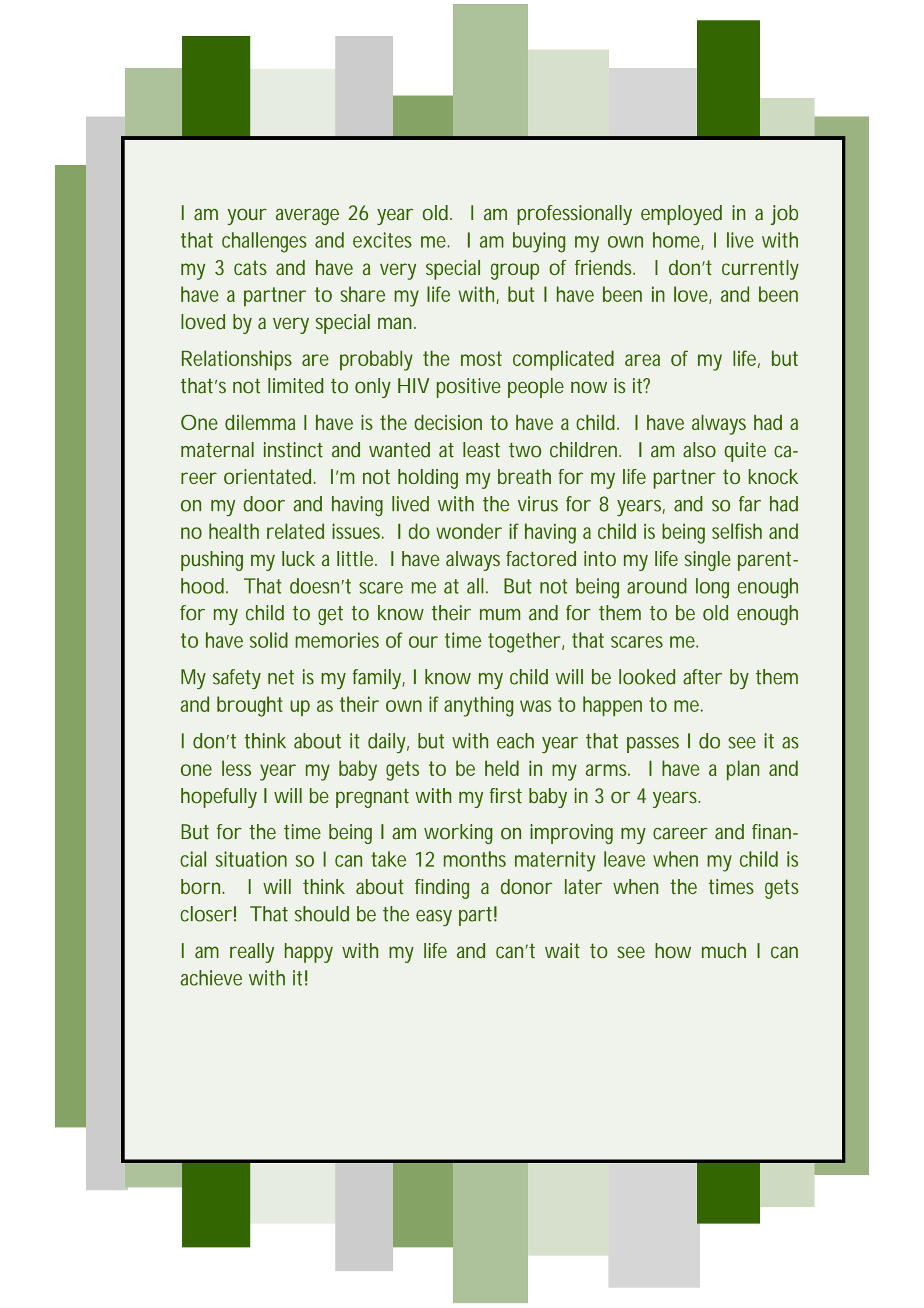
I am turning 27 next month. I was diagnosed HIV+ almost eight years ago; late June of 1996. Thinking back now, eight years seems like more than a lifetime ago. My memory is a little hazy, and as we all know, a clouded memory can help us reflect on times gone by with a smile, instead of those feelings of loss and pain we had at the time.

The first 18 months after my diagnosis were filled with feelings of despair and regret, life seemed more like a burden than an adventure.

I was mid year in my first year at university. Life should have been care-free, spontaneous and exciting, instead I had to deal with my diagnosis, treatments and above all, the concept that I was not invincible.

In the January of 96 I had returned home from backpacking through Europe. I had had unprotected sex while I was away so had the arbitrary test and the follow up 3 months later. Both tests were negative. In June I met a boy. We discussed our previous sexual experiences and he decided that he should be tested before we had unprotected sex. I agreed to go along for the ride and be tested again. I had not been with anyone since my previous tests so I had no reason to believe that the result would be anything but negative. But it wasn't. This test came up positive with the HIV antibody.

Well that was 8 years ago now and as I said, more than a lifetime ago. There are few consistencies in life and I have been lucky enough to have the loving support of a wonderful family since the day I was diagnosed. Without their continual support, I would not be who I am today. After diagnosis, all I wanted was a so called 'normal' life. I wanted to be able to continue my life the way I would if HIV wasn't a part of it. And I am very proud to say I have and will continue to do so.



I am your average 26 year old. I am professionally employed in a job that challenges and excites me. I am buying my own home, I live with my 3 cats and have a very special group of friends. I don't currently have a partner to share my life with, but I have been in love, and been loved by a very special man.

Relationships are probably the most complicated area of my life, but that's not limited to only HIV positive people now is it?

One dilemma I have is the decision to have a child. I have always had a maternal instinct and wanted at least two children. I am also quite career orientated. I'm not holding my breath for my life partner to knock on my door and having lived with the virus for 8 years, and so far had no health related issues. I do wonder if having a child is being selfish and pushing my luck a little. I have always factored into my life single parenthood. That doesn't scare me at all. But not being around long enough for my child to get to know their mum and for them to be old enough to have solid memories of our time together, that scares me.

My safety net is my family, I know my child will be looked after by them and brought up as their own if anything was to happen to me.

I don't think about it daily, but with each year that passes I do see it as one less year my baby gets to be held in my arms. I have a plan and hopefully I will be pregnant with my first baby in 3 or 4 years.

But for the time being I am working on improving my career and financial situation so I can take 12 months maternity leave when my child is born. I will think about finding a donor later when the times gets closer! That should be the easy part!

I am really happy with my life and can't wait to see how much I can achieve with it!

## A Mother's Story

I am a mother of four, grandmother of nine. I live in a country town and have felt distanced from the areas and lifestyles associated with HIV/AIDS. I guess the first time it impacted on me, was the Grim Reaper campaign. But why should I worry? It only involved the gay community and drug scene and that didn't involve me. IGNORANCE. What a blinder that can be!

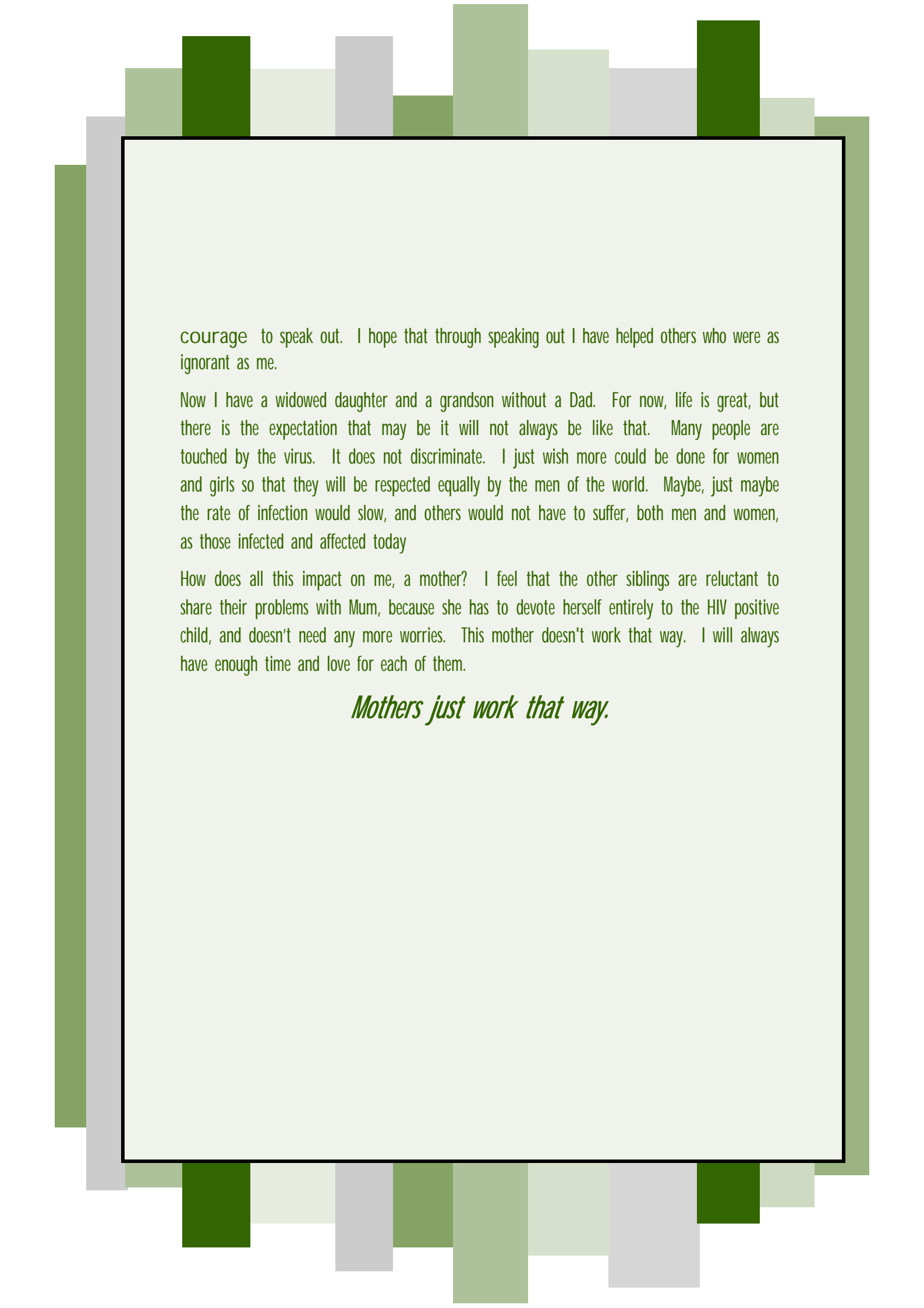
It first hit home when my daughter, son-in-law and grandson, who had spent three weeks living with us moved to WA for Wayne to take up Navy sea posting. I got a phone call from Chris to say that the posting had been changed because of a blood disorder. It was pretty scary, especially when the baby had to have blood tests too. Several really anxious days and then the disclosure.

Wayne was HIV positive. Shock!! Horror!! We had shared cups, cutlery, drinks, glasses. Were we at risk? How was our daughter coping? Don't tell anyone. IGNORANCE. FEAR. SHAME.

I went to Perth and the family met me at the airport. They didn't look any different!!. A talk with a Navy medic answered many of my concerns and I felt a little easier about the whole mess. But when our daughter became infected our lives were turned upside down. The first infection rattled us but this was really shattering.

Our philosophy then was life goes on. When they become really ill is the time to worry. Sure it is terminal, but what is the time frame? I have tried to learn as much as I can about the virus and its affect on people. This involves not only supporting those with the virus, but how much and with whom do you share.

Early days it was family and friends who I felt I could trust. Then one year during the Red Ribbon campaign I was asked to share with my church family. A big deep breath and into it. What a response! It was so warm and loving, to both my husband and myself, and gave me



courage to speak out. I hope that through speaking out I have helped others who were as ignorant as me.

Now I have a widowed daughter and a grandson without a Dad. For now, life is great, but there is the expectation that may be it will not always be like that. Many people are touched by the virus. It does not discriminate. I just wish more could be done for women and girls so that they will be respected equally by the men of the world. Maybe, just maybe the rate of infection would slow, and others would not have to suffer, both men and women, as those infected and affected today

How does all this impact on me, a mother? I feel that the other siblings are reluctant to share their problems with Mum, because she has to devote herself entirely to the HIV positive child, and doesn't need any more worries. This mother doesn't work that way. I will always have enough time and love for each of them.

*Mothers just work that way.*

## We are lesbians living with HIV

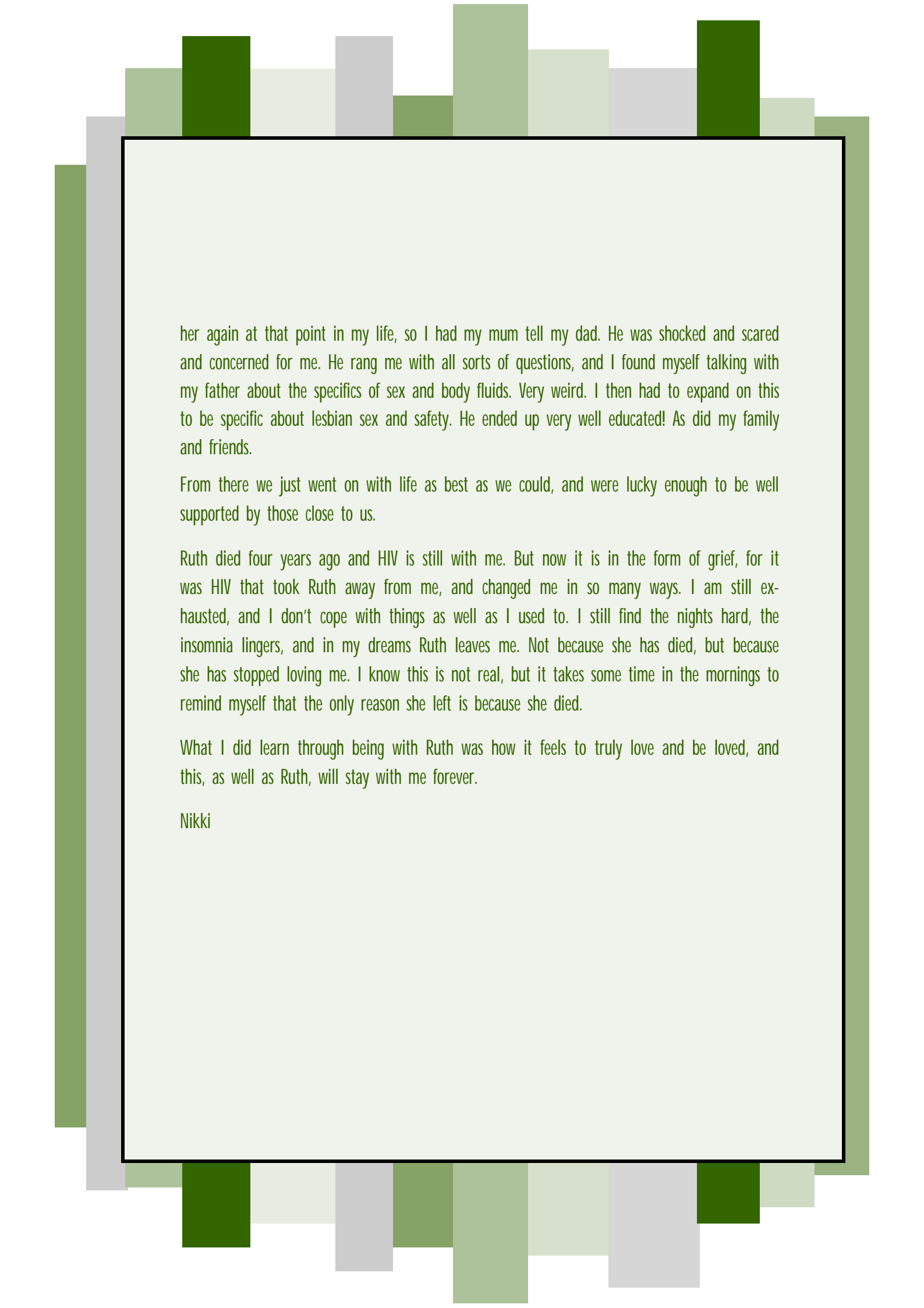
*A minority within a minority. She was HIV positive and I was HIV negative, and when she was diagnosed, we felt totally alone.*

The first thing I had to do was to make it known to myself, to actually really take in the fact that Ruth's HIV test came back positive. The shock was enormous. And then I too had to be tested. My test came back negative. How do you cope with something like HIV when there is so much ignorance and discrimination still out there. We didn't cope very well at first. We stayed silent, alone and afraid of the questions and opinions of others.

The nights were the worst, for it was quiet and still. Ruth would be sleeping, and I would be awake, wondering about our future, what would HIV do to her body, her mind and her soul. Who do I talk to about this, when Ruth didn't want many people to know? How do I answer the questions when people ask me "are you ok, you look tired". I would lie and say I had a late night. But I really wanted to tell the truth, to reach out and scream that this was unfair, why did this have to happen. And I wanted to challenge those who dared judge and discriminate.

If Ruth had had cancer, it would have been easier to tell. For people don't ask how one gets cancer. And they don't assume that the partner has cancer too. So much thought goes into who to tell and why to tell. I would get questioned constantly about Ruth's health when it became more obvious that she was unwell. Questioned by the car mechanic, the hairdresser, the people in our local deli, and those at our favorite market stall. I became an expert at changing the subject! I felt like I was living two different realities, one where HIV dominated and challenged, and one where I hid behind a mask of smiles.

As time went on, we became more comfortable in telling people. But in telling, we had to be prepared to reassure and educate, as HIV is still something people don't know about. Of course there would be questions. Telling my family was hard, as I had to be prepared for their questions and concerns. It took some time, as I had to come to a point where I was emotionally able to be open about this secret life of ours. I didn't have the strength to tell my dad, as his wife had crucified me when I came out as a lesbian, so I knew her opinion of HIV would not be good. I could not face



her again at that point in my life, so I had my mum tell my dad. He was shocked and scared and concerned for me. He rang me with all sorts of questions, and I found myself talking with my father about the specifics of sex and body fluids. Very weird. I then had to expand on this to be specific about lesbian sex and safety. He ended up very well educated! As did my family and friends.

From there we just went on with life as best as we could, and were lucky enough to be well supported by those close to us.

Ruth died four years ago and HIV is still with me. But now it is in the form of grief, for it was HIV that took Ruth away from me, and changed me in so many ways. I am still exhausted, and I don't cope with things as well as I used to. I still find the nights hard, the insomnia lingers, and in my dreams Ruth leaves me. Not because she has died, but because she has stopped loving me. I know this is not real, but it takes some time in the mornings to remind myself that the only reason she left is because she died.

What I did learn through being with Ruth was how it feels to truly love and be loved, and this, as well as Ruth, will stay with me forever.

Nikki