

DAVID

YOU

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ARE

NOT

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YOU ARE NOT

ALONE

I am not alone and
neither are you.

I was infected with HIV in 1986, at the age of 24. For years, I was convinced that I did not need to talk to peers. I remember the nurse practitioner asking me in 1990 if I wanted to come along on a weekend for HIV-positive women at Texel.

My immediate reaction was: If I wanted to go to Texel I would rather go with my friends. In hindsight I know I reacted that way out of fear. I was afraid that it would be a group of women who felt like victims and would be crying their eyes out all weekend. I felt I could not afford to be like that. I had to be strong and needed to fight to stay alive for as long as possible.

Years later and going through a bad depression, I realised that it was finally time – I had to deal with all the emotions about my infection with HIV, which I had managed to suppress for all those years. My way to tackle this was to start volunteering at the HIV Association. That way I could meet other people who were living with HIV in an informal setting and do something for my community at the same time. That brought me so much: recognition and the ability to share grief, but also a lot of laughter and dark humour.

Now, after all those years, I am entirely open about my HIV and I became an activist for the cause. My mission is to make HIV a normal disease, to provide the public with the correct information and in doing so help fight the stigma. I feel so liberated, never having to worry about who knows about my condition and who does not. I no longer feel ashamed and that is why people's opinions of me do not harm me anymore.

The road I travelled was long and along the way I learned that tackling my self-stigma is one of the most important things I have done in accepting my HIV. Or, in the words of someone in this book: You cannot change the reactions and prejudices of the outside world, but you can change the way you judge yourself and that makes all the difference.

In this booklet you will read encouraging stories of people living with HIV just like you. And at the back of this book you will find a list of initiatives, all organised to help us cope with our lives with HIV.

Make good use of it and, above all, never forget: YOU ARE NOT ALONE!

Marjolein Annegarn
Photographer, HIV activist and initiator
of this booklet

DAVID

David has known for 21 years that he has HIV. He was born in Cameroon and came to the Netherlands because he fell in love with a Dutch girl.

Before we got into a real relationship, I wanted to have myself medically examined. I was not ill, but I wanted to know if everything was alright before things became serious between us. I was fairly sure that I would not have anything, but three weeks later I received the results and they showed that I was HIV-positive. It was September 1998. I came to the Netherlands with a lot of ambition—I was young, strong and in love, and I wanted to study here.

When I was diagnosed, I thought that would all be over, that I would die here in the Netherlands, far away from my loved ones. My girlfriend could not deal with my diagnosis and asked me to leave her house.

I stood at the train station in Utrecht and felt so hopeless. There, I was approached by a young couple. They turned out to be working for Doctors Without Borders and they addressed me in French. I did not speak a word of Dutch. Out of nowhere, they asked if I needed help. I immediately told them what was going on and they took me in at their house.

These young people put their own lives on hold for three months to support me. They did not leave me alone, fearing that I might commit suicide, and they took me to a hospital in Utrecht. The doctors there touched me, while I thought that meant they were going to get the virus too. I really did not know anything. The doctor told me there was medication and that I was not going to die.



At Shiva I have seen so many times how valuable interaction with others living with HIV is... It really helps to get out of isolation and to be less lonely.

Sometimes contact also deepens when you tell people you have HIV.

People have come to love me even more because I have had the courage to be open. They say they look up to me.

Because of the actions of the people who took me in and because of how the doctors reacted, I slowly started to think differently about my situation. I regained a little hope. The young people with whom I stayed helped me to start an asylum procedure, which is how I ended up in an AZC asylum center.

I decided to be open about my HIV-diagnosis at the AZC. There were three friends there who I informed of my situation. They were close to me, but I subsequently really regretted telling them. They spoke to others about it, there was a lot of gossiping. People I interacted with every week suddenly acted differently and did not want to hang out with me anymore. It hurt me a lot, that people I trusted betrayed my confidence was a shock to me. I really wanted to be open but noticed that that can be used against you as well.

Fortunately, the situation is quite different now: I immediately told my current wife, and it has never been a problem for her. I have children and even a grandchild. But because of my experiences in the AZC I did not tell anyone about my HIV for years. Recently there was a situation where I felt the need to share it with someone I have known for a long time. He responded very well. It felt important to me that he knows who I am and what my life is like. We are close: we go to church together and we pray together. I wanted him to know. I felt relieved, there are no more secrets between us. Sometimes contact also deepens when you tell people you have HIV. People have come to love me even more because I have had the courage to be open. They say they look up to me.

It is especially difficult to be open to other people from Africa. Some of my fellow countrymen have a certain view on life, on the things that happen to us and on how people interact with each other. They believe in evil spirits and punishments from God and cannot look at disease in a biological, scientific way. If you fall ill, you must have committed a sin and be a bad person. That condemnation is even more painful than the disease itself.

With Shiva* and The Positive Brothers* things are quite different: African and Caribbean people with HIV support each other there. We receive the right information about the virus and help each other to live with HIV. That is so valuable. I think it is particularly important for the nurse consultant to bring the possibilities of peer to peer contact to people's attention.

At Shiva I have seen so many times how valuable interaction with others living with HIV is: It really helps to get out of isolation and to be less lonely. You cannot force that contact onto people, but you should certainly offer it.

*Information about the Shiva Foundation and The Positive Brothers and Sisters can be found at the back of this booklet.



SANDRA

Sandra found out in 2006 that she was HIV positive.

When I received my diagnosis, it came as a bolt from the blue and I was in a state of total panic. I sincerely thought I had to say goodbye to life soon. The person who infected me and I had been in a relationship for a while then, which wasn't good for me. But I was so in love that I didn't listen to my gut feeling. We had both just quit our jobs to start a new life in Sweden. In that moment, I had the feeling that I was standing on quicksand. My relationship, my job, my health—everything was reeling.

We still left for Sweden, but all my trust was gone, and I could not maintain our relationship. I returned to the Netherlands and started working for the Ministry of Defence again.

I didn't tell anyone about my HIV, except an old friend. I worked a lot in order to not think about it. I lived in a small room in the barracks and was only home on weekends. My colleagues were somewhat my friends, but I could not be open about it and hid behind a mask, remaining alone with my secret.

I buried everything for years. Yet there was a constant voice inside my head that said: You're different. My self-stigma was so great. I was so scared of my HIV that I focused solely on surviving and never even entered the coping process. At some point your body then says 'stop'.

Suddenly the entire left side of my body shut down and I started having some sort of hyperventilation attacks. This happened three years ago, so 12 years after my diagnosis.

I could only cry. Through a neighbour, I came into contact with an energy healer. She really became my tutor. I suddenly realized that everything has to do with self-esteem, self-love. It was not only HIV, but also the patterns that were passed down through my family that made me who I was. There my search for increased contact with myself began and I started taking my body's signals seriously.

Through a conversation with the military physician, I found out about the HIV Association. In those 12 years I hadn't even looked at their website. Now I was finally ready. I called the Service Punt* of the association because I wanted a meeting with someone who also lives with HIV (a peer to peer* conversation.) With Jacqueline, to whom I was matched, I had a great conversation in which I recognized so much, and for the first time I didn't feel so alone.

That was in 2018 and it turned out that the big AIDS congress was held in Amsterdam that summer. Jacqueline and I went to Amsterdam for a day to visit all kinds of HIV-related projects. We went to the RAI convention centre, the DeLaMar Theater and to the Museumplein for the Stigma exhibition, a display of unrecognizable portraits of people with HIV who, for various reasons, are not open about their condition. That touched me deeply, those rows of posters were so powerful! A group of people from the HIV Association provided information to passers-by. Curious, I stood close to hear how such conversations went. The exchanges were beautiful and when everyone went for a bite to eat and I saw that new people were looking at the exhibition, I started talking to them.

First I spoke with a couple of my own age. I shook their hands and said: 'Hi, I'm Sandra and I have HIV.' An extraordinary conversation unfolded, the man turned out to have lost his brother to AIDS. Afterwards, I had several other conversations in which I could truly make contact and openly talk about HIV. It was such a great day!

It was the ultimate liberation when I accepted myself. The self-stigma makes us feel less worthy, not the environment. You cannot change the environment, but you can work on your self-stigma. Then you can live life to the fullest again. It brings BEING, it brings LIFE. I am also convinced that it doesn't matter where you live in the Netherlands. We judge ourselves, it's in our heads.

In relationships, too, it makes all the difference if you no longer experience self-stigma. Last year, for the first time since my HIV, I had a relationship again. I really felt I deserved a relationship now and I also felt I was worth it, a totally different attitude than before. It must be good for me, because I love myself and if someone is not good for me then I'd rather be alone. I've told him beforehand how I felt about it. I thought it was exciting, but not difficult. He saw no problem with it at all and for him my HIV was no obstacle.

I really think everyone deserves to find strength and confidence in themselves, that really is the key to freedom.

The bottom line is: if you are kind to yourself, you will feel that you are truly of value.

Breaking the self-stigma is so important. That brings happiness to your life and provides the ultimate liberation.

Find confidence and strength in yourself, that really is the key to freedom.

*Information about the Service Punt of the HIV Association and about peer to peer conversation can be found at the back of this booklet.

JORGOS

Jorgos grew up in Germany and is 46 years old. He was diagnosed in 2009 and hasn't spoken to anybody about it for the first four years.

In the 1990's I worked in Germany as a social worker, helping people who were addicted to drugs and had AIDS. I was still young, and the job was intense. Everybody died and we received zero guidance. At a certain point it all became too much for me to handle and I ended up fainting during a funeral for one of my clients. Something broke in me, I didn't want to have anything to do with HIV and AIDS any longer. I moved to the Netherlands with my husband Eric, whom I had met in Germany.

In July 2009, after an HIV test, I received a call informing me that I had contracted the virus myself. Those images from the nineties surfaced all at once and they terrified me. At that point, I went completely into the closet and I did not speak to anyone about it for the next four years—not even to Eric.

The only person I spoke to was the nurse consultant.

At first, I didn't have to take the medication yet, which made me very happy, because then it all didn't feel so reel. But in 2013 I started getting worse and my doctor told me that it was now really time to start taking the drugs. I had shingles, a paralysis in my face and often dealt with pneumonia. Eric knew something wasn't right, but I just didn't want to talk about it.

I took my pills secretly for six months. The nurse consultant told me so many times to talk about it, but I just couldn't. I was terrified that people would think I was dirty, that they would say that I had achieved nothing in my life and that I was now an AIDS patient myself. I had an extremely negative self-image and felt so lonely at the time.

On the radio I heard a Greek song called 'The Smiling Child'. Something in me was touched and I thought: I want to smile again too.



Volunteer work has enriched my life and helped with my acceptance.

It's so powerful to do something beautiful with something bad that has happened to you.

I have never had the quality of life I have now.

While during the four years I did not speak to anyone about my HIV, I thought my life would be over if it were ever to come out.

Then I could finally say: help me, I can't do this alone anymore. My nurse consultant was so happy that I finally wanted to talk.

I also told Eric then. That was really difficult, I couldn't even say the word HIV out loud. I cried and couldn't say anything except 'I have...' At this point, Eric understood, but he told me: Say it, you must say it out loud. He responded well to it but was very sad that I had struggled with it in solitude for four years.

The hospital gave me advice on what to do. (There are many initiatives. We list them at the back of this booklet.) In the end I turned to the workshop series* for people with HIV. I was so afraid that I would run into someone I knew that I decided to do the workshops in Amsterdam, while I live in Enschede.

Registering for this series* is the best thing I have ever done. The counselors, Loek and Hannah, really were my saving grace.

There was so much recognition, just being able to look into someone's eyes and see that you are not alone. Contact with peers is such a powerful tool. You hear other people's stories, and you get the opportunity to tell your own. There was a lot of talk about feelings, both the negative and the positive ones. We discussed intimacy and sexuality, as well as practical matters.

I entered the first meeting with my shoulders slumped and looking at the ground. When I walked out of the sixth session it was with my head up and chest out, I had my life back. In fact, I have never had the quality of life I have now. While during the four years I did not speak to anyone about it, I thought my life would be over if it were to come out.

Now I can talk about it well, but I am still careful who I tell it, I must feel safe with someone. Not everybody has to know. I am convinced that one day I will be completely open, but that will take some time. Everyone does that at their own pace and that is perfectly fine.

Finally, I supervised the workshop series in Zwolle, myself. It felt so good to come full circle. I was able to do something for people with HIV again, just like in the 90s, but now with much more perspective to offer.

Volunteer work has enriched my life and helped with my acceptance. It's so powerful to do something beautiful with something bad that has happened to you.

I would say to people in the same situation: Ask for help, you don't have to do it alone. There are so many possibilities. The consultants must also keep offering these, even if someone says no repeatedly... keep offering it again and again.

*Information about the workshop series of the HIV Association can be found at the back of this booklet.



DERK + DOMINIQUE

Derk and Dominique have been together for 23 years. They were both diagnosed with HIV early in their relationship.

Dominique: Ironically, just the week before our diagnosis, I had decided that I wanted to become a buddy for someone with HIV. I already had a brochure about it at home.

Derk: After the diagnosis, I told my mother and a couple of friends. My mother didn't handle it well, she needed a great deal of comforting by me. After that conversation she never revisited the issue. Luckily, my friends did show a lot of understanding.

Dominique: I confided in my little brother. At the time he was in a relationship with a good friend of mine, who thus became aware of it as well. Unfortunately, then the entire village knew. That felt very unpleasant, we were not ready for all those confrontations yet. After these less-than-great experiences, we decided having each other was enough and that we didn't feel the desire to discuss the situation with others.

In 2000 my mother registered for a meeting for parents of children with HIV.

She went there because of me and for me, so I felt I should go with her. That evening someone from the HIV Association came over and asked me if I wanted to help out as a volunteer. Before I knew it, I was on the telephone team of their brand-new Service Punt.

Since then, I have always continued to do volunteer work for the HIV Association. That certainly helped me in the process of acceptance. In a casual manner you get to know others who are living with HIV. The dark humor, which really is only possible among peers, was also liberating.

Derk: We both really did it our own way. I had less need for contact with peers and just wanted to get on with my life. Talking about it with good friends did help. I could really feel some kind of consolidation in my circle of friends. You can truly rely on the ones that stay around.

And then we had children. We soon decided that we would not take our pills in secret and that if one of the kids asked about it, we would answer honestly. But just telling it for the sake of telling it, that didn't feel right. We did not want to become 'those parents with HIV' either.

My experience is that you always make it bigger than how others perceive it. When you tell people, it hits like an earthquake, but afterwards people tend to forget about it too.

Once we finally told the children, a weight fell off our shoulders.

Talking about it with good friends does help. I could really feel some kind of consolidation in my circle of friends.

You can truly rely on the ones that stay around.

We were afraid that our children would be burdened by it or that other kids might not be allowed to come over for play dates. As they got older, we realized the time to tell them had come. We did not want them to hear it from somebody else. In the end we waited until the youngest was out of primary school.

We had to look for the right time and especially for the right words, so that we would not make it too gloomy. We ended up telling them during a car trip to Friesland. That was a smart move, because there was time to ask questions and they all got the news at the same time. When we finally told it, it felt liberating.

It was a nice and intimate family moment, which also invited the children to be open about what was going on in their lives. I still remember that the youngest concluded: 'Oh, so basically nothing changes.' We told them that we like to keep it private, although it is not a secret, and that they can always ask us questions.

I recently asked my daughter if she ever had wanted to discuss it with a friend, to which she replied it was something she never really thinks about.

Derk: I just got on with my life, but some issues have built up as a result. For a long time, I had the feeling that I could do it all on my own. But last year I felt the need to reflect on my HIV and I decided to take part in the Monastery Days (Kloosterdagen), organized by Shiva*. Things then fell into place. I enjoyed talking to others and felt recognition. Maybe I should have done it earlier, because it has brought me a lot.

Dominique: My experience is that you always make it bigger than how others perceive it. When you tell people, it hits like an earthquake, but afterwards people tend to forget about it too. In your mind, you make it much larger than it actually is.

Derk: I can relate to that. If you don't talk about it, it will become an increasingly big issue in your head. You have to test it against reality now and again.

*Information about the Service Punt of HIV Association can be found at the back of this booklet.

**Information about Shiva's Monastery Days can be found at the back of this booklet.

BOB

Bob is 62 and was diagnosed 12 years ago.

In August 2008, when I was almost 50 years old, I was diagnosed with HIV. Supported by my partner Wilbert, I shared that with my family and close friends. I was afraid of how they would react, I felt filthy and guilty. I still get emotional when I think about their response, because it was entirely positive... that was heartwarming.

The feeling of being contagious and filthy I experienced mainly regarding my close friends. Their son, now almost an adult, was four years old at the time and often visited us. I tearfully told these friends that I am living with HIV. They never had a problem with it. I felt such a responsibility towards their child because I also romped and cuddled with him. Living with HIV, your biggest fear is that you will infect somebody else. You know that that is impossible if you properly take your medication, but it is an irrational fear.

In our village I am a fairly well-known person because I had a flower shop here for years, plus I give workshops and act as a host at the local theater. A lot of elder people come there, and I always greet everyone with a kiss. Although I think they would be understanding, I don't feel the need to tell people in that setting. It doesn't add anything. So not out of shame, let that be clear. I guess I don't want to make other people feel uncomfortable.

There was one situation which bothered me a lot. Wilbert has grown children and I did not dare to tell them for a long time.



We have had a granddaughter for a year now and my HIV hasn't been a problem in that regard either: her parents do not feel any reticence or fear.

HIV has not been an issue for me since then. I won't be shouting it from the rooftops, but if someone asks me about it, I will tell you honestly and openly about it. It turns out that the world, including my world, is much more tolerant than I thought. In my mind, I made it an increasingly big problem, but 'coming out of the closet' with HIV has made my life much happier. That is a real change: it gives me so much freedom.

To other people struggling, I would say: it is a condition like any other condition. It happened to you and it is not your fault. You are entitled to support and compassion, just like someone who has cancer. Confide in people you love. Try to find the courage to open up, if only to one person.

Don't struggle in solitude...
LIVE!

That was quite a thing for me. I was afraid that they would judge me or fear that I would infect their father. Because he doesn't have it and I was 'the danger' – that's how I felt it.

Ten years after my diagnosis, photographer Marjolein Annegarn asked if I wanted to participate in 'The Stigma Project'*; an exhibition consisting of unrecognizable portraits of people living with HIV. It turned out to be a wonderful project that started on the Museumplein in Amsterdam and then traveled throughout the country. When I saw the billboards displaying all those people who are not open about their HIV, I broke. It opened my eyes. Did I want to go through life with a secret that does not have to be a secret?

As part of the project, a book was published. That book for me was the key to be able to tell Wilbert's children. I gave them the book and told them that my story was in there as well. Their reactions were so nice: 'Why haven't you said anything earlier? There is nothing wrong, is there?' Tears still come to my eyes whenever I tell this story. Just imagine how deep that feeling ran and how worried I was. It was such a relief to me that they finally knew.

It turns out that the world, including my world, is much more tolerant than I thought. In my mind, I made HIV an increasingly big problem.

'Coming out of the closet' with HIV has made my life much happier.

That is a real change: it gives me so much freedom.

*Information about the Stigma Project can be found in the back of this booklet.



EVA

Three and a half years ago Eva was diagnosed as HIV-positive. At the time she was 24.

I immediately told the people closest to me. My social environment is great, with people who really want to be there for me. I think I would even have offended them had I not told them about it. I also needed them a lot to pull me through that first period. Everybody deserves that. You are selling yourself short if you don't open up and give people who love you a chance to support you.

With people who are less close, it felt better for me to wait to tell them until I would be more confident. You can also deal with other people's reactions better if you've got a handle on things yourself. If you possess the right information and are able to convey it with conviction, you can reassure people and tell them that you do not pose a danger to anyone. That you really cannot transmit the virus anymore because you are taking your medication.

I attended an event of the HIV Association and I followed its workshop series*, during which I received a lot of information. All that knowledge allowed me to really feel that I am not dangerous to anyone. If you are just proclaiming the theory but are not entirely convinced yourself, you will convey things differently.

Everyone has responded very understandingly. I have never actually had a bad reaction from the people I really care about. Initially I was fairly concerned about that.

You need people who can put things in perspective for you and with whom you can share your concerns.

In my experience, sharing things like this makes relationships more valuable.

You are selling yourself short if you don't open up and if you don't give people who love you a chance to support you.

I condemned myself, too, thinking: 'This only happens to people who have a lot of partners' – basically the image that others may have about a woman with HIV. It did not fit my self-image at all. I now know that that was self-stigma. My mom always says she would have expected it more from my brother, because he quite liked to party and had tattoos done in Asia. That just goes to show that prejudices are wrong and that it can really happen to anyone.

It would be very unhealthy for me to keep it a secret. I would hate it and not be able to sleep if I had to keep my worries all to myself. I think it would have gotten bigger and bigger in my mind too. I need people who can put things in perspective for me and with whom I can share my concerns. When I have deeper conversations with someone, I want to be able to tell who I am. You are also shaped by the difficult times in your life. Sharing things like this makes relationships more valuable.

When I had only been living with HIV for six months, I went to a meeting in Carré, organized as part of World AIDS Day (The Power of Love)*. Carrying a bag full of information material, I took the train home.

I got into conversation with a man who told me he was on his way to a concert and who asked me where I was going or where I had been. I hesitated for a moment, but then told him that I had come from an event in Carré about HIV. We started talking and I told him that I myself was living with HIV. He knew little about it, so I gave him all the brochures and we had a really nice exchange.

At one point I was curious about how it would affect dating. How would men react? I then did some sort of research on various guys. When I was in the pub and I had someone's attention, I would gauge his response. I would tell them about my HIV and ask if that would be a barrier for dating. It never was. Ultimately, it is about the person and not about HIV.

Their answer often was: You're a nice person and you look great, that is much more important. It was good for me to explore this in situations where there was no pressure, because I was not in love. Just to see how people think about it. And responses like those also give you the confidence that not everybody will run away screaming because you have HIV.

Because I am open about my HIV, I can live life more freely and I no longer have to worry that someone will find out. If someone spots me in a magazine now and confronts me with it, I can just start a conversation with them, because I have accepted it myself. I am strong and self-confident, which helps enormously.

*Information about the workshop series of the HIV Association can be found at the back of this booklet.

**Information about The Power of Love day in Carré can be found at the back of this booklet.

MARLIES

Marlies has just turned 80 and has known since 2002 that she is living with HIV.

After my divorce, I was in a relationship for years with a man who already had a partner. Then, in 1997, I suddenly didn't hear from him anymore. It was very unpleasant that he abruptly stopped contacting me and that I didn't know what was going on. Cellphones weren't common yet and of course I could not call him at home.

I got word that he had fallen very ill, but no one could tell me what exactly was wrong. He finally passed away without me ever speaking to him again. The grieving process was horrible because I could not share it with a lot of people.

I slowly got back on my feet, but in 2002 I became very ill myself. I was constantly out of breath, exhausted, and had fungal infections in my mouth and esophagus. Eventually I visited a pulmonologist who suspected I had HIV. The penny dropped, I realized that was what my boyfriend had died of. At first, I was very angry with him and I removed all his photos, but, of course, after a while the anger subsides and now the pictures are back where they were.

Everyone in my immediate surroundings knows that I live with HIV. I was way too ill to worry about what my family would say or think. No one at all stayed away because I have HIV, either. And then you recover and just start living your life again. You meet new people with whom you enter into new relationships. For me, it is no use telling my reading club, my tennis friends, or my Pilates group.



You should trust your loved ones a bit more: if they love you, they will continue to love you when you are ill or when you live with HIV.

My life has really changed after my diagnosis. Every new day is a gift. That is what this situation has brought me.

Perhaps you are mainly judged by yourself and not so much by the people who care about you.

At first, it was very difficult for me to sit in the hospital waiting room. I was so afraid of the stigma and of finger-pointing. It took me a really long time to truly believe that it would not kill me. In the meantime, I have been sitting in that waiting room for 18 years and have now realized that many different internists have consultation hours. So, if someone sees me there, it is not immediately clear that I'm there for my HIV. I don't really care anymore either. The first time I went to the pharmacy I was very fearful, too, I was terribly ashamed. I have also changed a lot in that regard. Now I think: I am just as entitled to my medication as someone who has cancer. And I thank God that I have HIV and not cancer.

I have learned that you can live very well with HIV. For a few weeks, I lived with the idea that I was going to die and then suddenly I received a gift: some extra years to my life. That changed my life a lot. I no longer worry about trifles, in many situations I now just think: what is it all actually about? I'm alive! I have children, grandchildren and amazing friends who all love me. My life has really changed after my diagnosis. I am no longer afraid of dying either, every new day is a gift. That is what this situation has brought me.

Sometimes the people you least expect are the ones who react very kindly. My brother is very conservative, but called me after he heard that I had HIV and asked: 'How is it, Mar, how nasty are those candies? So sweet. I think you should also give people the opportunity to support you.

When an old friend told me he has Parkinson's, I told him I live with HIV. At such a moment it is functional to tell someone about it, because it lets them know that you understand what they are going through. If there is a good reason, I will tell people.

I was in a relationship once, after I had learned that I had HIV. I then obliged myself to tell him about it at an early stage and this man handled it very well, even bringing a beautifully wrapped pack of condoms on the next date. Such things also help to boost your self-confidence.

All in all, the reactions of others have been way better than I expected. Perhaps in the end there is more self-judgment than judgement from the people that love you. If your fear of reactions from others causes you to keep it all to yourself, you are selling yourself short. You deny yourself support and your world becomes very small. You should trust your loved ones a bit more: if they love you, they will continue to love you when you are ill or when you live with HIV.

I think you make yourself very miserable by not talking to anyone about it.



LAURA

Laura is 46 years old and comes from Central Africa. She came to the Netherlands at the age of 30.

I met my Dutch husband in Africa and I came to the Netherlands for him. My children stayed in Africa, they were supposed to come later. At the time, I did not know I was living with HIV. But in 2010 my youngest in Africa fell very ill and eventually passed away. He turned out to have died of AIDS.

When I returned to Africa to bury my son, I fell very ill there myself. I spent two months in a coma on the intensive care unit. Back then, HIV was still a big taboo subject in many African countries. But two years ago, when I was back there again, people suddenly mentioned they were taking pills, so fortunately things are slowly changing there too.

My sister who also lives in the Netherlands, knows about my HIV. And in Africa my mother knew, of course. Naturally, I also had to tell my husband, who luckily responded very well to the news. I haven't told anyone else, because I was so afraid of the gossip and of being judged. I blamed myself too.

The fact that I have accepted it much more now is because I came into contact with Shiva*, through a Surinamese colleague. She told me that she and her mother would be visiting the hospital for an event the next day. I had also received a letter from the hospital stating that there would be an HIV event there.

When I asked her whether her mother was ill, she beat around the bush a bit. Telling her that I live with HIV was a big step, but I told her that I knew there would be an HIV-related event because I lived with the virus myself. She immediately invited me to join them. I had a lot of doubts and was very nervous. In retrospect, I'm enormously happy that I took that step. That day I accepted myself.

The power of that day is the strength you draw from others. The recognition... You're not the only one. You see that others have the power to be confident. I found that very inspiring, that you can live with HIV and be strong. It was a huge step to reveal my secret that day, but the contact with other women has given me so much power.

I am still not open towards the outside world or even towards friends. Only at The Positive Sisters* of ShivA do they know that I live with HIV. But this openness has changed my life a lot, I have learned so much from the other women. For example, when I met my current boyfriend, I immediately told him. I learned that from the other women at ShivA... Just tell it right away and if he isn't up for that, so be it.

My counselor had pointed out activities many times before, but I always said NO immediately, I was so afraid of whom I would meet there. I think the contact with ShivA works better than speaking with counselors, because the latter always feels very distant for people from Africa. They are not your friend or your colleague and so you don't tell them what really concerns you.

I think it would help if an African woman living with HIV were present at those consultations. We would be more inclined to accept advice and ask questions then. They should really ask who we would like to talk to, because you don't want to speak to someone from your own country either. Maybe we will say no the first time, but just keep offering... We might say yes the second or third time.

There is a big barrier to participating in activities for women with a migration background. There is a lot of low literacy and the tone with which activities are announced sometimes just doesn't work. There is a lot of depression and women end up in isolation. It's important to use the right words and to strike the right tone when addressing this group.

We African women do not go looking for information about HIV ourselves. I didn't know anything, I thought my kids could get it if they touched my clothes or used my towel. At ShivA I learned that the virus can only survive outside of your body for a very short time and that if you take your medication, you can no longer transmit the virus. That gave so much relief. I try to explain to other women with the same background that they can learn a lot from ShivA and that it will really make their life with HIV easier.

Now, I also coach women myself. You really see someone become more powerful and blossom after having been given the right information. They can then move on with their lives. It actually doesn't take that much.

I found that very inspiring,
that you can live with HIV
and be strong.

The power of that day is the strength
you draw from others.

The recognition...
You're not the only one.

*Information about The Positive Sisters and Brothers of ShivA can be found at the back of this booklet.

**Meetings are regularly organized for people with HIV in various hospitals. Ask your counselor for more information.

RICHARD

Richard was infected in 2012. He is in a relationship with Henk.

Henk and I have been in a relationship for 42 years and we have a good life together. When I was diagnosed with HIV, he responded very well to that. I didn't feel like it, but he immediately started looking up various things about HIV on the internet. At one point he found an article about the HIV Vereniging's (HIV Association) workshop series*, six evenings where both the counselors and participants live with HIV. I would recommend anyone to attend that workshop series. You receive a great deal of practical information, feelings are openly discussed and you have a lot of support from each other.

Peer to peer contact is such a powerful instrument, seeing how others deal with HIV is truly inspiring. The interaction with the group was very special. We became a very close-knit bunch and I still keep in touch with most of the participants. Corine, one of the workshop leaders, was a real example to me. The way she deals with HIV, that's what I strive for. Matter-of-factly, sure of herself. Of course, it takes time to get that far, but the example she set was so powerful.

At first, I didn't tell anyone except Henk. But through the workshop series I also learned about other initiatives of the HIV community, like the annual Power of Love** Day in the Carré Theater in Amsterdam. There I got to know new people, too. I felt nervous, but also enjoyed it. I got more involved, step by step, and also became more open to the outside world. The next step was that I started as an educator the HIV Association at schools and other places myself.



Peer to peer contact is such a powerful instrument. It has been very important to me because you see how others deal with things and you let them inspire you.

My experience has taught me that it is important to take time for the process of acceptance and openness.

It feels enormously liberating when you stop condemning yourself.

That was pretty nerve-racking, but also a good time to test how I was doing. I was no longer worried that I would run into someone I knew. I was clearly more relaxed about the whole thing.

Meanwhile, I told more and more friends about it and it never turned out to be an issue. I've never had bad reactions. The more often I got good responses from people, the easier it became to tell people about it next time.

At first, I really didn't want people to find out. Perhaps that was self-stigma, I blamed myself for allowing it to happen to me. On top of that I was afraid of infecting Henk and I felt guilty towards him. I am of Indonesian descent and to the outside world everything has to seem nice and good. I'm very good at pretending things are better than they actually are. That may even have helped me initially, but at a certain point it just didn't feel right anymore. Then, very slowly, I became more open.

Only my family is still not aware of my HIV. My 93-year-old father has already had a lot to deal with, I do not want to burden him with it. It wouldn't help me if he knew about it and it would just cause him unnecessary worries. My sister and a few other family members know that I volunteer for the HIV Association, but no one has ever asked me if I myself live with HIV.

Whether I wanted to be photographed recognizably for this interview, that was something I had to think about for a while. But in the end, I decided it was a next step in the process for me. It allows me to see how much I've grown over the past eight years.

My experience has taught me that it's important to take time for the process of acceptance and openness. To keep thinking carefully whether this is the right moment to take a next step. Sometimes, after a trainings weekend with the counsellors of the HIV Association, I came back so inspired that I said to myself: now I'm going to tell people. But then I always waited to see if I still had that feeling a week later.

If you want to reduce self-stigma, you first must be aware that it is there. Being aware that you feel ashamed or that you blame yourself. Time has helped a lot for me, as well as conversations with other people dealing with HIV. It feels enormously liberating when you stop condemning yourself. If you have a lot of self-stigma and someone says something negative about your HIV which you agree with deep inside, for example that the situation is your own fault, that will hit you hard. But if you no longer blame yourself, it will also be easier to disregard the judgment of others.

It is good for me to recount my story in this way, as it so clearly shows the way in which I have processed and dealt with my HIV.

*Information about the workshop series of the HIV Association can be found at the back of this booklet.

**Information about The Power of Love day in Carré can be found at the back of this booklet.



TIM

Tim is 24 years old and was born in Indonesia.

The beginning of my life was not easy. I was born with spastic legs and when I was a year old, my Indonesian mother passed away. No one knew what the cause of her death was, but when I was three I fell so ill that I almost did not survive. After we went to the Netherlands for medical care, we found out that I had HIV and that my father had the virus too. My mother had always kept quiet about her HIV.

When I turned twelve, we decided that I would attend secondary school in the Netherlands. My father had not yet told me I had HIV. My pediatric nurse consultant told me with the help of the book 'Brenda has a Dragon in Her Blood'. You also have a dragon like that in your blood, she said, which I actually thought was kind of cool. I mean: how many kids have their own dragon? The consultant told it like it was not a terrible thing, instead turning it into a light story and therefore I didn't feel bad about it at all.

My father asked my consultant to tell me because he found it very difficult to do so himself. He still feels very guilty and does not tell anyone about his HIV. We have agreed that if I want to tell someone, I'll talk to him first. We are very close and I want to protect him, but it does not feel right that I can't be as open as I would like, it feels like being chained by the leg. I want to be honest with everyone, but I also do not want to hurt my father.

My friends all know about my situation and it has never been a problem. If I tell someone, I try to do so in a light manner, just like how my pediatric nurse told me.

The first time I opened up about my HIV was in first grade of high school, during a biology class on STDs. The textbook contained such dated information on the subject that I felt that I should comment on it. Despite being very nervous, I asked to speak and said: What this book states about HIV has been incorrect for some time now, I have it myself and it is no longer a deadly disease.

The class thought I was brave for saying that (I was 13 at the time) and they applauded me. Of course, it was passed on at school and that didn't feel good at all. I had delivered the message to my class with all the information about N=N. The other students had not received this information and I did not want them to be afraid of me.

I asked the principal if I could rent the auditorium so I could inform the whole school, all 1200 students at once. I did, it was an impulse but I am still glad I handled it that way. My father still doesn't know this story, I don't dare to tell him.

Throughout my high school days, I was cheerful, had a lot of friends and a lot of fun. When during my secondary education I went through a difficult time.

The educational program didn't really suit me and I started to worry about who I really was and what my place in the world would be. Then the anger and frustration first surfaced: 'Why am I dealing with all this, these spastic legs and also this HIV.' I was scared. I skipped school. I was afraid to talk to my father about it, not wanting to disappoint him. I did tell my nurse consultant that I was not feeling happy, after which she sent me to see a psychologist. I started meditating and learned what I actually wanted and who I was.

Today I have a job and a serious relationship. When it became clear that my girlfriend and I really wanted to continue together, I wondered how I would tell her about my HIV. I decided to bring it up during a lunch and to tell it lightly: Hey, I do have HIV, I think you should know that. She wasn't terribly shocked and actually responded well. She said she was happy with me and that this was no reason to leave me. It has never really been a problem.

I truly believe in keeping the message light. But you must first be able to feel for yourself that it is a subject which does not require graveness, only then can you convey it like that. Casually, with a beer in hand and during a relaxed conversation.

I have accepted my HIV as an integral part of me. It is one of the things that makes me Tim. Tim with his dragon. I'm even thinking about getting a dragon tattoo.

I have accepted my HIV as an integral part of me. It is one of the things that makes me Tim. Tim with his dragon.

When I tell someone, I try to do so in a light manner. Casually, with a beer in hand and during a relaxed conversation.

HIV ASSOCIATION

Workshop series 'Positief leven'

Six informative meetings in a fixed group of 5-10 people throughout the Netherlands. For people who were recently diagnosed or are in need of contact with peers. Trained volunteers, who also live with HIV, will supervise the workshop.

www.hivvereniging.nl/workshopreeks

Group activities and meetings

Volunteers organise activities throughout the country and inform people by digital channels. (website, Facebook, WhatsApp, Twitter). This can be regional or for a special target group. You can join us for a lunch, dinner, or an informal café evening or for an informational meeting.

www.hivvereniging.nl/ontmoeten

Peer-counseling

Supportive 1 to 1 talks with a trained expert who is also living with HIV. For people who were recently diagnosed. We make a connection between you and a peer counsellor who fits your questions.

In 2 to 5 meetings, at a location of your choice, they will help you with acceptance and finding your way.

www.hivvereniging.nl/ontmoeten/peer-counseling

Service Punt

For all your questions about living with HIV, signing up for activities, peer-counseling and the workshop series. You can contact the Service Punt via telephone and talk to a trained volunteer who also lives with HIV. Your privacy is guaranteed, and you can call anonymous.

If you would rather talk face to face with a volunteer of the Service Punt that is also a possibility.

You can reach us on Monday, Tuesday and Thursday from 14.00 – 22.00 uur op 020 689 25 77 or via e-mail

servicepunt@hivvereniging.nl

SHIVA FOUNDATION

SPIRITUALITY, HIV & AIDS

At Shiva you will find group activities and the possibility for individual help. Your privacy is guaranteed.

Positive sisters and brothers

The Positive Sisters (and Brothers) is a successful, unique peer project that matches and supports African and Caribbean migrants with so-called Positive Sisters and Brothers:

African / Caribbean volunteers who themselves also are HIV-positive and who are trained and supported by Shiva during the entire period of the match. You can get in touch by asking your HIV-consultant or by calling Shiva.

Monastery retreat for people with HIV

Twice a year Shiva organises a monastery retreat (Thursday to Sunday) at the Lioba monastery in Egmond-Binnen for people living with HIV. With yoga, meditation, working on what needs attention in your life at that moment, meeting others with HIV, massage, singing bowl concert and lots of me-time in the beautiful surroundings of the monastery.

I love my life – Day for African and Caribbean Women

Regionally organised days in various hospitals where Shiva's Positive Sisters and the women they accompany come together for information and empowerment.

Individual help...

is possible via phone, mail or live. Shiva offers individual talks and help. You will find someone who listens without prejudices and who is experienced in religious and other life questions.

These talks are free and confidential.

020 61 60 460 / 06 43 778 713
shiva-everdien@xs4all.nl

www.shiva-positief.nl/wat-doet-shiva

STICHTING MARA ROTTERDAM

MARA Rotterdam offers individual confidential contact and meetings where you can meet others who are living with HIV in Rotterdam.

Spiritual guidance / Life's questions coach

Confidential talks in which you can talk about what is important to you. These talks are free and can take place at MARA's office or at your home.

Positive Forces Together

A project for and by people living with HIV. This buddy project matches you with a volunteer who lives with HIV and has accepted it.

The Group

Especially for young men (under 35) with a migrant background who have sex with other men (msm) there is a meeting once a month.

Diner group

Every Friday evening there is a HIV diner at the COC-building. Everybody is welcome to join us for a delicious three course diner.

karlijn@maraprojecten.nl
Telefoon/sms/app: 06 41 535 322

VOLLE MAAN: THE POWER OF LOVE THE NICEST DAY TO HAVE HIV

Yearly meeting at the Royal Theatre Carré in Amsterdam around World Aids Day, December 1st

www.poweroflove.amsterdam

THE STIGMA PROJECT

Photo and interview project by Marjolein Annegarn. If you want to order the book send an e-mail to marjolein@goedbeeld.nl

www.goedbeeld.nl/the-stigma-project

STICHTING HELLO GORGEOUS

Stichting Hello Gorgeous's mission, is to normalise living with HIV by fighting the stigma. They do so by means of their beautiful magazine Hello Gorgeous, which is published 4 times a year.

www.hellogorgeous.nl/

RESET is a series of empowerment workshops for people living with HIV. Three sessions each of 2,5 hours in a sequence of three weeks. Supervised by Hello Gorgeous's trainers who live with HIV themselves.

reset.hellogorgeous.nl

CHILDREN'S BOOK: BRENDA HEEFT EEN DRAAKJE IN HAAR BLOED (BRENDA HAS A LITTLE DRAGON IN HER BLOOD)

This book (only in Dutch) tells the story of a little girl who lives with HIV, written by her foster mother.

Writer	Hijltje Vink
Publisher	De Banier
ISBN	9789033626135

The book is written in 1998 and can only be purchased second hand.

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