

Lessons and questions for discussion

*“This little light of mine
I am going to let it shine
Let it shine.”*

On pages 194–201, we summarise some of the key lessons I have learnt from my journey of life with HIV and other challenges. Each of the eight themes, such as *Relationships* and *Dealing with loss*, also have questions to encourage you to think about what these lessons mean for you in responding to HIV and other issues in your life.

You can use these lessons and questions on your own, in workshops and support group discussions. You are welcome to copy these *Lessons and questions for discussion* pages, and you may want to add your own lessons and questions.

Issues like *Stigma and denial* and *Taking ARVs and handling side effects* may be difficult to think about or deal with – see the list of *Useful contacts* on pages 202–203 for help.

STIGMA AND DENIAL

Lessons

- At first I didn't know how to deal with my HIV positive diagnosis – I didn't want to believe it and thought I was immune as a married person, although now I know anyone can get HIV regardless of marital status.
- As women, we often face two kinds of stigma: being an unmarried woman and living with HIV.
- I learnt to overcome my fears – seeing HIV as a manageable health condition needing support, care and medical attention over time helped me to begin to feel strong enough to think about sharing with others.
- When I saw others who were ill, I made a silent pact with myself to do all that it takes to keep well, regardless of how scared I sometimes felt inside.
- My silence was making me feel uncomfortable and was suffocating me – I needed to open up, as I no longer felt like my true self by keeping quiet about my health.
- Living with HIV is not what classifies me – yet, it is a part of who I am and one that I cannot deny and ignore.

Questions

- What steps can we take to address HIV stigma in our homes and communities?
- What can we do to break the silence around HIV?
- How can we move away from denial around HIV/AIDS and get people to be more open and accepting?

ACCEPTANCE AND DISCLOSURE

Lessons

- Disclosing my HIV status helped me to accept myself from within – I learnt to adjust to my state of health by saying “This is who I am” and actively looked for support from others.
- Disclosing to family is vital, but should not be forced – starting with my closest relatives one at a time and being fully accepted by them helped me to be strong.
- Disclosure is better than keeping HIV status a secret – I chose to disclose at a time when I am still healthy, as it is harder for loved ones to find out at a time when you are not well.
- When you disclose to lovers, you fear rejection – hard as it is to do, I feel it helps to disclose early on in the relationship rather than later when trust has been established.
- Disclosure is better when you prepare those you tell – with time I learnt to prepare the people I disclosed to.
- Disclosing to my son was difficult but liberating – I realised that, if gently told, children have the capacity to understand and respond very lovingly.

Questions

- What steps have you taken to accept that you are living with HIV? For example, have you considered joining a support group after your HIV diagnosis?
- What is the best way to disclose to your partner and family?
- How can you support your spouse living with HIV?
- Have you considered disclosing to your children – if not, when are you planning to?

CONDOMS AND SAFER SEX

Lessons

- Being married doesn't mean that you are risk-free – I was too trusting and afraid to demand condom use the moment my husband started spending time away.
- Most women are still unable to protect themselves from getting HIV because their economic and gender inequality leaves them vulnerable.
- If both of you are HIV negative, keep yourselves that way and remain faithful, first to yourselves and then to each other.
- If you are already living with HIV, do whatever is possible to stay healthy and practise safer sex.
- As much as the thought of unprotected lovemaking is appealing, I continue to insist on safer intimacy and condom use – I prefer an unhappy partner than an unplanned pregnancy, HIV re-infection or another sexually transmitted infection.
- Where two people are in an unhappy relationship, chances are one or both will have extra-marital affairs and unsafe sex – this is when many new HIV infections happen.

Questions

- What makes it hard for you to negotiate safer sex?
- How can you encourage your partner to use protection, for example, condoms?
- What makes practising safer sex difficult in a marriage?
- How can we be true to our cultural values, yet protect ourselves from HIV infection?

RELATIONSHIPS

Lessons

- In any new relationship, be careful about trusting too soon – rather go slow and delay intimacy.
- Be responsible to yourself – never let a man think for you or pressurise you, however caring and responsible he may seem.
- Where there was a potential relationship with someone new, I felt the need to tell him I was living with HIV in an open, unapologetic way.
- Being rejected due to my HIV status made me brace myself for a ‘wobbly love train’ ahead.
- Getting burnt in relationships made me reject people that honestly cared about me – the sooner I realised that most men do not stay around for keeps, the easier it was to move on.
- Relationships need lots of communication even without the complication of HIV – if we talk more openly with our partners about sexuality, relationships can improve.
- Women should not be viewed differently – we are capable of giving and receiving love, and HIV shouldn’t be a barometer to disqualify us from relationships.

Questions

- Do you think it’s good to delay your sexual debut and why?
- What advice would you give young women who are pressured into relationships?
- How can we address the greater stigma faced by women when they test HIV positive in a relationship?
- How can you deal with relationship rejection because of HIV?

COPING AS A WOMAN AND A SINGLE MOTHER

Lessons

- As a young woman, I wanted to understand my own body long before any talk about becoming a good wife or partner to someone later on in life.
- As a woman, I had my own fears shortly after testing HIV positive – I made myself life goals to achieve to focus on the whole of my life, not just my health.
- My son and I were determined to make it on our own – even when I didn't have work, I provided our daily bread and we did not feel sorry for ourselves.
- I told myself that I was not a 'widow' or 'victim' – instead I am a woman trying to survive the odds without looking back or blaming someone.
- In our support group, we learnt to smile again and called ourselves *Sizophila* (*We shall survive*) as a way of sustaining a hope burning within us to live long.
- As a woman, I have chosen not to compromise what I am just to keep and have a man – I am a woman that wants to be treated with respect as a person and for my role in my relationships with people.

Questions

- How can we encourage young girls not to marry before they are informed about their own bodies?
- How can women avoid HIV when partners are reluctant to use condoms?
- What type of support is lacking for children whose parents are living with HIV and how can we address that?
- How can we support single parents living with HIV?

TAKING ARVS AND HANDLING SIDE EFFECTS

Lessons

- I had to get over the mental hurdle of not wanting to be seen taking tablets every day and the burden of being on ARVs when others couldn't access them.
- Delaying starting ARVs could have been very damaging to my health – I had to decide what was best for me and to listen to those who were surviving well on treatment.
- Starting ARVs is vital when your body's CD4 cell count is low – I never bothered about my low CD4 count because of my faith that one day it would improve.
- Share ARV treatment experiences and get tips – for example, I have a medicine diary next to my bed to remind me to refill my daily doses.
- I had to be very strong to survive the side effects of my earlier ARVs that made my breasts swell and my clothes hang – if this happens, speak to someone going through the same thing for support and to your doctor for alternatives.
- Taking ARVs is a lifelong commitment – never stop your treatment without your doctor's advice on other ARV option.

Questions

- If you are at a point when you need to start taking ARVs, have you spoken to your health care providers about what's best for you?
- If you are already taking ARVs, have you had any side effects and how did you deal with them?
- What advice would you give to someone considering taking ARVs?
- How can you support your spouse or partner facing body-changing side effects from ARVs?

DEALING WITH LOSS

Lessons

- I couldn't make sense of the loss of my husband and felt deserted and robbed – cherishing the beautiful son that symbolised our love gave me the power to carry on.
- Dealing with so much loss in my family caused me to delay sharing my HIV status, as I was trying to shield them from more traumatic news.
- It was very painful to accept the loss of my sister and equally hard to understand why she couldn't open up to me as someone so close to her.
- I felt emotionally paralysed and it was so hard for me to accept the choice of some dear friends who are not with us today because they chose not to take ARVs.
- To prevent unnecessary deaths, we must reduce stigma and give clear information on the benefits of ARVs and treatment for opportunistic infections, together with good adherence and monitoring.
- In every loss, there is a tranquilliser of memories and support that make it possible to sail on, and to live life with no regrets.

Questions

- How have you dealt with the loss of loved ones?
- What advice can you give to others facing deep loss?
- What else can we do to prevent losing more people to the HIV/AIDS pandemic?

HAVING A POSITIVE ATTITUDE

Lessons

- Knowing that I have HIV wasn't the best news, but I am happy that I know – I now pay better attention to my well-being, probably better than before I knew my HIV status.
- Living with HIV should not be about blaming others – I focus on acceptance and finding the best ways to stay healthy.
- Having positive thoughts and relieving stress, for example, simply enjoying a walk with my son, made me feel stronger.
- I began to picture myself doing things that I would do if I was not living with HIV – this helped me to see that I could do whatever I wanted, and all I needed was to take the first step in my healing journey.
- I began to think of the HIV within me as very much part of me – my own *Umzala*, the cousin who was always going to be with me and who I needed to be a good host to.

Questions

- Have you been for an HIV test? If not, what's holding you back?
- How have you dealt with finding out you are living with HIV?
- What advice can you give to others about living positively with HIV?
- What else can we do to ensure a more supportive environment for people living with and affected by HIV/AIDS?