

Lessons and questions for discussion

“To love oneself is the beginning of a lifelong romance.”

Oscar Wilde

On pages 213–221 we summarise some of the things I have learnt in my journey of living with HIV. The questions encourage you to think about what these lessons mean for you in your own situation, and to work out your own way of responding to HIV and other challenges in your life.

You may wish to use these lessons and questions on your own, in workshops or in support group discussions. When you do this, you are welcome to photocopy these *Lessons and questions for discussion* pages. You can also add your own lessons and questions in the empty spaces.

These issues may be difficult to think about or deal with – on page 222 is a list of some organisations you can contact for further help.

STIGMA, DENIAL, SILENCE AND DISCRIMINATION

Lessons

- After testing HIV positive, my first step to reducing stigma was to accept inside myself that I am living with HIV – I had to overcome my inner voice of denial and say: “This is real and it’s happening to me.”
- HIV is not a badge of shame – when we live with HIV, it is one part of who we are and one part of our lives.
- Once you stop blaming the past and start accepting your HIV status, you will be much more able to look after yourself and to support others.
- When you feel stronger, you can link up with other people living with HIV and speak out openly to challenge stigma and discrimination. For example, you could challenge a newspaper that labels us “HIV sufferers”.

Questions

- Why are stigma, denial and discrimination around HIV/AIDS still so strong in South Africa?
- What can we do to get people talking more openly and to reduce stigma and discrimination around HIV/AIDS? For example, does it help to use positive, sensitive language in speaking and writing about HIV/AIDS?
- In what ways have you tried to break the silence around HIV and living with HIV?

HIV TESTING

Lessons

- I delayed having an HIV test because of stigma, fear and focusing on my work and relationship issues, instead of putting myself first.
- Finding out your HIV status is the first step to taking care of yourself – staying HIV negative if you test HIV negative, and living healthily and getting the care, support and treatment you need if you test HIV positive.
- Knowing your HIV status is an insurance policy for your future and the future of the people you love.

Questions

- Have you had an HIV test?
- What is stopping you from having an HIV test? Have you thought about getting advice and counselling to encourage you to test?
- Do you regularly retest for HIV if you are HIV negative, yet sexually active?

SAFER SEX

Lessons

- I felt so much better about myself when I was able to disclose I was living with HIV to my partner, before anything intimate happened between us.
- Having unsafe sex does not bring trust in a relationship – trust is about loving someone enough to want to protect them.
- Having safer sex, for example, using a condom, is not about being promiscuous – it's about being responsible and trying to prevent HIV transmission or re-infection.

Questions

- What do we mean by *safer sex*?
- Do you practise safer sex all the time? If not, what stops you?
- What is the best way of negotiating safer sex, for example, with a regular partner or with a partner outside of a committed relationship?

DISCLOSING, GETTING SUPPORT AND EDUCATING OTHERS

Lessons

- Starting to disclose that I am living with HIV helped to take a big weight off my shoulders – I realised I don't have to carry it alone.
- Take it one step at a time, beginning with disclosing to one person who you trust, for example, another person who is openly living with HIV.
- Disclosing is like dropping a stone in a pond – one disclosure gives you the strength to disclose to more people when you are ready.
- Don't rush a disclosure – for each disclosure, find a good time and a quiet place that feels right for you, and follow up to see how the person you have disclosed to is feeling afterwards.
- Disclosing is an ongoing process of receiving support, giving support to others around HIV and other challenges in their lives, and educating family, friends and work colleagues about HIV and AIDS.

Questions

- If you have been unable to disclose that you are living with HIV, what is holding you back?
- What has been your experience of disclosing, for example, to a partner, to a child or to a parent?
- How has disclosing helped you, and what tips can you suggest to make disclosing easier for others?
- What are the best ways to educate others about HIV and AIDS to make them more aware before and after you disclose to them?

COMING OUT ABOUT YOUR SEXUAL ORIENTATION

Lessons

- It is okay to be different, for example, to be gay – the most important thing was to accept who I am and to be myself.
- Choose one trusted person to talk to first, for example, a friend, a family member, a counsellor or someone else who is openly lesbian/gay.
- Take it one step at a time and at your own pace – you don't have to tell everyone at once.
- Social and legal recognition of same-sex unions encourages people to have committed, loving relationships.

Questions

- Has it been difficult for you to talk about your sexuality and to come out, for example, at home or at school?
- How did you feel once you started the process of coming out to one or two close people?
- How can you help someone who you know is struggling to be open about his/her sexual orientation?
- How can you help create greater tolerance and acceptance of difference and diversity in South Africa, for example, the equal right of everyone to dignity and to marry?

TAKING ANTIRETROVIRALS

Lessons

- I went onto ARVs in the private sector when my CD4 count dropped to 300 instead of waiting until my count was 200 to qualify in the public sector – I wanted to take control of my body and my life.
- In the public sector, you can qualify for ARVs if your CD4 count is over 200 and you are experiencing opportunistic infections like TB or pneumonia.
- I never miss a dose of my ARVs – I think of them as if they are my daily dose of vitamins.
- Try to get as much information as you can about ARVs and other medication for treating infections by asking, reading and attending treatment literacy workshops – the more you know, the better prepared you will be for when you need to take ARVs or other medication.

Questions

- After testing HIV positive, did you have counselling to help keep you strong mentally and have you had regular check-ups to monitor your CD4 count?
- Have you considered starting to take ARVs if your CD4 count is under 200 or you are experiencing opportunistic infections?
- How are you coping on ARVs? Have you spoken to others coping well with ARVs to get advice on how to cope better, for example, monitoring your viral load and keeping an eye on drug side effects and resistance?
- How can we ensure that people taking ARVs in the public sector have access to more affordable drug options when experiencing side effects or resistance to some drugs?

VISIBILITY AND PARTICIPATION AS PEOPLE LIVING WITH HIV

Lessons

- As people living with HIV and AIDS, we need to make sure that our faces are seen and our voices are heard – we need to speak up for ourselves.
- “Nothing about us without us” – we can use our experience of living with HIV to help guide policies and programmes, and make them more sensitive and effective in dealing with the issues that affect us.
- Our greater visibility will help to reduce stigma and build a culture of consulting us as people living with HIV, based on our democracy and the values in our South African Constitution.

Questions

- What does the *GIPA Principle* mean to you (the idea that, as people living with HIV, we should participate in policies, issues and programmes that affect us)?
- What stops you from being able to link up with other people living with HIV to make sure that our voices are heard?
- How can we ensure that we stand together as people living with HIV to participate more effectively in things that affect us?

FACING THE FUTURE WITH HOPE

Lessons

- Today is the first day of the rest of my life – and I will do everything I can to make sure it's a healthy, stress-free, long, fulfilling life.
- With access to ARV treatment, HIV is a manageable condition if you live positively and take care of yourself, for example, adhere to your treatment, eat healthily and exercise regularly.
- Loving and being loved is a powerful medicine in reducing stress, worries, aches and pains.

Questions

- What does the idea of *positive living* mean to you?
- What is your recipe for having hope in the future while living with HIV?
- How can knowing your HIV status help you to plan a better future for you and your loved ones?

Examples of South African contacts for help, advice, counselling, support, treatment and public education

- AIDS Helpline (National Department of Health): 0800 012 322 + www.doh.gov.za
- AIDS Law Project: 011 356 4100 + www.alp.org.za
- AIDS Legal Network: 021 447 8435 + www.aln.org.za
- Centre for the Study of AIDS: 012 420 4395 + www.csa.za.org
- Community Health Media Trust: 021 788 9163 + www.beatit.co.za
- Durban Lesbian and Gay Community and Health Centre: 031 301 2145 + www.gaycentre.org.za
- OUT Lesbian, Gay, Bisexual, Transgender Well-being: 012 344 5108 + www.out.org.za
- Treatment Action Campaign: 021 788 3507 + www.tac.org.za
- Triangle Project: 021 448 3812 + www.triangle.org.za
(services and safe spaces for lesbian, gay, bisexual and transgender people)