



LETS TALK DISCLOSURE

YOUR DISCLOSURE SUPPORT GUIDE FOR TACKLING TOUGH TOPICS, TOGETHER

THINK, TALK, ACT!



OXFAM

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Knowledge for action: The power to make a difference!



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This booklet 'Let's Talk Disclosure: Your Disclosure Support Guide for Tackling Tough Topics, Together' is an HIV disclosure guide to support discussions on, and the process of, disclosure for young people and their caregivers.

It has been developed by SAfAIDS, with funding and technical support from Oxfam, as part of their 'Securing Rights in the Context of HIV and AIDS Programme - (SRP)'.

The booklet uses research findings from a study with young people and their caregivers from selected districts under Midlands, Matabeleland North, Matabeleland South and Bulawayo provinces in Zimbabwe.

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Knowledge for action: The power to make a difference!

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TOUGH TERMS!

AIDS	Acquired immunodeficiency syndrome refers to a set of infections common in people living with HIV whose bodies have become weak. AIDS can lead to death. By taking ARVs correctly and consistently, people living with HIV can stay healthy and prevent progression to AIDS.
ARVs	Antiretroviral medication is taken by people living with HIV to help them stay healthy and prevent development of AIDS.
Depression	A medical condition where someone has severe feelings of sadness and hopelessness.
Discrimination	When someone is treated unfairly or differently because the person is, or is thought to be, different from others.
FGD	A focus group discussion is a method for gathering information during research – a group of people have a relaxed conversation about the research questions.
HIV Transmission	The spread of HIV from one person to another.
Human Rights	A set of internationally agreed freedoms which all people equally entitled to, whatever their gender, race, religion, nationality or other status.
MMPZT	Million Memory Project Zimbabwe Trust.

SAYWHAT

Students and Youth Working on Reproductive Health Action Team.

PMTCT

Prevention of mother-to-child transmission of HIV services enable people living with HIV to have HIV negative babies.

Stigma

Making someone feel ashamed or excluded because they are, or are thought to be, different. Some people self-stigmatise, which means they feel ashamed about themselves or they exclude themselves from joining in certain activities.

Treatment Adherence

Taking medication, like ARVs, every day consistently and correctly as prescribed or told to by the doctor or health personnel.

YPBLHIV

Young person born and living with HIV.

WORKING WITH YOUNG PEOPLE IS CRITICAL

Oxfam's work with young positive people

Zimbabwe has made a lot of progress in addressing HIV. Since 2005, the new HIV infection rate has dropped from 1 in every four adults to 1 in every seven adults; but there is still a lot of work to be done.

- In Zimbabwe, 110,000 young people aged 10-19 years old were estimated to be living with HIV in 2013 (UNICEF 2014).
- In the same year, 9,000 children aged 0-14 were newly infected with HIV in Zimbabwe, nine in every ten of whom were exposed to HIV infection at, or soon after birth, through mother to child transmission (UNICEF 2014).

Oxfam supports all young social change leaders in the global effort to improve health and overcome poverty. *Oxfam's Securing Rights in the context of HIV and AIDS Programme (SRP)* in Zimbabwe aims to reduce the spread of HIV by supporting communities to access their rights to prevention, quality treatment, care, support and sustainable livelihoods.

As part of the SRP, a research study carried out between November 2014 and February 2015, identified disclosure as a significant barrier to securing young people's rights. Over 200 young positive people aged 10–24 years from Midlands, Matabeleland North, Matabeleland South and Bulawayo shared their experiences through group discussion, letters and interviews. The voices of their caregivers are also included.

The result is a collective voice to support conversations around disclosure to help guide young people and their carers through a healthy and positive disclosure process. **Think, Talk, Act!**



This booklet has been developed for young people born and living with HIV (YPBLHIV) and their caregivers, parents and guardians, to help them tackle hard topics around disclosure, and work towards a healthier and happier disclosure process, together.



The booklet can also be used by others working with young HIV positive people, such as teachers, NGOs, healthcare workers, religious and community leaders, youth group leaders, youth champions and peer leaders – and anyone else who wants to help a young person to understand and discuss their HIV status. Use it to talk about:

- What we mean by disclosure; the different types of disclosure that exist and that young people may experience.
- Why disclosure is important, and the benefits of disclosing to young people.
- Guidance, tips and steps to support a positive disclosure experience.
- Rights and responsibilities as they relate to disclosure.
- How others in a child's circle of care can support a healthy disclosure process.
- Where young people can get additional support.



You can use this booklet to guide you through the process of disclosure to a young person, with carers and others, as well as to discuss issues around a young person disclosing their HIV positive status to others. The booklet is a useful tool for everyone who has tested HIV positive, to help them through the process of acceptance and disclosure. There is a quick quiz at the end, too!

UNPACKING DISCLOSURE



Before we start talking about how to disclose and when to disclose, we need to understand what we mean by HIV disclosure.

DEFINING DISCLOSURE

HIV disclosure means telling another person or people about an individual's HIV-positive status.

This might mean telling someone that they are HIV positive (e.g. a parent to a child who is HIV positive).

Or it could be an HIV positive person telling someone else about their HIV status (e.g. telling a friend or relationship partner that they are HIV positive).

Disclosure can also mean when another person tells a third person about someone's HIV status (e.g. a parent telling a child's teacher that the child is HIV positive).

It is important to remember that disclosure is NOT a one-off event.

Planning ahead can support positive acceptance and better communication and relationships.

TYPES OF DISCLOSURE



There are lots of different kinds of disclosure – let us look at them in more detail.

WHO IS DISCLOSING TO WHO?



Caregiver to YPBLHIV/ YPBLHIV to Others – also called Primary Disclosure

- This is when a caregiver or parent discloses a young person's HIV positive status to them; or
- When a young person tells someone else about his or her HIV positive status (e.g. when a young person living with HIV tells a relationship partner, such as a girl- or boy-friend, a friend or other person about his or her HIV positive status).

Caregiver to Others / Others to YPBLHIV – also called Secondary Disclosure

- This is when a person other than the caregiver (e.g. a healthcare worker or teacher) discloses a child's HIV status to him or her on behalf of the primary caregiver.
- It can also refer to when someone shares a person's HIV positive status with others, either with or without the HIV positive person's permission or knowledge.
- Remember that in Zimbabwe, the Blood Transfusion Service relies on blood donations from school pupils. Don't leave it too late and let your child find out they are HIV positive at school when the Blood Transfusion Service comes around.



"My mother was the right person to tell me about my status - I went with her to the New Start Centre"

Teenager, Bulawayo

"I was at school when I was told my HIV status and I did not like it"

Teenager, Midlands

HOW DISCLOSURE CAN HAPPEN

VOLUNTARY VERSUS ACCIDENTAL DISCLOSURE

Voluntary disclosure is when the person disclosing does so on purpose – they have planned to do so at that time and in that way, to that person.

Accidental disclosure is when a person finds out about being HIV positive by accident, e.g. by overhearing others talking, or seeing documents about their HIV status. Accidental disclosure can be very hurtful and confusing.



PLAIN VERSUS SILENT DISCLOSURE

Plain disclosure means the person disclosing HIV positive status does so in very simple terms – without any room for confusion.

Silent disclosure is when the person living with HIV becomes aware of their HIV status through hints and clues (e.g. through going to the clinic regularly or having to take medication). Silent disclosure can be confusing for a child and discourages open discussion.



*"There are other children within the household that are not taking medication and the child notices. It makes it difficult to explain to a child on why the difference."
Parent on why Silent Disclosure happens Matabeleland*

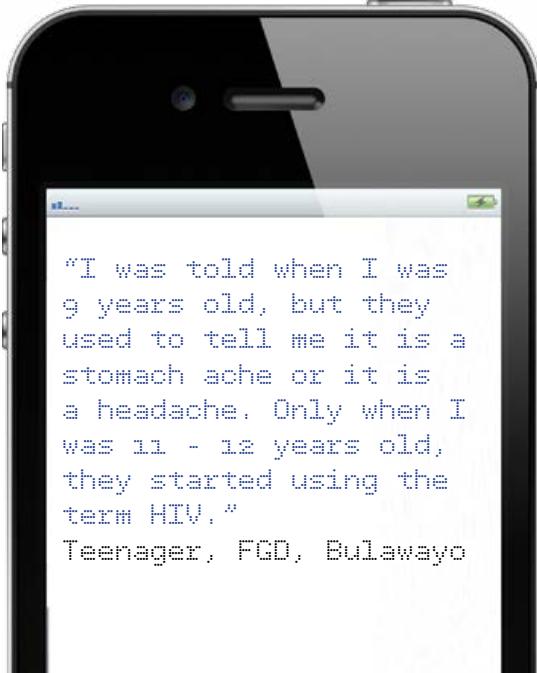
PARTIAL VERSUS FULL DISCLOSURE



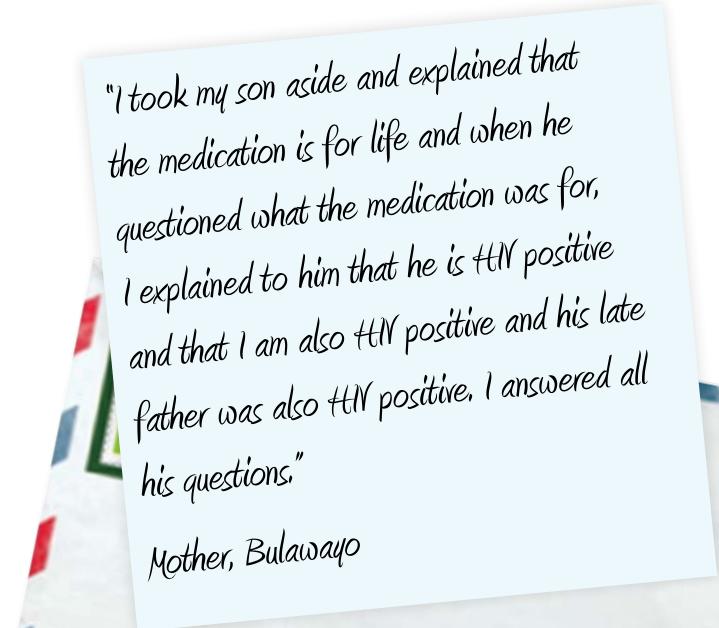
Partial disclosure is when only some information is given to a child, e.g. explaining that the child has to take medicine every day but not mentioning HIV. Partial disclosure is a useful stepping stone to full disclosure and is suitable for very young children.

Full disclosure is when a child or young person is told that she or he is HIV positive. Full disclosure must be followed up with full

information and emotional support to help them overcome any fear or confusion they may feel and to ensure they understand that they can live a healthy and normal life.

A black smartphone is shown vertically. The screen displays text in a monospaced font, which is a quote from a teenager. The text is as follows:

"I was told when I was 9 years old, but they used to tell me it is a stomach ache or it is a headache. Only when I was 11 - 12 years old, they started using the term HIV."
Teenager, FGD, Bulawayo

A light blue sticky note is placed over the bottom right of the smartphone. It contains a handwritten quote in black ink. The text is as follows:

"I took my son aside and explained that the medication is for life and when he questioned what the medication was for, I explained to him that he is HIV positive and that I am also HIV positive and his late father was also HIV positive. I answered all his questions."

Mother, Bulawayo

PREMATURE DISCLOSURE TIMELY AND VERSUS DELAYED DISCLOSURE

When Disclosure Can Happen

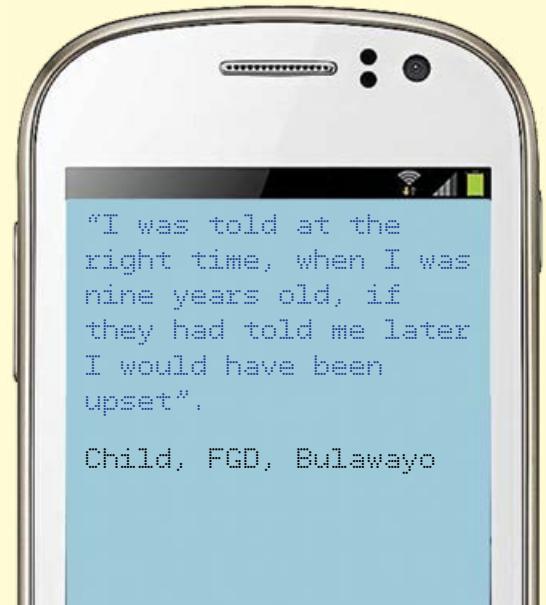
Premature disclosure is when a caregiver tells a child about their HIV status before the child is able to cope with the knowledge or understand it.

Timely disclosure means that a caregiver discloses a child's HIV positive status at the right time, when the child is emotionally well prepared and mature enough to deal with the new information – AND before he or she is sexually active or is considering a sexual relationship. Timely disclosure means that a young person has time to understand and deal with being HIV positive before they start to think about relationships or marriage.

Delayed disclosure is when a caregiver discloses to a child when it is too late (e.g. after the young person is already sexually active or is thinking about becoming sexually active. Dealing with emotions about being HIV positive at the same time as those associated with sexual maturity can be very confusing for a young person.

"I have disclosed to my child but he questioned 'where did I get it from? I do not understand what you are talking about...' We then agreed to talk to him when he is a bit older and explain on how he got the virus."

Mother on Timely Disclosure, Bulawayo



DISCLOSURE DONE RIGHT – IMPROVING DISCLOSURE BY CAREGIVERS TO CHILDREN



HOW:

- Bit by bit - Disclosure is best done as a process, beginning with partial disclosure at a young age, through to full disclosure before the age of 12-years old.
- In a safe space where you will not be interrupted - at home, or where you are both free to express yourselves and deal with any emotions (including anger and love).

WHEN:

- The child is in good health
- Between 8 and 12-years old (WHO Guidelines)
- As questions arise – do not avoid them (seek help when you need it)

"A child needs to know the truth about their HIV status but they can also be emotionally affected by knowing that they are HIV-positive, so they need some assurances that they are as normal as any other child and can do what all their uninfected peers can do. My son received the information well."

Mother, Zvishavane

"The way we, parents, conduct ourselves is what facilitates good disclosure and health. If my wife and I understand health and HIV issues, we always talk about these and involve our children in such discussions openly, with children feeling free to discuss any subject with their parents, all will be alright. That enables children to report cases of stigma and discrimination that happen outside the home (e.g., at school) which depress them. Parents can then provide psychosocial support to those children."

Father, Zvishavane, Midlands

AVOIDING ACCIDENTAL DISCLOSURE AT SCHOOL

Students are often involved in blood donation campaigns at school. Whilst contributing to blood donations is very important, this can be a risk for accidental disclosure for children living with HIV, as all blood donors are tested for HIV and other infections before giving blood. Early disclosure to a child avoids accidental disclosure at school!

"I called my son, sat him down and started to tell him the truth bit by bit. I said, 'Son, as you know, you have been taking this medication for a while - it is because you have HIV. You are just like all other children of your age and can do everything that they do and will be successful just like them, or better. But what you need to do is to take your tablets at all the times that you are required to, and do not skip your pill taking times. There are people who may say bad things about you, but do not care about them or worry about what they say, because there is nothing special about them, or anything bad about you."

Mother, Zvishavane



Young people usually feel more positive after they have been disclosed to, provided it is done right! Parents disclose to your child early, teachers, health care workers and community leaders work to stop stigma and discrimination that prevents healthy disclosure!

TOP TIPS!

It is important to talk to young people about:

- The difference between HIV and AIDS – by taking their medicines correctly they will remain healthy and will not develop AIDS.
- Why they have to take medicines even though they do not feel ill – ARVs help to build their strength and keep them healthy, preventing AIDS and other infections that would make them sick.
- The ways in which HIV can and cannot be passed on to someone else – and how to prevent it.
- What being HIV positive means for them, e.g. always taking their medicines exactly as the doctor says; not touching anyone else's blood; never sharing razor blades; always using condoms correctly and consistently if they are, or become, sexually active.
- How they became HIV positive (this may invite the need to inform the child about parents' HIV status and, if deceased, the cause of death as well).
- What kinds of support are available – including helping them to join a support group or access counselling or any in-school support available.
- How to deal with negative reactions, stigma and discrimination – understanding that stigma and discrimination are always wrong.



Be supportive, caring and loving to help your child accept and live positively with HIV. If you are not sure about how HIV is passed on, or what your child can and cannot do safely, speak to a healthcare worker and get the correct information before passing it on to the child. Passing on wrong information can be very harmful and can add to stigma and discrimination:

"I remember a child next door who was diagnosed HIV-positive; each time he would try to play with others the mother would say, 'you, come back home, don't you know that you are sick and may infect others.'" For that child to know what his sickness was and what the problem was in his playing with others, it was difficult. He was always in confusion and his health kept deteriorating. That child is late as we speak. What is ideal is to tell a child that as much as they have been diagnosed with HIV, their life does not end there. They need to be shown that they still have their potential to do great things if they abide by their treatment courses prescribed at the clinic."

Woman, talking about how to support a YFPB/HIV, Zvishavane

REFLECTION TIME! DISCLOSURE DONE RIGHT!

The picture below is of a young person being told she is HIV positive by their caregiver. The speech bubbles have been left blank for you to fill in. What do you think the caregiver should tell the young person? What would you like to be told? Discuss this and make notes in the caregiver's speech bubble as you go.

What questions would you like to be answered? Write these in the young person's speech bubble and discuss them too.



THE RIGHT AGE FOR DISCLOSURE – WHAT YOUNG PEOPLE SAID!

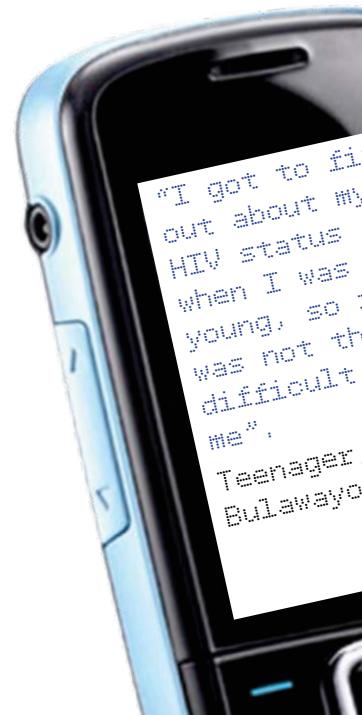


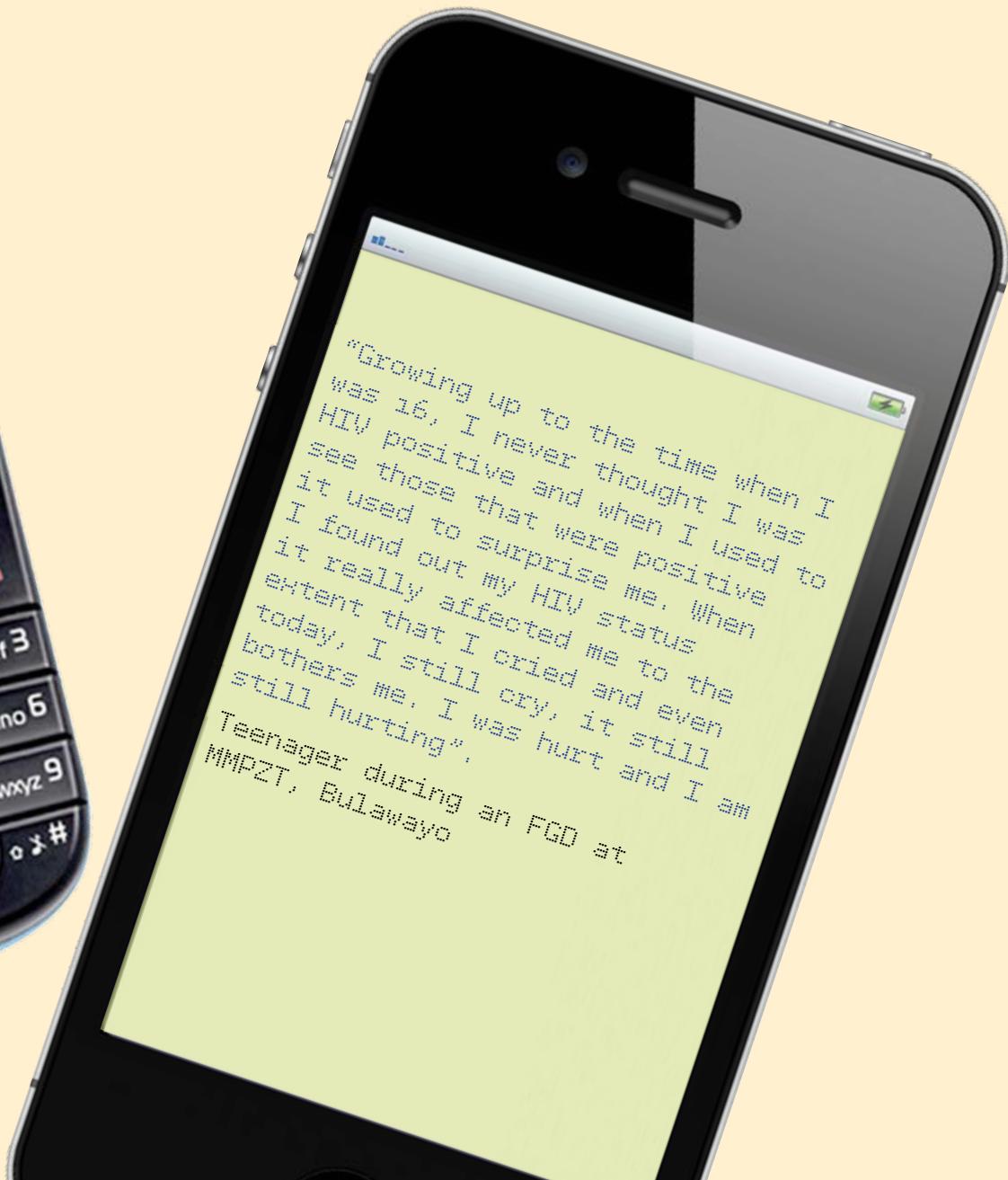
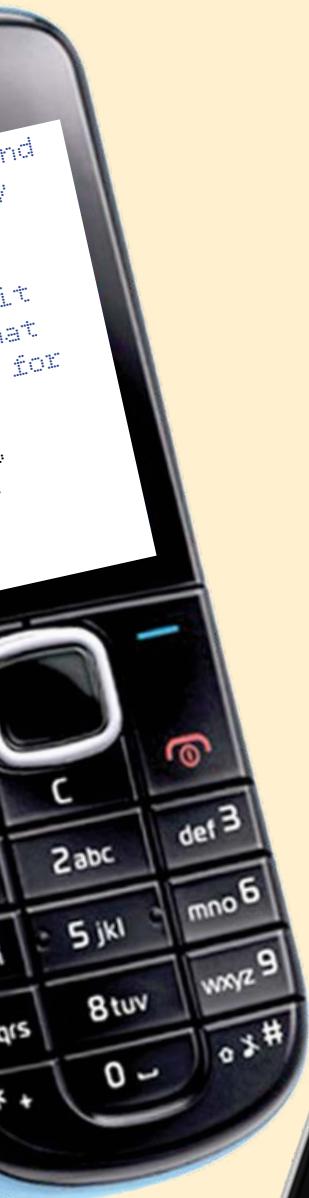
This page has feedback from young people. What do you think?

DISCUSSION TIME!

- Why do you think this person found learning about their HIV status easy?
- How old do you think young people should be when they find out about their HIV status? Why?
- Why was it hard for the other person to find out about their HIV status to start with?
- What helped this young person to deal with his/her emotions?
- What could others do to support this young person?
- How can we help deal with young people's anger at late disclosure?

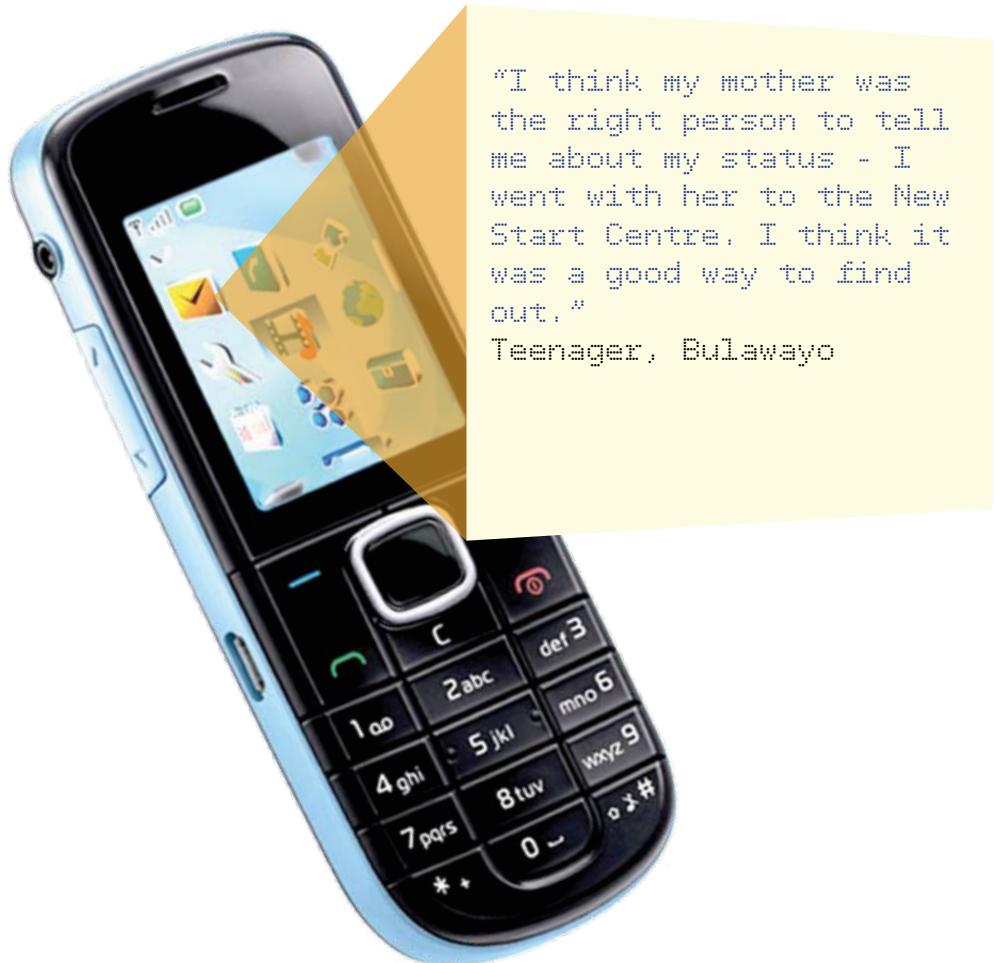
"I found out when I was 15 and felt different from the rest of the people and always felt like isolating myself. I was hurt knowing that I am positive. Now it is different though - I joined a support group with other young people living with HIV and now I feel free. Meeting with others made realise that we are not different. Interacting and seeing others made me free".
Teenager, Bulawayo





DISCUSSION TIME!

- Do you agree that finding out from one's parent and going for testing together is a good way to disclose?
- Why do you think of that?



DISCLOSURE DONE RIGHT – IMPROVING DISCLOSURE EXPERIENCES BY YOUNG PEOPLE TO OTHERS



Before disclosing to others,
think about the following:

WHO TO TELL

First, ask yourself:

- **Do I trust this person?** It is your right to keep information about your health private and this should be respected by the person or people you tell. Before telling anyone, make sure they understand that telling them about your HIV status is a very big decision for you and one that you have made because you trust them completely.
- **Who do I want to tell** and how will it help me if I tell them?
 - ✓ Family members, friends and school teachers may be useful to tell so they can support you in the ways you need (taking medicines, accepting sick-notes, giving you time to visit the clinic, or if bullying occurs).
 - ✓ Your supervisor at your workplace, as they can help to ensure that you are given time for clinic appointments. Your employer may also have a workplace wellness programme that can help you.

"I disclosed to my friend and
sometimes when we are with
friends and they start saying
discriminating statements, he
advises them that it is not right
to say that"
Teenager, Bulawayo

- ✓ **Who do I need to tell?** Doctors and other health care providers and service providers that you do not usually see (such as family planning services, when you move or when you are away from home).
- ✓ Particularly for younger children living with HIV, a school teacher or nurse may need to know so they can provide support at school.
- ✓ Any person with whom you are in a relationship that could develop into a sexual relationship, so that you can work together to prevent onward HIV infection. If a partner cannot accept your HIV positive status then they are not the right person for you!.

Be Careful! The decision to have sex is a serious one – do not rush into it. Trust is the MOST important issue and knowing your status and that of your partner is important too before sex. The risks of infecting an HIV negative partner are high if one has unprotected sex before disclosure.

WHEN TO TELL

- **How much do I want to tell?** Do you want to talk about the struggles you have had? How you became HIV positive? Or do you just want to say that you are HIV positive but taking ARVs and are healthy and strong? Remember – the person you tell may have questions too. Having accurate information will help you answer questions that the person you tell may have – to help them get over their concerns.



HOW TO TELL

- **How can I protect myself when disclosing?** Protecting your self is very important.
 - ✓ Test the person - start a general conversation about HIV and see what they say. You can use a leaflet or other materials about HIV to get started
 - ✓ If they react negatively, ask why? Some more information might be needed before you can disclose safely!
 - ✓ If they seem supportive and caring, push the topic to a more personal level – what would you do if your sister/brother etc. were positive? Take it one small step at a time.
 - ✓ Bring along someone else who knows (a caregiver or health worker) to help.
 - ✓ Think about where you will tell them – somewhere private, where you will not be disturbed is a good idea.
- **Am I ready for negative reactions?** Not everyone will be nice when you tell them your positive status. You must be ready if someone reacts badly. Even if you have 'tested' them you need to be sure that you can stay confident and happy in yourself, whatever others may say. This is where a support group really helps!

"There is need to properly evaluate before disclosing to a friend because they may tell others".

Teenager, Bulawayo

WHEN IT ALL GOES WRONG

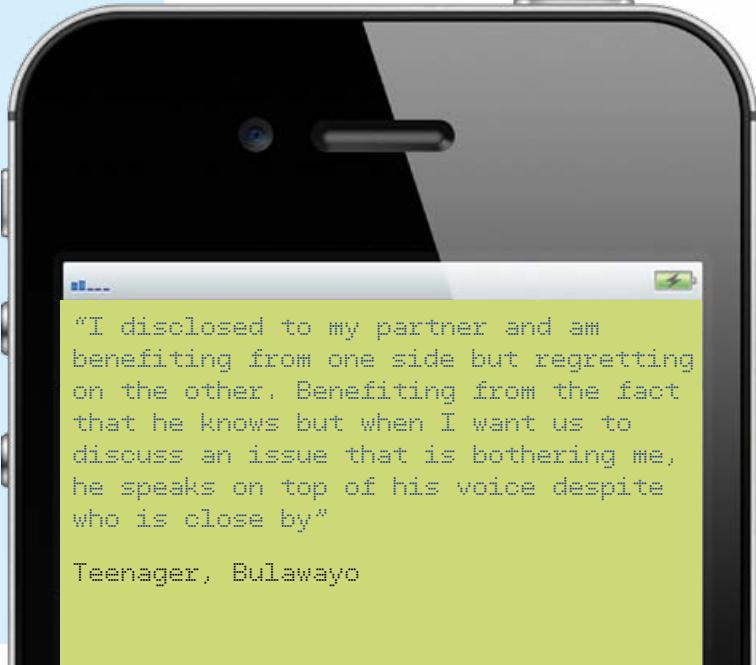


If you disclose to someone who does not react well or tells others, or if people start to treat you differently or badly, try the following:

- Speak to them – make sure they understand how much they are hurting you.
- Speak to an adult you trust for advice.
- See a counsellor and talk about your feelings.
- Stay positive – you are not in the wrong, they are – a good friend or loving partner would not disrespect you in this way.
- Join a support group for other YPBLHIV and speak to other YPBLHIV – you will feel a lot better after talking to others in your situation – you are not alone!

"Telling my friends was the worst thing - they started to sideline me in everything. We used to bath together but when I told them about my status this never happened. I started to play alone... this affected my schoolwork as I no longer had a study mate. I couldn't participate in class anymore because I had lost my self-esteem. I could not raise my suggestions in class or at home as I thought that I was not worth speaking. In my family I was given my own plate, spoon and cup. I also became the topic in my community, as people started gossiping about my status."

Teenager, Zvishavane



"I disclosed to my partner and am benefiting from one side but regretting on the other. Benefiting from the fact that he knows but when I want us to discuss an issue that is bothering me, he speaks on top of his voice despite who is close by"

Teenager, Bulawayo

ACTIVITY TIME! SHOULD I OR SHOULDN'T I?

Below are some different people you may consider disclosing to at some point – think about why it would be helpful to you and what the risks might be for each. Write them down under benefits and risks. Discuss what you could do to reduce the risks as you go along.

WHO?	BENEFITS?	RISKS?
Aunt / Uncle / other family member		
Best friend		
Teacher		
Boyfriend / Girlfriend		
New doctor		
Employer		

BENEFITS OF DISCLOSURE

FEELING BETTER ABOUT ME!

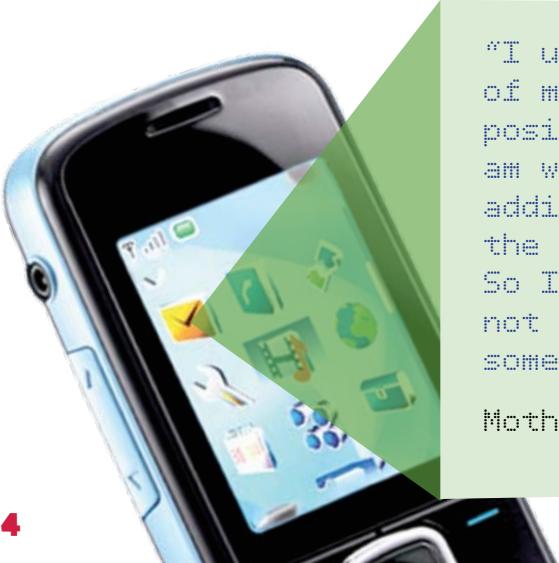


Timely disclosure from a primary caregiver to a young person can improve relationships, communication and trust.

Open and honest communication encourages love, care and confidence – making all the challenges of being positive easier to deal with.

Young people who know their HIV status are better able to tell those who need to know – teachers, carers and relationship partners. This builds a stronger circle of care.

Young people who know their HIV status also enjoy increased access to support services in their communities, including joining support groups and accessing professional counselling services, which keeps them healthier and happier.



"I used to fear what other people would say of me if they discovered that I was HIV positive. But now I have learned that I am what I am and you are what you are. In addition, the HIV virus is not visible to the eyes, but it is hidden in the blood. So I am not different from someone who is not HIV-infected and can live longer than someone HIV-negative."

Mother, Zvishavane

STOPPING STIGMA!

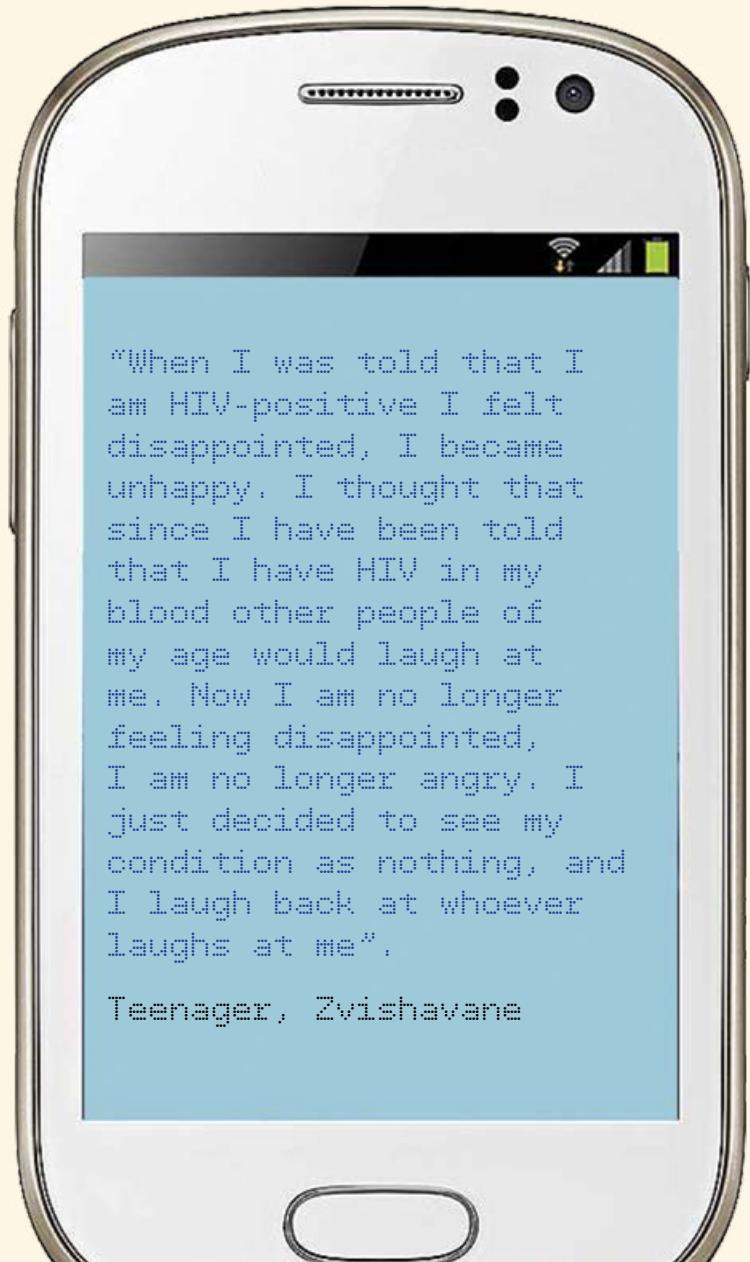


Young people who know their HIV status from an early

age have had more time to process the news, accept their status and understand that they are normal young people, despite being HIV positive.

They are also much better prepared and equipped to live positively with HIV, including dealing with the challenges of relationships, future marriage and starting a family.

The more people who are aware of their own HIV status and who are open about it, the less stigma and discrimination there will be!



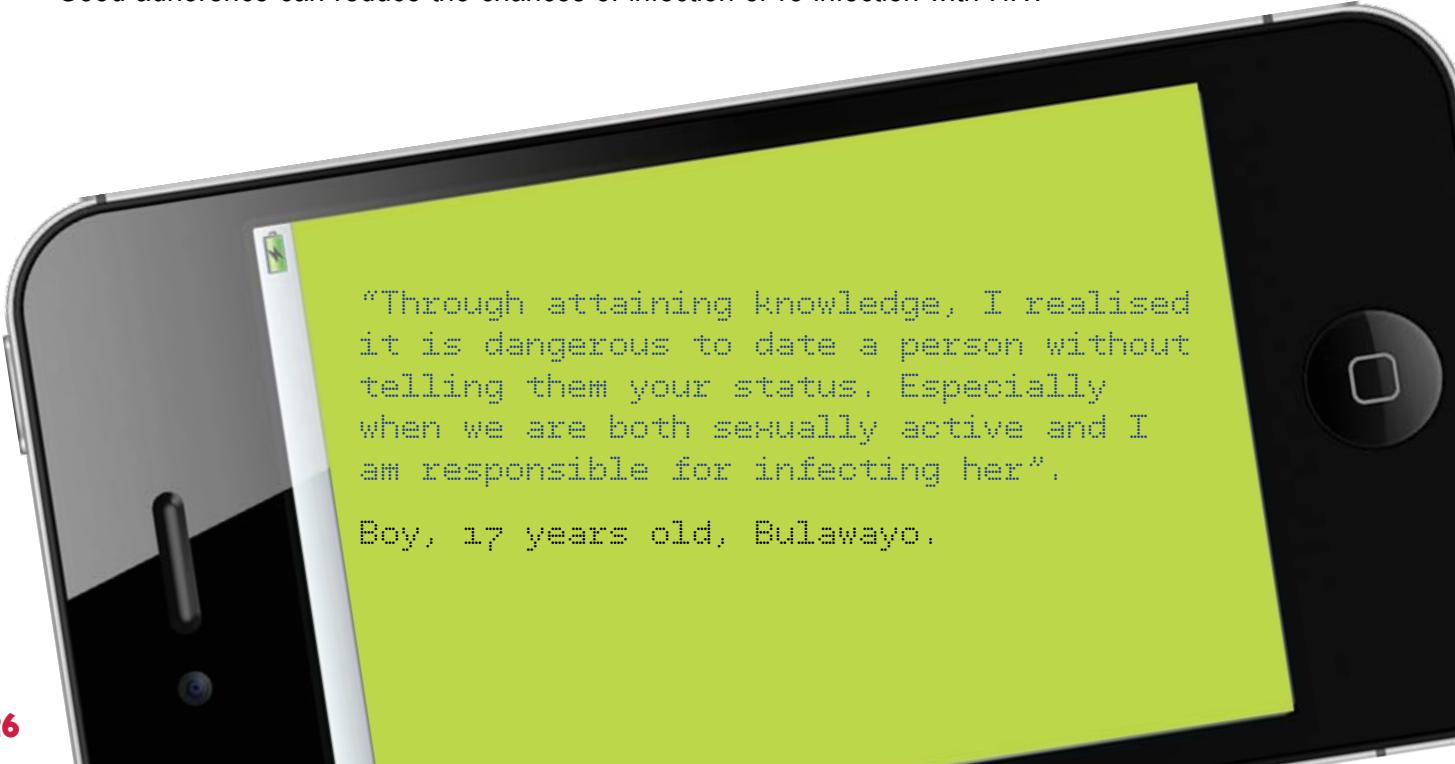
STAYING SAFE!



Young people who know about their HIV status early know more about how HIV is passed on to another person, how condoms can be used to prevent sexual transmission of HIV, emergency treatment for accidental exposure (PEP), as well as prevention of mother-to-child transmission (PMTCT) services, when planning for a family of their own.

Relationship partners who know each other's positive HIV status are more likely to use condoms for sex than those without this knowledge.

Young people who know their HIV status adhere better to treatment than those who do not know. Good adherence can reduce the chances of infection or re-infection with HIV.



"Through attaining knowledge, I realised it is dangerous to date a person without telling them your status. Especially when we are both sexually active and I am responsible for infecting her".

Boy, 17 years old, Bulawayo.

REFLECTION TIME! BENEFITS OF DISCLOSURE

In the space below, list the benefits that you can think of – or that you may have experienced – that are the result of being told about your HIV status.

What about challenges – can you think of any that may happen – or that may have happened to you - after being disclosed to?

Discuss with your family, support group or others you trust and make notes below - try to find solutions to any challenges you identify

BENEFITS OF DISCLOSURE:

CHALLENGES OF DISCLOSURE:

MY SOLUTIONS:

LIVE, SPEAK, ENJOY

DISCLOSURE, MY RIGHTS AND MY RESPONSIBILITIES

<i>I HAVE A RIGHT TO...</i>		<i>I HAVE A RESPONSIBILITY TO...</i>
The Right to Life	Know my HIV status and access health services	Take up medication (ARVs) and adhere to my treatment exactly as instructed by my doctor
The Right to Be Treated Equally	Be treated equally and with respect	Treat all others with respect and avoid self stigmatising myself and isolating myself from others
The Right to Information	Access health information	Seek information relevant to my health needs and make informed choices and decisions that protect me from re-infections and keep me healthier
The Right to Choose a Partner	Choose my relationship partner and enjoy a safe, satisfying and loving relationship	Treat my relationship partner with love and respect as I would expect him or her to treat me
The Right to Plan a Family	Plan whether to have children or not – as well as when, with who and how many	Seek factual and comprehensive information and services on family planning, viral load, CD4 count and PMTCT services before pregnancy to protect the baby from HIV infection
The Right to Health	Access quality health care information and services	Live positively with HIV, protect the health of others and prevent onward HIV infection
The Right to Confidentiality and Dignity	Choose if to, when and to whom to disclose my HIV status to	Respect the confidentiality of others and treat everyone around me with dignity

THE MYTHS AND THE TRUTHS OF DISCLOSURE

MYTH	TRUTH
<i>“Children are better able to cope with knowing their HIV status when they are older”</i>	Younger children deal very well with bad news and it gives them more time to build their confidence.
<i>“Young people living with HIV must be promiscuous”</i>	Most young people living with HIV became infected at birth or due to sexual abuse.
<i>“Telling a young person they are HIV positive will cause more harm than good – they will be excluded”</i>	They will find out anyway. Telling them early helps to prepare them better.
<i>“People living with HIV cannot have a relationship or family”</i>	Treatment can act as prevention and ensure a long and healthy life; PMTCT means healthy children.
MYTH	TRUTH
<i>“Talking to young people about issues around HIV and sexuality encourages them to engage in sex”</i>	Children who can discuss issues around sexuality are more likely to delay sexual activity and to engage in safer sexual practices when they do so
<i>“Information about HIV and disclosure is all young people need to make sure they avoid risky behaviours”</i>	Knowledge of HIV alone does not necessarily lead to behaviour change, including not taking risks. Provision of factual information, counselling and feeling supported keeps them safe and helps them reduce risk taking.



DISCLOSURE AND CONFIDENTIALITY

- Your right to confidentiality or privacy, means that you have the right to choose: whether to disclose; to whom to disclose; and when and how you do it.
- People whom you disclose to have a responsibility to respect your privacy and not share your information with others.
- Your doctor or healthcare worker has to know about your HIV status in order to help and treat you, but it is against the law for him or her to pass on any information about your health to others without your permission.
- If you or your caregiver choose to disclose to a trusted teacher, the teacher has a responsibility to keep your information private. They must seek your approval (if 16-years or older) or that of your caregiver (if you are below 16-years) before they share – know to whom, why and how you will benefit, before you agree.

DISCLOSURE AND SEXUALITY

- This is a confusing and emotional time for everyone, more so if you are young and inexperienced. Both disclosure and sex require maturity, factual information about how to protect yourself and your relationship partner, understanding the consequences of having sex with someone and being willing to accept responsibility for one's actions.
- Not being confident about disclosing to a relationship partner is a good sign that you are not yet ready for sex. Not telling a partner in good time can lead to hurtful rejection and distress. If you don't trust them enough to tell them your HIV status, then you are not ready to have sex with them!

- Love protects; it is more than sex. Relationship partners can show that they love and care about each other in many ways that do not include sex. Respect for each other, loyalty, honesty, trust and caring for each other are important signs of a healthy relationship. Having sex is not necessarily a sign of love and commitment. Disclosure shows you care.
- Support, counselling and accurate information about HIV reinfection and prevention, safer sex methods and PMTCT is very important for your good health and the health of others.

<i>IT IS IMPORTANT TO DISCLOSE TO...</i>	<i>WHY?</i>
A child or young person living with HIV, if they do not already know	So that they know that they are living with HIV before they enter the sometimes confusing period of puberty and adolescence and think of engaging in sexual activity. They need to know how to prevent onward HIV infection.
Your partner if you are in a relationship	So that you can support and help each other to stay healthy and live positively, whether or not your relationship involves sex. If you do decide – together – to engage in sex, it is very important to disclose first so that you can protect against onward HIV infection. Everyone should go for HIV testing to know their HIV status before having sex. Some people find it easier to suggest couples' joint testing as a way to disclose to a partner in a safe space.
A health worker, family planning clinic, PMTCT service provider or counsellor	To get factual information on HIV; receive medical and emotional support and help with responsible decision making; and improve health. If you are in a relationship, visit a health worker with your partner to discuss your options together.

SUPPORTING BETTER DISCLOSURE

MY CIRCLES OF SUPPORT



Caregivers' support

A primary caregiver (parent or guardian) is a very important source of support. Young people say they are the best person to disclose to them that they are HIV positive. An open and honest relationship with a primary caregiver is an important success factor in helping young people live happily and healthily.



You are also the main source of moral and emotional guidance. Help them to form healthy values and make responsible and mature decisions.

School teachers' support

Schools tend to have high levels of stigma and discrimination, which can make dealing with disclosure very difficult for YPBLHIV. Not all school teachers and staff are supportive and caring of YPBLHIV and some even discriminate themselves – which is very wrong.

School teachers and staff have a responsibility to reduce stigma and discrimination in schools.

If you are being discriminated against in school and your teacher can't help, speak to another adult you trust and ask them to help; they may need to speak to the school head.

When disclosed to school teachers and nurses, can provide an important source of support at school, when caregivers are not available.

Do the right thing!

Pastors' support

For people who attend church, their pastor, imam, church leader or Sunday school leader can provide important religious guidance for young HIV positive people. Issues around HIV are associated with many taboos and, sometimes, a person's morality is questioned. This is harmful as it increases stigma and discrimination around HIV and makes it difficult for people living with HIV to access the services they need to stay healthy and prevent onward transmission of HIV.

A church leader's role is to speak out against stigma and discrimination, encouraging love, respect and support for all and correcting myths around HIV and morality.

Peer support

As young people grow, their relationships with, and the acceptance of, their friends becomes more important.

Many young people living with HIV are afraid of being excluded if their friends know about their HIV status. This often leads to risk taking, such as not taking their pills for fear of being seen or engaging in sexual activities that will negatively affect their future.

Good friends are supportive, kind and encourage their friends to make healthy and responsible decisions. Remember, those who stigmatise PLHIV are the ones in the wrong — not you.

Fear of stigma and discrimination by other young people create fear of telling their others that they are living with HIV. It is important to have positive friends who can help you through the hard times.

Healthcare worker support

Healthcare workers and community volunteers play an important role in providing accurate information and access to health services for young people living with HIV.

Healthcare workers can provide effective support by being available and welcoming to young people – encouraging them to be open and share any concerns they may have and ensuring that they are youth-friendly.

Healthcare workers should involve other young people in their work - young people are more comfortable talking to other young people, as they feel less judged!

It is against the law for a healthcare worker to share anyone's medical information without permission. A young person can seek help from a local authority if this has happened.

As a health care worker or volunteer you must be trustworthy and give young people confidence that what they say will not be shared. Walk in their shoes!



ACTIVITY TIME! MY CIRCLE OF SUPPORT

Fill in your circle of support below – who provides support to you? What kind of support?



DISCUSSION TIME:

Is there any kind of support that you need, or may need, but are not currently receiving? Who might be able to provide that support? How can you make sure you get that support?



FACING UP TO DISCLOSURE FOR YOUNG PEOPLE BORN AND LIVING WITH HIV!

- **Talk it through:** As a young person, speak to your caregiver, healthcare worker or anyone else in your circle of support and explain how you feel. Just talking about it will help you start to feel better.
- **Get help:** Many young people find it helpful to speak to a professional counsellor about their feelings and dealing with HIV disclosure.
 - ✓ A professional counsellor is specially trained to help people deal with and come to term with difficulties, stress and depression. Seeking professional help is nothing to be ashamed of – it shows maturity and responsibility.
- **Know you are not alone:** Feeling alone and wondering ‘Why Me?’ is often a major cause of upset for young people when they find out about their HIV status. Joining a support group is a great way to meet other people in the same situation, with whom you can talk about the challenges you are facing, helping you feel less alone.
 - ✓ Join a support group – or start one in your community if there isn’t one already. Joining a support group does not mean that you stop talking to those in your circle of support about your problems – it is an additional support - not a replacement for their support.

- **Get creative:** Some people find it easier to express and deal with their emotions and feelings by writing them down or drawing them – why not try it out!
 - ✓ Try discussing the story or picture together afterwards with your friend or caregiver.

- **Be informed:** Having detailed information about HIV will help you to understand what it means and how to manage it.
 - ✓ Try to gather different information for the whole family to read – encourage them by having leaflets, brochures, books, etc. on hand. There are also a lot of radio and TV shows for YPBLHIV, and the internet has a lot of information there is also a lot of Information on the Internet.

- **Forgiveness:** If you were born with HIV, you may feel resentment or anger towards your parents. Letting go of this anger will help you to find peace and acceptance. Speak to a counsellor if you need help. Understand that anger is often a natural part of the acceptance process.

- **Accept and love yourself:** You are still the same person you were before learning that you were living with HIV. HIV does not define you. Focus on all of your positive qualities and feel happy to be you! Be proud of all your achievements. Recognise and be grateful for all your strong points.
 - ✓ If you are struggling to accept the news – it may be helpful to talk to someone else who has been through a similar situation.
 - ✓ If you know of someone else who is struggling, reach out to them – supporting each other will help you both feel better and will you will also feel good about doing something kind for someone else!



FACING UP TO DISCLOSURE FOR PARENTS AND CAREGIVERS!

- **Talk it through:** Encourage the young person to explain how they feel. Just talking about it will help them start to feel better.
 - ✓ Speak to a healthcare worker, counsellor or other parents of YPBLHIV for advice on how to help your child deal with their emotions. Whatever happens, remain calm and do not get angry.
- **Get help:** Many young people find it helpful to speak to a professional counsellor about their feelings and dealing with HIV disclosure. It is also helpful for caregivers and young people to visit a counsellor or healthcare worker together to talk through their difficulties. Seeking professional help is nothing to be ashamed of – it shows responsibility.
- **Know you are not alone:** Joining a support group is a great way to meet other people in the same situation with whom you can talk about the challenges you are facing, helping you feel less alone.
 - ✓ As a caregiver, encourage the young person to identify and join a support group – or to start one in your community if there isn't one already. Joining a support group does not mean that they will talk to you any less about their problems – it is an additional support - not one to replace your support.

- **Get creative:** Some people find it easier to express and deal with their emotions and feelings by writing them down or drawing them. As a caregiver, encourage the young person to express their feelings in whatever way they feel comfortable. If they feel better writing them or drawing them, try discussing the story or picture together afterwards
- **Be informed:** Having detailed information about HIV will help you to understand what it means and how to manage it.
 - ✓ As a caregiver, try to gather different information for the young person and the rest of the family to read – encourage them by having leaflets, brochures, books, etc. on hand. There are also a lot of radio and TV shows for YPBLHIV, and there is a lot of Information on the Internet. Make sure the young person knows that they can always come to you with any questions they may have
- **Forgiveness:** A young person born with HIV may feel resentment or anger towards his or her parents. Letting go of this anger will help them find peace and acceptance. Speak to a counsellor if you need help.
 - ✓ As a caregiver, understand that anger is often a natural part of the acceptance process. Do not get angry yourself. Listen, be supportive and caring – it will pass.

- **Accept and love yourself:** Assure the young people that they are still the same person they were before learning that they were HIV positive. HIV does not define a person. Focus on all of their positive qualities. Show them how proud you are of all their achievements. Your actions and compliments will help the young person to recognise and be proud of all their strong points.
- ✓ People who are struggling with disclosure – either caregivers finding it difficult to tell their children, or young people struggling to accept the news – may find it helpful to talk to someone else who has been through a similar situation. If you know of someone who is struggling, reach out to them – supporting each other will help you both feel better and will also make you feel good about doing something kind for someone else!

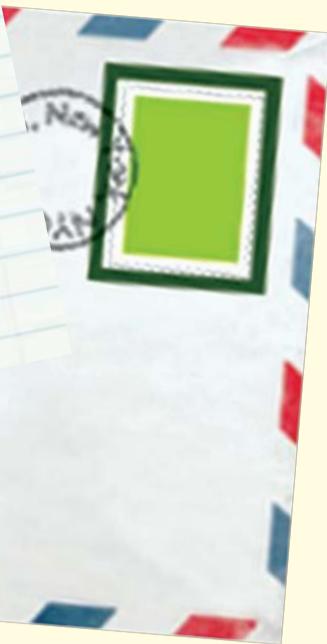
"Young people may be angry when they first find out, especially if they find out late. They might

ask: "Why am I the only one in this situation?"

"Why did you not abort the pregnancy to save me from this stress?" "Why did you not tell me all

along?" "Why did you expose yourself to HIV in the first place?"

Mother of a GPBLHIV, Indaba Ward, Yugwi,
Zrishavane, Midlands



STORIES OF HOPE

LADY SWAGGA SINGS TO HER FUTURE

“I was born with HIV and I knew my status when I was in Form 1 in the year 2007. I started participating in the youth programme six years later. The programme has helped me so much. I wish I had got involved sooner.

You see, knowing that I am an HIV positive young person was a bad thing to me - I had never wanted to participate in any HIV programmes. I was so arrogant whenever I heard anyone talking about anything to do with HIV and I was not serious about taking my medication. There are many HIV positive young people out there who are the same and I want to encourage them not to be negative about being positive.

After I joined the Bethany Programme, quite a number of things changed in my life. My self-esteem and confidence are now high, no matter what people say. I can now stand the stigma and discrimination I used to face in my community - people would call me ‘Fadzai Chimufiria-Fadzai inferior thing’. Now, I know that I can do what other young people can do. I even managed to compose and record my song called, “Ndoitazvandoda, kuraramazvandoda” (I’m living my extraordinary life) under my stage name, Lady Swagga.

The support group has helped me so much because I meet with other young people who are HIV positive.

I see a green light in my life - I have even become a celebrity in my community. I sang my song at the Day of the African Child Commemoration and I managed to wow the whole crowd.

Being HIV positive is not the end of life. Your status doesn't matter. It doesn't matter where you are coming from. What matters most is about where you are going with your life as a young person living with HIV. I may not be where I want to be right now, but what makes me happy and strong is that I am no longer where I used to be. That alone gives me the courage to move on with life, knowing that one day I will get there”.

Discussion Time!

- Why do you think it was difficult for Fadzi to accept her HIV positive status at first?
- What helped her to accept her status and live positively?
- Does Fadzi's story give you hope? In what way?

GOGO LOOKS TO THE FUTURE

“I was able to disclose to my grandson. I told him plainly that he was infected with HIV. I said to him, “Do not be embarrassed about your status, and make sure to tell your teacher about it.” He accepted it. I encourage adults to disclose their children’s HIV status because my grandson accepted the reality when I told him. If you see him you will understand what I mean. Right now he is enjoying the holidays with his mother (before returning when schools open).

The teacher told me that he informed her of his status, saying “Ma’am, I am HIV-positive and sometimes when I miss school please bear with me because I will have gone to the clinic to collect my drugs”. The teacher said “It’s okay”. She accepted this situation and she no longer engages him in strenuous tasks and treats him like her own son, understanding that her child is like this and that.

He used to live with his mother, but she was too afraid to disclose. The boy was always in the blankets, sick, because she was not adhering to his treatment routines and had not disclosed the child’s HIV status. She would skip dates when she was supposed to collect his medication so I felt I had to take my grandson and care for him.

When I started living with my grandson, I discovered that it was important to adhere to what is expected - the do's and don'ts of caring for children living with HIV. A caregiver should know the times when the child should eat, what types of food he should eat and about his medications. He should not be verbally abused. Verbally abusing a child living with HIV worsens his situation - they are delicate people. Do not harass him or rebuke him in public, in front of his friends. An HIV-positive child is just like any other child who is born; HIV is an imposition on a person and no one chooses to be infected with it.

Discussion Time!

- How did this boy's grandmother help him?
- Was it a good thing that his grandmother told him about his HIV status and encouraged him to disclose to his teacher?
- Does this story give you hope? In what way?

DISCLOSURE QUIZ!

Give back! Help us improve this booklet. Complete the quick quiz below. Then tear off and share to the following addresses:

Oxfam Contact Details: Arundel Office Park Block 9, Norfolk Road, Mt Pleasant, Harare or

Oxfam 60 Duncan Rd, Suburbs, Bulawayo. Zimbabwe.

Visit our page www.facebook.com/OxfamZim or email to info@oxfam.ca

TO ANSWER TICK EITHER TRUE OR FALSE

TRUE? FALSE?

Knowledge Section

Disclosing to a young person is better when they are at least 14 years old

I will not be able to have a relationship or children because I am living with HIV

Accepting my status is an important first step to a happy and healthy future

Disclosure only happens once and you do not have to do it again

It is important to disclose to a new doctor

Joining a support group helps a lot of YPBLHIV

Stigma and discrimination are some of the biggest barriers to disclosure

If someone treats me differently because I am HIV positive, it must be my fault.

Teachers have a responsibility to protect young people from stigma and discrimination at school

Everyone has a right to health services and information

TO ANSWER TICK EITHER TRUE OR FALSE

TRUE? FALSE?

Reflection Section

I learned something new from this booklet

This booklet helped me understand the disclosure process better

I feel better able to support YPBLHIV now

This booklet has helped me think about disclosure

This booklet has helped me talk about disclosure

This booklet has helped me act on a disclosure issue

My caregiver and I talk more about HIV now that we have worked through this booklet together

I would recommend this booklet to other YPBLHIV and their caregivers

I have shared this booklet with someone else.

Thank you!

WHERE CAN I GO FOR MORE SUPPORT?

NAME	HOW CAN THEY HELP ME?	CONTACT DETAILS	
Bethany Project	Disclosure, psychosocial, counselling and treatment adherence and prevention support for children up to 16 years and caregivers.	1588 Zvishavane Township. Zvishavane. Zimbabwe. Phone: +263 (0) 712 755 990 / 773 409 121 Email: bethanyproject@gmail.com Website: www.thebethanyproject.org	
Childline	Free telephone and post service for young people needing advice, support and help, including issues of abuse.	Free phone helpline: 116 Free Post Service: Childline Freepost, Box CY 1400 Causeway, Harare. Zimbabwe. Website: www.childline.org.zw	
MMPZT	Disclosure, psychosocial, counselling, treatment adherence and prevention support for young people aged 14–24 years and caregivers.	Mpilo Opportunistic Clinic (Former Mpilo Infectious Diseases Hospital) 2nd turn off to your right along Old Vic Falls Road - adjacent to the main Mpilo Hospital, Bulawayo. Zimbabwe. Phone: +263 (0) 772 803 477 Email: tchirimambowa@mmpztrust.org Website: www.mmpztrust.org	
Oxfam	Information and referral to other service providers.	Arundel Office Park Block 9, Norfolk Road, Mt Pleasant, Harare. Zimbabwe. Phone: +263 4 369 603, 369 564, 369 873 Facebook: www.facebook.com/OxfamZim Email: info@oxfam.ca Website: www.oxfam.org.uk/Zimbabwe	Bulawayo Office: 60 Duncan Road Suburbs, Bulawayo Phone: +263 09 230 377
SAfAIDS	Information and referral to other service providers.	17 Beveridge Road, Avondale, Harare. Zimbabwe. Phone: +263 04 336 193 / 4 Email: info@safadays.net Website: www.safadays.net	
SAYWHAT	Disclosure, psychosocial, counselling, treatment adherence and prevention support for students and youth.	Hillside Teachers College. P/Bag 2, Hillside, Bulawayo. Phone: +263 (0) 772 880 418 Website: www.saywhat.org.zw	
ZNNP+	A network of support groups for PLHIV – referral to support groups for YPBLHIV.	28 Divine Road, Milton Park, Harare. Phone: +263 04 741 824 Email: Website:	
Zvishavane District Hospital	Access to treatment and adherence services.	Zvishavane District Hospital Sub Office Zvishavane District Hospital Gweru Road, Zvishavane. Zimbabwe. Phone: +263 (0) 772 426 859, 712 565 251	



OXFAM

I commit to disclosing in the right way at the right time and to care for, support and encourage UPBLHIV in any way I can.

Signed:



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