A young person’s guide to their RIGHTS, SEXUALITY AND LIVING WITH HIV

HEALTHY, HAPPY AND HOT
Sexual and reproductive rights are recognized around the world as human rights. Every person living with HIV is entitled to these rights and they are necessary for the development and well-being of all people and the societies in which they live.
This guide is here to support your sexual pleasure and health, and to help you develop strong intimate relationships. It explores how your human rights and sexual well-being are related and suggests strategies to help you make decisions about dating, relationships, sex and parenthood. It explores the rights of young people living with HIV to:

- express and enjoy their sexuality (page 3)
- decide if, when, and how to disclose their HIV status (page 5)
- experience sexual pleasure (page 7)
- take care of their sexual health (page 9)
- practise safer sex (page 11)
- choose if, when, how many, and with whom to have children (page 13)
- access support and services that respect their dignity, autonomy, privacy and well-being (page 15)

Young people living with HIV may feel that sex is just not an option, but don’t worry — many young people living with HIV live healthy, fun, happy and sexually fulfilling lives. You can too, if you want to! Things get easier (and sex can get even better) as you become more comfortable with your status.
Remember
Sexual and reproductive rights are recognized around the world as human rights. Sexual rights relate to a person’s sexuality, sexual orientation, gender identity and sexual health. Reproductive rights relate to a person’s fertility, reproduction and reproductive health. There is some overlap between the two concepts. Every person living with HIV is entitled to these rights and they are necessary for the development and well-being of all people and the societies in which they live.

This guide is for:

- young people who are living with HIV or who have a partner who is living with HIV
- young people who have recently been diagnosed with HIV as well as those have been living with HIV for a while or since birth
- young people living with HIV who are married, in a relationship with one or more partners, as well as those who are single, dating, or just want to have sex
- young people living with HIV who are just starting to think about dating and sex as well as those who have more experience
- all young people living with HIV: men, women, transgender people and those who are figuring out their gender identity
- young people living with HIV who are interested in dating and having sex with people of the same sex or opposite sex, as well as those who are exploring and questioning their sexual orientation

No matter who you are, this guide is for... YOU!
Sharing your HIV status is called disclosure. Your decision about whether to disclose may change with different people and situations. You have the right to decide if, when, and how to disclose your HIV status.

You know best if and when it is safe for you to disclose your status.

There are many reasons that people do not share their HIV status. They may not want people to know they are living with HIV because of stigma and discrimination within their community. They may worry that people will find out something else they have kept secret, like they are using injecting drugs, having sex outside of a marriage or having sex with people of the same gender. People in long-term relationships who find out they are living with HIV sometimes fear that their partner will react violently or end the relationship.

Safer sex is a shared responsibility. When you share your HIV status, you and your partner(s) can work together to make your sex life pleasurable and safe! Many young people who are living with HIV or have a partner who is living with HIV find that they get the most sexual pleasure when they know that they are having sex as safely as possible.
Some people find out they are living with HIV while they are in a long-term relationship or marriage. Many people find that their partners are supportive. It can be hard to talk with your partner about your status. It may mean having to talk about a secret that you or your partner have been keeping from the other — like one of you had sex with someone else or uses injecting drugs. You may fear a violent reaction, losing the relationship, or maybe even losing your home, access to money, or your children.

There are many places that can help you figure out how to tell your partner and understand your rights to property and children if the relationship ends — for example, your local people living with HIV group, counsellor, women’s groups, and legal clinics.
Tips for telling sexual partners your HIV status:

- Practise disclosing to people you trust, this could include family members or friends. Remember though that people will not all react in the same way.
- Speak to other young people living with HIV, or members of your support group, to learn from their experiences on different ways to disclose.
- Consider things like the best time to tell the person. When dating, some people tell their partner when they first meet while others wait till later. Do whatever makes you the most comfortable. If you are in a long-term relationship, try to find a time when your partner is calm and has time for a long conversation.
- Test how your partner(s) may react to your HIV status by asking them questions like ‘what do you think about HIV?’ and ‘have you met anyone with HIV?’, or talking about a news story. This will help you get a sense of what they think about HIV and how they might react.
- Think of disclosing in a location that you feel comfortable and safe in — a private place like in your house, a friends house or in a public place where other people are around.
- If you think your partner(s) may get violent or angry, try to tell your partner in a safe environment and have a plan in place for your safety. The counsellor at your local clinic may be able to help you figure out how to do this, and can also provide advice on how best to disclose.
- Be ready for a conversation about HIV after you disclose. Your partner(s) may have questions about living with HIV, such as the risk of transmission, and safer sex. They may also have questions about your relationship. A counsellor can also help with this.
- More often than not, disclosing is a process rather than a one-time event. Expect several conversations. Your partner(s) may need time to deal with their emotions. They may have new questions about HIV.
- Plan to go out with people you trust after you disclose. You can celebrate a positive outcome, discuss strategies for supporting a hesitant but willing partner, or get support for dealing with a negative reaction.
Some countries have laws that violate the right of young people living with HIV to decide whether to disclose. Young people living with HIV can take steps to protect themselves.

Strategies to protect yourself:

- Find out the specific laws in your country, visit www.gnpplus.net/criminalisation/ and read Verdict on a Virus (IPPF, GNP+, ICW) www.ippf.org/en/Resources/Guides-toolkits/Verdict+on+a+virus.htm or speak to your service providers or local support group.

- Open communication and trust are important for healthy relationships. At the same time, it is also wise to take steps to protect yourself from criminalization. The best way to protect yourself is to share your status with your partner(s) before becoming intimate (including kissing, oral sex or full penetrative vaginal and anal sex). New laws criminalising the transmission and exposure of HIV to others are based on whether the person living with HIV has disclosed their HIV-positive status to their partner(s) or kept it hidden. If you have disclosed to your partner, it could be a good idea to keep ‘proof’ that you have told your partner about your HIV status.

- Demonstrate that you have taken steps to reduce the chances of your partner(s) becoming infected. This includes choosing lower risk sexual activities, using condoms consistently and adhering to your treatment (if you are on ART).

- Get involved in advocacy to change laws that violate your rights. Contact your local network of people living with HIV.
Sexual pleasure

Young people living with HIV have the right to sexual pleasure

Sex can feel great and can be really fun! Many people think sex is just about vaginal or anal intercourse... But, there are lots of different ways to have sex and lots of different types of sex. Sex can include kissing, touching, licking, tickling, sucking, and cuddling. Some people like to have aggressive sex, while others like to have soft and slow sex with their partners. There is no right or wrong way to have sex. Just have fun, explore and be yourself!

Remember

It’s your body. You choose what you do, when you do it, how and with whom. Only do what you feel comfortable with doing, and tell your partner straight away if you feel uncomfortable.
Improve your sex life by getting to know your own body. Play with yourself! Masturbation is a great way to find out more about your body and what you find sexually stimulating. Don’t stop there: Find out how your partner’s body works, what makes them feel good and what gives them pleasure. Talking with your partner about what you each like and what feels good is the best way to have great sex.

Your skin is the largest erogenous zone on your body, and your mind plays a big role in your desire for sex and sexual pleasure. Caress and lick your partner’s skin. Explore your partner’s body with your hands and mouth. Mix things up by using different kinds of touch from very soft to hard. Talk about or act out your fantasies. Talk dirty to them. Tickle, tease and make them feel good.

Do you know about the clitoris and prostrate? The clitoris, which is located in the female body just above the vaginal opening where the labia meet, is the only organ in the human body to have the sole purpose of sexual pleasure. The prostate is a gland that helps produce sperm; it is found inside the rectum and can be very pleasurable for men when stimulated.
Young people living with HIV have the right to take care of their sexual health

There are many good things about sex, such as intimacy and pleasure. Sex also comes with risks such as the possibility of HIV, other sexually transmitted infections (STIs) and unplanned pregnancies. Knowing that how you are expressing your sexuality is also reducing these risks can reduce your worries and increase your sexual pleasure. You have the right to information to help you make informed decisions and understand your sexual health, and to health services to help you monitor and take care of your sexual and reproductive health.

STIs are infections that can be transmitted through sexual contact. People living with HIV may get some STIs more easily and can have more serious symptoms.

Depending on what kind of sex you have, STIs can affect the genitals, anus, mouth and throat. STIs can be passed to babies during pregnancy and delivery.

Having an STI can increase the chances that your partner will get infected with HIV. Untreated STIs can lead to health problems like infertility, cervical cancer, and anal cancer.

Remember

Many people living with HIV don’t think they need to practise safer sex if they have sex with another HIV-positive person. But you can still be at risk of picking up other STIs that could affect your health.
Many young people living with HIV also have Hepatitis C. Hepatitis C can also be transmitted sexually. Make sure your healthcare professionals know about your co-infection; they can get you treatment, which will improve your health and well-being. Interactions between HIV and Hepatitis C treatments can be complex and cause side effects. Make sure you talk with your healthcare provider if you are on treatment and experiencing side effects.

Living with HIV makes people more vulnerable to catching other diseases like Tuberculosis (TB). Depending where they live in the world, many young people living with HIV will also get TB at one point or another. Make sure that you go to the doctor regularly if you are living with HIV to ensure that you are screened for TB.

HIV can make you prone to vaginal infections — yeast, bacterial vaginosis, and pelvic inflammatory disease (PID) — and abnormal growth of cells on your cervix that can turn into cancer if left untreated. Keep your vagina healthy by getting an annual gynaecological exam — including a Pap smear test — and getting any sores, bumps, or irritations on your genitals treated as soon as possible. Ask your healthcare provider for more information about gynaecological health.

HIV can reduce your resistance to infections that cause open sores or warts on your penis and even discharge. If untreated, these infections can get worse or can be passed onto others and can increase your vulnerability to picking up other infections. Keep your penis healthy by checking regularly for sores and discharge (remember to check under the foreskin) and getting a penile examination from your doctor. Ask your healthcare provider for more information about male sexual health services.
Young people living with HIV have the right to practise safer sex

As a person living with HIV you may feel like you have all the responsibility for talking about safer sex and keeping your sexual partner(s) from getting HIV. But remember it is your sexual partner(s)’s responsibility too. Just because you have HIV does not mean all the responsibility is on you.

Sex is often a social activity. This means that practising safer sex involves talking with your partner(s). These conversations are easier the more comfortable and knowledgeable you are about your body and sexual health. Safer sex should be something that is discussed openly with your partner. Discussions should involve decisions around types of sexual activities you engage in, and agreeing on ways to reduce the risk of HIV, other STIs, and unplanned pregnancies.

Sometimes, however, people feel unable to speak with their partners and negotiate safer sex — this is especially true for women in countries or communities with significant gender inequalities. If you are not able to talk with your partner(s), consider speaking with a counsellor or some other support.

Some people have sex when they have been drinking alcohol or using drugs. This is your choice. Being drunk or high can affect the decisions you might make about sex and safer sex. If you want to have sex and think you might get drunk or high, plan ahead by bringing condoms and lube or putting them close to where you usually have sex. That way you won’t forget them in the heat of the moment. Your partner must be able to freely consent to sexual activity. It is not okay to have sex with someone who is so drunk or high that they are staggering, incoherent or have passed out.
Tips for making sex safer:

• Knowing how HIV and other STIs move from one person to another can help you and your partners make decisions about how to make your sex safer. Ask your local sexual health clinic for more information.

• Making assumptions about whether someone has HIV or STIs is not a good way to take care of your sexual health. People can have HIV or an STI and not have any symptoms. The only way to know for sure if you or someone else has HIV or an STI is to get tested.

• If you’re having sex, it’s a good idea to have a sexual health check up at least once a year or when you change sex partners. If you have oral or anal sex, ask your health provider to also check your mouth, throat and rectum. Encourage your partner(s) to get checked regularly too. You can even go to check ups together with your partner(s), if they agree.

• Male and female condoms are great tools for preventing the transmission of HIV and other STIs as well as unplanned pregnancies. To be most effective, the condom must be put on before there is contact between your genitals and your partner(s)’s genitals, anus or mouth. You can find out more and even get free condoms at your local sexual health clinic.

• Using lubricant with condoms can increase the sensation for you and your partner(s) and decreases the chances of the condom breaking. Make sure your lube is water-based. Oil-based lubes can make condoms tear and cause infections in your vagina or rectum.

• Young people living with HIV have different treatment and care needs. Some people will need to go on treatment earlier than others. Make sure that when you start your treatment you take it according to the prescription. If you have a partner that knows your HIV status and is supportive, it can be a good idea to get them to help remind you to take your HIV treatments. This support can be a good way to ensure you regularly take your treatment as prescribed by the doctor. Good adherence helps you to keep your viral load down, which can make you less infectious.

Sometimes people choose not to have safer sex. If this is something you and your partner agree to, then it is your choice. It is not always possible to talk to your partner(s) about or to practice safer sex — for example, maybe you know that your partner will get angry or aggressive, or you don’t have access to condoms or a safe place to have sex.

There are other ways that you can somewhat reduce the risks of HIV, other STIs, and unintended pregnancies without using condoms.

• You can limit the amount of body fluids like semen and vaginal secretions that you and your partner(s) share.

• You can use lubricant to reduce the chances of micro-tears in the vagina and anus.

• You can get tested regularly for HIV and other STIs.
Young people living with HIV have the right to choose if, when, how many, and with whom to have children

Sometimes it can feel like everyone has an opinion about whether and when you should have children. Some young people living with HIV are encouraged by service providers, family and friends to not have children, while other young people living with HIV face pressure by family, friends and their partner(s) to have children. Knowing your rights and family planning options can help you make decisions about positive parenthood and manage other people.

Often young people living with HIV want to have kids. People living with HIV can have healthy pregnancies and share a long life with their children. Pregnancy itself will not make your HIV infection worse and HIV does not change your pregnancy.

There is about a 25–30 per cent chance that your child will get HIV during pregnancy, labour and delivery, or breastfeeding if nothing is done to prevent vertical transmission (when HIV is transmitted from the mother to the baby). This risk goes down significantly when preventative measures are taken. Talk to your healthcare provider about vertical transmission prevention services (also known as prevention of mother-to-child transmission or PMTCT clinics) and other maternal and child health services, where available.

Make sure you feel confident speaking to your service provider about these issues. If they cannot help, or you have a bad experience, speak to your counsellor and try to find another healthcare provider.

Make a plan

Your local family planning clinic can help you create a plan – whether it is for having children safely, preventing or terminating unplanned pregnancies, or figuring out how to start a family if you are single or in a same-sex relationship.

Your family planning strategy is more likely to be successful when you work together with your partner. If you are sexually active with someone of the opposite sex, take time to talk together about this possibility and come up with a strategy for a safe pregnancy or to prevent unplanned pregnancies.
You may worry about giving HIV to your partner(s), picking up another STI, or contracting HIV while trying to get pregnant. There are ways to have a family that can reduce the risk of HIV transmission. Your local prevention of mother-to-child transmission clinic, support group for people living with HIV or other people you know who are HIV-positive, can provide more information on getting pregnant.

Using contraceptives

Some people want to avoid getting pregnant. There are many different methods to prevent pregnancies, called contraception. You can use a barrier method like male and female condoms, spermicides and diaphragms; hormonal methods like the birth control pill; sterilization; and natural methods like pulling out (withdrawal method). The methods vary in how effectively they prevent pregnancy, whether they are permanent or temporary, their side effects, and whether they also prevent HIV and other STIs. Many people use two methods of contraception. You may need to experiment with different kinds of contraception to find the right method(s) for you. Your healthcare provider can provide more information about these methods and the advantages and disadvantages of each. If you choose to use a contraceptive pill please take advice from your health service provider to make sure there are no interactions with your HIV treatment if you are currently on effective anti-retroviral HIV treatment.

Sometimes women get pregnant or think they might be pregnant, even if they and their partner(s) have used contraceptives. There are options to terminate unplanned pregnancies. Hormonal emergency contraceptives can be used in the days after the possible conception to start the woman’s period. Women living with HIV can also have safe abortions. Unplanned pregnancies can be stressful for both partners and can strain the relationship, whether you decide to continue or terminate the pregnancy. You can get support and counselling from your local family planning clinic.

Remember

People living with HIV can also start a family by adopting children. In some places there are legal barriers to people living with HIV adopting children. There are movements of people living with HIV working to ensure that all people have the same options for adoption around the world. Visit www.ippf.org and www.gnpplus.net for more information.
Young people living with HIV have the right to support and services that respect their dignity, autonomy and well-being.

There are many people, groups and organizations that provide support and services for people living with and affected by HIV. Look for support and services that respect your dignity, right to freely make choices about your body and health, and help you live positively. This includes respecting your sexuality and your right to pursue pleasurable and safe sex and positive parenthood.

We all need a friendly ear and some supportive advice. There are many potential sources of support for young people living with HIV, including friends, family, post-test clubs, support workers and people living with HIV networks. Your partner may be able to provide support for some of the issues you are facing. For example, if you are on anti-retroviral treatment, your partner can help support you to remember to take the treatment when you are supposed to; this can help your overall health and well-being. If your partner is also living with HIV you can provide support to each other.
Many communities have centres that offer youth-friendly health services. These are places where you can access information and health services to help you take care of your sexual health, like STI tests and advice on condoms and contraceptives. They often have hours that are convenient for young people, and staff who understand young people, will not judge you and will treat you with respect. You should find out whether there any centres near to you where you can go without needing the permission of your parents or guardians. You should also make sure that you can trust the staff not to tell anyone you were there or why. You can also get information and health services to help you take care of your sexual health from your healthcare provider or local sexual health clinic.

Remember

Some healthcare workers and service providers think that young people or people living with HIV should not have sex. They may let their personal opinions get in the way of providing good information and services. Remember that you have sexual and reproductive rights. You can report bad service to the manager, ask to see another staff person at the clinic, or find another clinic where you feel respected.
Look for support and services that respect your dignity, right to freely make choices about your body and health, and help you live positively. This includes respecting your sexuality and your right to pursue pleasurable and safe sex and positive parenthood.

Acknowledgements

This publication has benefitted from the contributions, efforts and energy of many people. The main authors were Lia De Pauw and Alex McClelland of Spark Public Health Group Inc. The main editors of the publication were Adam Garner and Tim Shand. We are especially grateful to: Doortje Braeken, Rachel Lander, Kevin Osborne and Arushi Singh of IPPF and Alice Welbourn of Salamander Trust.

Designed by Jane Shepherd.

This publication supports the implementation of Sexual Rights: an IPPF Declaration.