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HIV & sex



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This is an interactive booklet. All page numbers, either on the contents page or mentioned within the booklet, are clickable. You can also click on the names of resources and organisations to go to the relevant web pages.

This booklet is about sex, intimacy and sexual health for people living with HIV. These are essential aspects of health and wellbeing for everyone, including people living with HIV.

The booklet is not intended to replace discussion with your doctor – or with other healthcare professionals, support agencies, your partners and friends. It may help you to decide what questions to ask, who to ask and where to find useful information.

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Sex, you and HIV

Good sex, intimacy and physical pleasure are integral aspects of wellbeing. This is no different if you are living with HIV. People with HIV want the same things as everyone else – love, affection and the pleasure and satisfaction

you can get, and give, by having sex. Sexual expression and enjoyment are part of what make you human. Having sex and relationships in your life are likely to be as important for you as they ever were, possibly even more so.

"Having a healthy sex life contributes to your overall health and wellbeing."

Living well and staying healthy with HIV means looking after yourself – and that means your emotional self, too. Cutting

yourself off from giving and receiving pleasure or from human contact isn't good for you. You may become isolated or depressed, which is also not good for your health.

It's fine to choose to be single or celibate
– but it should be a choice you've made
for positive reasons. And it doesn't need to be a
permanent choice – you might decide not to have
sex for a period while you come to terms with your
HIV diagnosis, for example.

Sex can feel good, bring you closer to other people and satisfy a powerful desire. That is reason enough to continue to enjoy it as often as you wish. But there are other recognised health benefits too: sex can help you relax and sleep better; sex can be very good exercise; sex can relieve pain, improve circulation and lower cholesterol levels. Having a healthy sex life contributes to your overall health and wellbeing.

Undetectable = Untransmittable (U=U)

Paying attention to sexual health is about more than not passing HIV on or avoiding sexually transmitted infections. Nonetheless, it is vital to know that if you maintain an undetectable viral load, you cannot pass HIV on to your sexual partners. You will also be taking care of your health.

If you have been diagnosed with HIV, the best way to remain healthy, or to regain health, is to start taking HIV treatment. Effective treatment (antiretroviral therapy or ART) decreases the amount of HIV in your body fluids; this is called your viral load. By lowering your viral load, treatment prevents HIV from damaging your immune system and helps your body reverse any damage that has been done.

Effective HIV treatment suppresses the amount of HIV in your body fluids to the point where standard blood tests are unable to detect any HIV or can only find a tiny trace. Doctors call this virological suppression but it is often known as having an undetectable viral load or simply, being undetectable.

"If you have an undetectable viral load, you do not have to worry about passing on HIV through sex."

Having an undetectable viral load does not mean you are cured of HIV. If you stopped taking treatment, your viral load would increase and once again be detectable. Having an undetectable viral load *does* mean that there is not enough HIV in your body fluids to pass HIV on during sex. In other words, you are not infectious.

For as long as your viral load stays undetectable, your chance of passing on HIV to a sexual partner is zero. As the campaign slogan puts it, 'Undetectable equals Untransmittable' or 'U=U'.

This has been a life-changing finding for many people living with HIV. If you are on effective treatment with an undetectable viral load, you do not have to worry about passing on HIV through sex, even if you do not use a condom.

While remaining undetectable preserves your health, the knowledge that U=U has also been able to help many people living with HIV have more fulfilling sex lives and less anxiety around sex.

During the first few weeks after you get HIV, vour viral load is usually very high. There is a considerable risk of passing on HIV at this point. In fact, many people acquire HIV from someone who has only recently acquired it themselves (and does not know it).

After this period of early infection, your viral load usually drops. However, there is still a considerable risk of passing HIV on during this time.

After starting HIV treatment, viral load usually falls rapidly. Within three to six months, most people's viral load has become undetectable (below 20-50 copies/ml). You are recommended to wait until you've had at least two undetectable results in a row, over a six-month period, before relying on it.

The British HIV Association (BHIVA) – the leading UK group representing professionals in HIV care - states that if you have been on treatment for at least six months, with good adherence and a sustained undetectable viral load, there is no risk of onward transmission of HIV.

Once your viral load is undetectable, research shows that it is unlikely that occasionally missing a dose of medication would cause your viral load to become detectable again. However, missing doses frequently may lead to a detectable viral load and should be avoided.

What is the research behind U=U?

The science behind U=U has been accumulating for decades. Four major international studies proved that U=U by studying couples where one partner is HIV positive and undetectable and the other is HIV negative.

The largest of these studies were PARTNER 1 and PARTNER 2, whose final results were announced in 2016 and 2018, respectively. Between the two of them, they recruited 972 gay couples and 516 heterosexual couples in which one partner had HIV and the other did not. Over the course of the study, the gay couples had 77,000 acts of condomless penetrative sex and the heterosexual couples 36,000 acts. The PARTNER studies did not find a single HIV transmission from an HIV-positive partner who had an undetectable viral load (measured as below 200 copies/ml).

Importantly, for the PARTNER studies, all the couples had had sex without condoms. The HIV-negative partners were not taking pre-exposure prophylaxis (PrEP, see page 42) or post-exposure prophylaxis (PEP, see page 45).

While some of the HIV-negative partners in these studies did acquire HIV, researchers were able to use genetic testing to show that all these infections came from other people and not their main (undetectable) partner.

How do I explain this to a sexual partner?

If you have sexual partners who are not living with HIV, explaining U=U to them is likely to be mutually beneficial.

If you had previously relied on other means of preventing HIV transmission (such as using condoms or PrEP), you may jointly decide that these methods are no longer necessary because of U=U.

It may take some time for an HIV-negative partner to accept the U=U message and to rely on it as the sole method of preventing HIV. Some HIVnegative people may reject the message or deny its accuracy. It may be helpful to direct your partner to resources such as this booklet and others found on www.aidsmap.com that explain the accuracy and significance of U=U. Another option could be for your partner to hear about U=U from a healthcare worker or another reliable and trusted source. Despite sharing this information, some people may still not accept that U=U. In this kind of situation, it is important to find a balance between providing your partners with information and taking care of vourself.

While remaining undetectable is one way you can ensure that you do not pass HIV on, your sexual partners may also have other sexual partners. It is important for them to be aware of how they could contract HIV outside of your relationship, possibly

from someone who does not know that they have HIV. In these instances, prevention methods such as condoms or PrEP may still make the most sense for someone who is HIV negative.

Many people find it difficult to talk about sex, even with the person who is closest to them. If this is the case, you might want to discuss your concerns with someone at your HIV clinic, sexual health clinic or a support organisation. This can help you clarify your thoughts and what you'd like to say.

In the past, healthcare workers sometimes referred to 'negligible' or 'minimal' levels of risk, or a 'small chance' of contracting HIV from a person with undetectable HIV. However, the research is now very clear: people on effective treatment with an undetectable viral load cannot pass the virus on regardless of the type of sex act (oral, vaginal or anal), presence of other sexually transmitted infections, their gender, and whether the HIVpositive partner is active or passive (top or bottom).

Sometimes, couples counselling can give you a chance to talk about difficult issues with your partner with the help of a trained counsellor. Your clinic or a local HIV organisation may be able to arrange this. In the UK, if you're not sure where to start, you could contact the Terrence Higgins Trust helpline, THT Direct, on 0808 802 1221.

Most clinics in the UK report a viral load as undetectable if it is below 20-50 copies/ml. However, if your viral load remains below 200 copies/ml (the cut-off used in all studies that provided evidence for U=U), there is no risk of passing HIV to your sexual partners.

There is no need to worry if your viral load is slightly above the detection limit of 20-50 copies/ml. A temporary rise in your viral load (often call a 'blip') is not usually a cause for concern as long as your viral load is below 200 copies/ml on the following test.

What about other sexually transmitted infections (STIs)?

It is important to remember that while effective HIV treatment will protect your partners from your HIV, it does not protect them or you from other STIs.

For this reason, regular sexual health check-ups are recommended. Using condoms will help prevent STIs. Regular testing and timely treatment of STIs also ensures that they are less likely to be passed on. There is more information on STIs in the fourth part of this booklet (see page 56).

Another concern is whether having an STI could lead to an increase in viral load. This does happen to people with HIV who are not taking treatment. HIV-negative partners are also more likely to get HIV if they have an STI. But it is not the case for people taking HIV treatment who have an undetectable viral load. In the PARTNER studies, there was not a single HIV transmission from someone with an undetectable viral load, even though many people had STIs.

If you maintain good adherence to HIV treatment, catching an STI will not raise your viral load from 'undetectable' to 'detectable'. Effective treatment prevents sexual transmission of HIV even if there are other STIs present.

Feelings about sex after your HIV diagnosis

Your feelings about sex may be affected by your thoughts about the virus, how your diagnosis affects the way you see yourself, and how these aspects come together to influence your sex life as an HIV-positive person.

While negative attitudes about HIV have changed over time, many of these have stuck around and have contributed to the large amount of stigma experienced by people living with HIV. Stigma is made up of these negative attitudes, fears and prejudices about HIV. It can result in people living with HIV being insulted, rejected and gossiped about.

In some instances, when people living with HIV experience stigma, they start to view themselves negatively and it can impact their sex lives.

This is also known as internalised stigma or selfstigma – when people living with HIV start to have thoughts and beliefs that they are infectious, not desirable and not worthy of experiencing pleasure and intimacy.

While many negative ideas about those living with HIV have not yet caught up with important medical findings, such as U=U, it is important for

=U, it is important for you to know the facts about how HIV is transmitted (and how it is not) in order to feel empowered about your sex life.



Initial reactions to your diagnosis

Different people's sex lives are affected in different ways by their HIV diagnosis.

A strong initial reaction to an HIV diagnosis is often the feeling of 'going off' sex. Most people who are infected acquire HIV sexually and thus, sex may be associated with negative feelings. Not wanting to pass HIV on to a sexual partner is also often a reason for avoiding sex altogether. These feelings can be eased by knowing that once you have started treatment and your viral load is undetectable for six months or longer, you are not able to pass HIV on.

In contrast, your interest in sex could become stronger and more intense. You may find that you want to explore sexual desires without the fear of contracting HIV.

Whatever you are feeling is part of your adjustment to your diagnosis and it does not need to be cause for concern. The shock experienced after your diagnosis is temporary and your response to living with HIV will change as you learn how best to manage it.

Feeling good about having sex

For many people living with HIV, becoming undetectable and knowing that they cannot transmit HIV has been a turning point in how they view their sex lives. It has allowed them to move away from thinking of sex in terms of infection and risk, and to focus instead on the pleasurable aspects of sex.

"You can enjoy a healthy, pleasurable sex life without passing HIV on to your sexual partners."

We now have numerous ways to prevent
HIV transmission during sex. Adopting a
proven prevention method, whether
it is using condoms consistently and
correctly or remaining undetectable,
means that you should feel secure
about having sex that is enjoyable and
free from worry. It's important to know
that you can enjoy a healthy, pleasurable
sex life without passing HIV on to your sexual

partners and that people living with HIV can have children who do not have HIV.

Good sex, intimacy and pleasure all contribute towards your quality of life. Your HIV diagnosis does not mean that you have any less of a right to have pleasurable and fulfilling sexual experiences.

Telling people you have sex with that you have HIV

Sharing your HIV status with anyone can be difficult, but telling a sexual partner may be particularly daunting. This is sometimes called disclosure.

Considerations regarding whether or not to disclose, when to do it and how will depend on various factors. The nature of your relationship will influence this process: telling a casual partner you have HIV is likely to be different from telling a longterm partner.



Your thoughts and feelings about HIV and sex are likely to be deeply affected by reactions from sexual partners, be they positive or negative. This means that you need to think about all the pros and cons of disclosure and how best to go about it.

Many people living with HIV have been subjected to rejection and hurtful reactions, even when they take necessary precautions to prevent transmission. There may be times when you are met with shock, anger, disappointment or disgust. If you feel forced to disclose when you are not ready, it can have a negative impact. Disclosure needs to be on your terms. It is your information to share.

It is important to remember that there may be legal considerations regarding telling your sexual partners that you have HIV (see page 34). Beyond these considerations, disclosure needs to be navigated in a manner that makes you feel safe, confident and sexually empowered.

Telling a long-term partner

If you are in an ongoing relationship, telling your partner might open up a crucial source of support. If you are undetectable, letting them know about U=U may help them feel less anxious about sex. It has helped many couples feel that one of them having HIV is not 'a big deal'.

On the other hand, it could be a difficult situation for both you and your partner to deal with. There could be questions about how you acquired HIV. It may take some time for you and your partner to work through the issues that come up. There may be concerns about whether you could have passed HIV on to your partner, or whether you could in the future.

Equally, there's also the possibility that it was your partner who passed HIV on to you. It's important that your partner gets tested for HIV – staff at your HIV clinic can help with this.

Some people face particularly difficult situations. You may rely on your partner for money or be worried about violence.

If you need help or support to think these issues through, reach out to find out what is available through your clinic, a local support group or contact THT Direct (0808 802 1221).

Telling a new partner

Telling new sexual partners, or potential partners, can be intimidating. You might be worried about being rejected if you tell someone you have HIV. Your partner may have concerns about the risk of HIV being passed on but not be aware that effective HIV treatment prevents this.

"You might be worried about being rejected if you tell someone vou have HIV."

Talking about prevention, even with casual sexual partners, opens up a space where vou can mention the benefits of U=U and you can also ask about which prevention methods they've used. While sharing your status with an HIV-negative sexual partner can be very difficult, it gives you the opportunity to speak about ways in which your partner's health can be protected.

Timing can be important. It can be difficult to talk about HIV when you have only just met someone but putting it off may cause problems later on. Upfront disclosure may be helpful: some gay dating apps have the option to show your HIV status to everybody who views your profile.

"It may be helpful to talk to other people living with HIV about how they deal with this."

Some people find that this upfront form

of disclosure filters out people with discriminatory beliefs and means that they don't need to mention HIV with everyone they chat to.

While upfront disclosure on dating apps works for some, there are also many HIV-positive people who find that it is inherently stigmatising and that it does

not give a potential partner the chance to know you without the label of 'HIV positive'. You need to think about the safest and most empowering way for you to share your status.

Often, sex happens in the heat of the moment. There may not be an opportunity to mention that you have HIV, or your partner might not want to discuss it. You may also find that your partner initiates sex without using a condom. Think in advance about how you would respond to these situations. Don't assume, just because your partner doesn't want to talk about HIV or is willing or even eager to have sex without a condom, that they are also living with HIV or taking PrEP.

You can get advice from your clinic, a local support group or **THT Direct (0808 802 1221)**. It may be helpful to talk to other people living with HIV about how they deal with these kinds of situations.

Dealing with sexual problems

A healthy sex life, intimacy and physical pleasure are important parts of your overall health. This should not change because of your HIV diagnosis. However, some people living with HIV find it difficult to enjoy a healthy sex life. Although sexual problems (often called sexual dysfunction) can be a problem for anyone at different times in their lives, studies show that people with HIV are particularly prone to them.

Four types of sexual problems are commonly reported. There may be:

- problems with sexual desire: usually a loss of interest in sex.
- problems with arousal: difficulties getting or keeping an erection, or becoming relaxed and lubricated.
- orgasm problems: not having an orgasm at all, taking a long time to have one, or rapid (premature) ejaculation.
- pain during sex, which may cause avoidance.

Sexual difficulties may have a physical cause, but they may also be caused or aggravated by psychological, emotional and relationship factors. Often there is not a single cause for sexual difficulties, but rather a combination of factors may be involved.

Physical Poor physical health, imbalanced hormone factors levels, heart and circulatory problems, smoking, being overweight, pregnancy, older age, and physical disability can all affect sexual desire and performance. Having an STI can cause pain and discomfort during sex.

> Some medications can contribute to sexual dysfunction. These include some drugs taken to treat depression and other mental health conditions, drugs to treat high blood pressure, some forms of contraception, and opioid painkillers. Recreational drugs and alcohol can also contribute to sexual problems.

Relationship Issues such as difficulty speaking about HIV with factors your partners, concerns about prevention and safety, trust issues, infidelity, and decreased intimacy can contribute towards sexual problems.

Psychological These may be particularly relevant for people factors living with HIV. There are specific psychological stressors linked to having HIV, such as the fear of transmitting it to others, the stigma surrounding the virus, concerns about discussing your status with others, and body image changes. These can potentially affect your feelings about sex.

> Similarly, the way you feel about your body and sexuality, low self-confidence and poor self-image can all contribute to sexual difficulties.

Anxiety, depression, mood problems and the medications used to treat them can contribute to sexual difficulties (such as inability to reach orgasm).

Getting help Whatever the problem, it is important to first talk to your HIV doctor or GP. They can rule out any other underlying health condition as the cause, and you can discuss what options there may be for treating problems.

> It is important to seek out help that not only attends to the physical causes of sexual difficulties, but also considers psychological causes and consequences.

"Talking therapies. which allow you to talk through issues, can often help."

If you find that your sexual problems are present all the time and in all situations (for example, both with any sexual partner and when trying to masturbate alone) then it's likely that physical factors, the effects of recreational drugs or alcohol, or taking certain medications could be responsible.

If, on the other hand, you find that your problems only emerge in certain circumstances, for example with a particular partner, or when you're having sex in particular situations, then psychological or relationship factors are likely to be more important.

Where psychological causes contribute significantly to sexual problems, psychosexual or talking therapies, which allow you to talk through issues, can often help. These include counselling, cognitive behavioural therapy and psychotherapy.

Even if the primary cause of sexual problems is physical, talking therapies can reduce the associated psychological component. They may also help with HIV-related stigma, reducing anxiety related to sexual problems and fear of HIV transmission. Talking therapies are available through your HIV clinic or GP.

Specific sexual problems or situations

Vaginal It is normal for vaginal lubrication to vary dryness depending on your health, age, and where you are in the menstrual cycle. Using lubrication can help alleviate discomfort associated with vaginal drvness.

Menopause Menopause is when you stop having periods and are no longer able to get pregnant naturally. It is a natural part of ageing that usually happens between the ages of 45 and 55.

> Oestrogen and testosterone levels fall significantly during and after menopause and can cause a reduction in sexual desire. During and after menopause, the vagina becomes less flexible or elastic and the tissue becomes

thinner. There is also reduced blood flow to the pelvic region. This can also lead to increased vaginal dryness and pain or discomfort during sex.

To relieve vaginal dryness and loss of libido, a small amount of oestrogen can be administered directly to the vagina using a vaginal cream, tablet or ring. Using a vaginal lubricant can also help with dryness.

hole sex)

Pain during If you are experiencing pain during sex, it is receptive important to have a physical examination done vaginal sex by a clinician who has experience with sexual (or front problems.

> Discomfort or pain can occur for many reasons. Having an STI or other infection such as thrush (a yeast infection) or bacterial vaginosis can all cause discomfort or pain during sex. Some people experience it in the week or two before their period.

> Injuries to the vagina or vulva, which can happen during childbirth or sexual assault, may cause pain or discomfort during sex, as can some common medical disorders.

> Experiencing pain during sex can lead to increased anxiety or fear about having sex, because of the anticipation of discomfort. This fear or anxiety can lead to decreased arousal, performance anxiety, and vaginal dryness. Feeling or anticipating pain during sex can also lead to involuntary tightening of the vaginal muscles, known as vaginismus.

During Many people find that their sexuality is affected and after during pregnancy, after pregnancy in the pregnancy postpartum period, or when breastfeeding (also known as chestfeeding). Sexual problems during this time can be caused by physical and hormonal changes after childbirth, concerns about body image, and psychological causes.

Problems with Some people report problems with ejaculation: ejaculation either they ejaculate too quickly, or ejaculation is delayed or absent. Some things that can help with ejaculating too quickly include behavioural techniques, such as masturbating before sex or stopping sex right before orgasm. Using condoms or an anaesthetic cream or spray can also reduce sensitivity and help prevent premature ejaculation.

Pressure to use Pressure to use condoms can have an impact condoms upon sexual performance. Some people find that their penis is less sensitive to touch when using condoms, which may contribute to erectile dysfunction. In this instance, knowledge about being undetectable, and therefore not being able to pass the virus on to others even when not using condoms, often comes as guite a relief. It is important for partners to discuss their feelings regarding condom use in order to ensure that sex is pleasurable, but also that both partners feel safe.

Low Many people with HIV have low testosterone testosterone levels (hypogonadism). Testosterone replacement treatment may help with sexual problems, such as restoring sexual desire, improving erection quality and enhancing the effectiveness of erectile dysfunction medications. Erectile dysfunction medications may be helpful but not as effective if underlying hypogonadism is not treated.

Erectile Erectile dysfunction (or impotence) is when you dysfunction cannot get or keep an erection that enables you to have sex. Many people struggle with erectile dysfunction, especially as they get older. It is also more common in people with HIV than in the general population.

> There may be physical or psychological causes, or more frequently a combination of the two. Erectile

dysfunction is often associated with conditions that affect blood flow in the penis, including diabetes, high cholesterol, high blood pressure, cigarette smoking, obesity and heart disease Other factors commonly linked to erectile dysfunction include older age, low testosterone levels, alcohol or drug use, anxiety and depression.

Medications such as sildenafil (Viagra), tadalafil (Cialis), vardenafil (Levitra) and avanafil (Spedra or Stendra) are used to treat erectile dysfunction. They work by increasing blood flow to the penis. making it more sensitive to touch. They do not primarily increase sexual desire and only work when you are sexually stimulated.

The medications vary in dosage, how guickly they start to work, how long they work for, and their side effects. Possible side effects include facial flushing, nasal congestion, headaches and indiaestion.

There can be drug-drug interactions with other medications you take, potentially including anti-HIV drugs. When taken with ritonavir or cobicistat (boosting agents included in some HIV treatment regimens), levels of the erectile dysfunction medication may be increased, potentially leading to serious side effects. On the other hand, when taken with anti-HIV drugs that are non-nucleoside reverse transcriptase inhibitors (NNRTIs), levels of the erectile dysfunction drug may be lowered.

The recreational drug 'poppers' should not be used with any erectile dysfunction medications as this could result in a potentially fatal drop in blood pressure.

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HIV, sex and the law

In England, Wales and Northern Ireland, it is possible you could have legal action taken against you if all of the following apply:

- O You suspect or know you are HIV positive
- You suspect or know you have a detectable viral load
- You still have sex without a condom without telling your sexual partner about your HIV status
- O Your partner acquires HIV as a result.

This issue may affect how you approach your sex life after an HIV diagnosis.

Several people in England, Wales and Northern Ireland have been charged with committing an offence because their sexual partners acquired HIV through sex without a condom, and they had not told them they were HIV positive. (The legal term is 'reckless transmission'.)

In England and Wales there is no legal obligation to disclose your HIV status to a sexual partner, but if you are later charged with transmitting HIV, proving that your partner knew you were HIV positive would help your defence.

If you take precautions to protect your sexual partner from HIV by using a condom or ensuring your viral load is undetectable by adhering to treatment, it is extremely unlikely you would be charged with reckless transmission.

"If you use condoms consistently and correctly, you would have a good defence if transmission did occur."

If your partner knows you have HIV and consents to sex without a condom, do not assume that they are also HIV positive or on PrEP, as you may be charged for any resulting infection if your partner goes to the police. In those rare circumstances, proving that they consented to the risk would help your defence.

In Scotland, the law is different. As well as the possibility of being charged for passing on HIV in those circumstances, it is possible to be prosecuted for putting another person at risk of acquiring HIV, even if they don't become HIV positive. (The legal term used is 'reckless endangerment' or 'reckless exposure'.) As in England and Wales, proving that you disclosed your HIV status to your partner and they consented to the risk would help your defence.

Most cases come about because someone has made a complaint. This was usually because they feel they didn't have all the information to protect themselves from HIV and/or because they feel deceived or betrayed in some way.

Around 30 people have been convicted and sent to prison in the UK. There have been more arrests and investigations, some of which have lasted for many months, even in cases which didn't go to court.

They have had a serious impact on the lives of both the accused and the people making the complaint. Legal guidelines in England, Wales and Scotland say that there is usually no case if:

- you didn't know, or suspect, you have HIV or
- vou can prove you told your partner you are HIV positive and
- you took reasonable steps to avoid passing HIV on to your partner.

Lawyers think that if you use condoms every time you have sex, and for the entire duration of sex, you would have a good defence if transmission did occur.

The British HIV Association (BHIVA) states that anyone with sustained, undetectable levels of HIV virus in their blood cannot transmit HIV to their sexual partners. If you are following your doctor's advice in taking HIV treatment consistently and correctly to reduce your infectiousness, that is also likely to be considered reasonable action to prevent HIV transmission.

But neither of these defences have been tested in a court of law.

The law is also not clear on your liability if you use a condom and you notice that it breaks or comes off. Advice is that you should tell your partner that you have HIV if they do not already know

and advise them to seek treatment called postexposure prophylaxis (PEP, see page 45). This is where a course of HIV treatment is given (within 72 hours) to prevent HIV infection after someone has been exposed to the virus.

Ultimately, it is your decision when and whether to tell your sexual partners that you have HIV. You may want to consider whether the kind of sex you are having involves a substantial risk of HIV transmission. (See the next section for more information.)

If you are being investigated, or you think that someone may make a complaint against you, it's important that you get good advice and support from an HIV support organisation. You need to find an experienced lawyer straight away, before you make any statement to the police. In the UK, the Terrence Higgins Trust helpline, **THT Direct**, can help you find both these; you can speak to them in confidence on **0808 802 1221**. You may also want to speak to THT Direct or another support organisation if you are thinking of making a complaint.

You can find more useful information on the Terrence Higgins Trust website, www.tht.org.uk.

HIV and preventing sexual transmission

This part of the booklet goes into more detail about the different ways you can prevent sexual transmission of HIV so that you can have pleasurable sex that is free from worry. This includes having an undetectable viral load, PrEP, PEP and condoms.

Most people get HIV through sex without a condom from a partner who is not on treatment and has a high viral load. As viral load rises, so does infectiousness. During the first few weeks or months after HIV has entered a person's body, their viral load is usually extremely high and they are very infectious. On the other hand, when viral load is so low as to be undetectable, there is no risk at all of HIV transmission.

If you are not yet undetectable, it's good to be clear about when there is and when there isn't a risk of passing HIV on to someone else.

- Unprotected anal and vaginal sex are the most common ways that HIV is passed on.
- During anal sex without a condom, the risk is higher for the receptive (passive, bottom) partner when the insertive (active, top) partner has a high viral load. However, there is still a risk for the insertive partner when the receptive partner has a high viral load.
- ☐ Similarly, for cisgender men and women



- The risk of transmitting HIV during other sexual activities is much, much lower. Oral sex is considered to be extremely low risk.
- It's impossible for HIV to be passed on through kissing, cuddling or stroking.
- There is no risk of passing on HIV during routine social contact. No-one has ever caught HIV from sharing household items like cups, plates or cutlery, using the same toilet, or breathing the same air as someone with HIV.

Being undetectable

Having an undetectable viral load is the most effective way of preventing sexual transmission of HIV.

If you are on successful treatment for six months or more, and have a sustained undetectable viral load, there is zero risk of passing HIV to a sexual partner. This is true even when not using condoms. (See page 8)



Pre-exposure prophylaxis (PrEP)

Pre-exposure prophylaxis, or PrEP, is a form of HIV prevention in which HIV-negative people take medication to protect themselves from HIV. PrEP involves taking medication on an ongoing basis before and after possible exposure to HIV.

Research shows that daily PrEP is at least 99% effective in preventing the sexual transmission of HIV, as long as the drugs are taken regularly, and exactly as directed. It works for men and women, cisgender and transgender, heterosexual and gay. While PrEP can prevent HIV, it does not prevent other sexually transmitted infections (STIs) or pregnancy.

It's usually recommended that PrEP be taken every day. This maintains protective levels of the drugs in the body.

An alternative approach is called 'event-based PrEP' or 'on-demand PrEP' – only taking the medication several hours before having sex and for a few days afterwards. This may be possible for those who know in advance when they will have sex. However, it is only recommended for cisgender men who have sex with men who need protection during anal sex.

Who needs to take PrFP?

PrEP is recommended for HIV-negative people who do not consistently use condoms or think it likely they won't, have partners who do not know their HIV status, have sexual partners that may have HIV without realising it, or have had a bacterial STI recently.

HIV transmission is most likely to occur with an HIV-positive partner who doesn't know that they have HIV and has not yet started treatment, and

therefore has a high viral load. In these instances, PrEP is highly beneficial for the HIV-negative partner.

However, if you are HIV positive and undetectable, your sexual partner does not need to take PrEP. As there is no risk of transmission with an undetectable viral load, PrEP would not be recommended.



"If you are HIV positive and undetectable, your sexual partner does not need to take PrEP."

your sexual relationship.

Once again, it is important to have a discussion about this, as is the case of deciding not to use condoms anymore. If your HIV-negative partner has other sexual partners of unknown status, it would be best for them to remain on PrEP. While you can no longer pass HIV on, your sexual partner could still contract it from other people outside of

PrEP may also be the right option for your sexual partners if you are not yet on treatment or have recently started, as it is highly effective at preventing sexual transmission of HIV. It could be used together with, or instead, of condoms.

Post-exposure prophylaxis (PEP)

Post-exposure prophylaxis, or PEP, is a method of preventing HIV transmission. It involves using a four-week course of the drugs used to treat HIV, taken as soon as possible after a person may have been exposed to the virus (within 72 hours).

Unlike PrEP, it is an emergency measure, rather than one to be used as a regular method of preventing HIV transmission. PEP is intended for isolated incidents that carry a high risk of exposure to HIV, such as condom breakage during sex with a person known to have a high viral load, or following sexual assault with penetration and ejaculation. PrEP consists of two drugs, whereas three drugs are recommended for PEP.

PEP can be prescribed by sexual health and HIV clinics, or hospital accident and emergency departments out of hours, if there has been significant risk.

To have the best chance of it being effective, PEP needs to be taken as soon as possible after the potential exposure to HIV. It is best to start PEP within 24 hours, but certainly within 72 hours; it is not effective if taken after 72 hours.

Do not be tempted to offer an HIV-negative sexual partner your HIV medication in efforts to prevent a potential infection. Some anti-HIV drugs work better as PEP than others. A full PEP course should last a month. Sharing your HIV drugs could be risky as some can cause an allergic reaction. There is also a chance that the person you are giving your HIV drugs to could already have HIV and not know it. In this case, taking a few doses of your

HIV medicine could give the HIV in their body a chance to develop resistance to those drugs. This would limit their future treatment options.

Condoms

Before the medical breakthroughs of PrEP and U=U, condoms were relied on as the primary method of protection against HIV. This has changed now that there are other ways to prevent HIV.

However, a benefit to using condoms is that, when used correctly and consistently, they do not only prevent HIV, but also many other STIs. They can also help prevent unwanted pregnancy.

Both male and female condoms are available. To be effective, condoms need to be used consistently and correctly each time you have sex. You can read more about how to use condoms on www.aidsmap.com.

Many people living with HIV have found that U=U has given them the freedom to explore sex without condoms. While condoms remain

the most effective way of preventing other STIs, in addition to HIV, many people who choose not to use condoms find other ways of managing this risk. For instance, frequent testing for STIs leads to improved detection, quicker treatment and less chance of passing them on.

For more detailed information on all these prevention methods, go to www.aidsmap.com.

Conception, pregnancy and contraception

People living with HIV can give birth without passing on HIV to their baby. So long as you are taking HIV treatment and have an undetectable viral load, most of the advice is the same as it would be for anyone else thinking about having a baby.



Having an undetectable viral load is important if you are thinking of having a baby. Providing you have an undetectable viral load and neither you or your partner have any sexually transmitted infections (STIs), you can safely have sex without using a condom.

People living with HIV can give birth to HIVnegative babies. When a person is taking HIV treatment and they have an undetectable viral load, the risk of the baby being born with HIV is just 0.1% (or one in a thousand). Between 2015 and 2016 in the UK, only 0.3% of people with HIV (including people with a higher viral load) gave birth to babies with HIV.

For cisgender men living with HIV, it is important to know that HIV can't be passed directly from the father to the baby.

> When thinking about conception, the advice will depend on each couple's circumstances. Advice will be based on your general health, whether you are taking anti-HIV drugs, your viral load and whether your partner has HIV.

If you or your partner have a detectable viral load, it is important to discuss conception options that reduce or remove the risk of transmission during sex to you, your partner and your baby. Before deciding not to use condoms, get advice from your HIV healthcare team so that they can confirm what would work best for you. If your partner is HIV negative, this could include them taking PrEP (see page 42). PrEP is safe to take during pregnancy and breastfeeding

All pregnant people living with HIV are advised to start taking medication by week 24 of pregnancy, if they are not already. This is because an undetectable viral load prevents transmission during conception, pregnancy and birth.

" If you have an undetectable viral load, vaginal delivery is usually recommended.

If you are planning on getting pregnant and are already taking anti-HIV medication. talking to your healthcare team will give you a clearer understanding about your current medication and if it is still the best option during pregnancy. If your current anti-HIV medication is effective. you can keep taking it.

If you have an undetectable viral load, vaginal delivery is usually recommended. For those with a high viral load (for example, over 400 copies/ml), a caesarean delivery lowers the risk of HIV transmission. The delivery method that is best for you and your baby will also depend on medical factors that are not related to HIV and should be discussed with your doctor.

52 After giving birth After giving birth 53

After giving birth

Your baby will need to take anti-HIV drugs (known as infant PEP) for a period of time after birth. This will be in liquid form. This does not mean that your baby has HIV. The length of time your baby will need to take medication will depend on your viral load. If you are undetectable throughout pregnancy, your baby will be given medication for two weeks. If you have a detectable viral load, this may be extended to four weeks.

In the early years of your baby's life, HIV tests will be done several times: just after birth, at six weeks,

12 weeks and at 24 months (final HIV antibody test). If these tests are negative and you have never breastfed, you will know for sure that your baby does not have HIV.

In terms of feeding, the best way to ensure that HIV is not

transmitted is to formula feed, as there is no risk of HIV being passed on.
When deciding on your preferred feeding method, HIV is an important factor to consider, but it is not the only one.

You may consider breastfeeding (also known as

"The best way to ensure that HIV is not transmitted is to formula feed."

chestfeeding) for other reasons. If you do consider breastfeeding, it is important that you have an undetectable viral load and stay in regular contact with your healthcare team.

It is important to discuss this with them before deciding to breastfeed.

It is important that you **stop breastfeeding** if your HIV becomes
detectable, you or your baby have tummy
problems or your breasts and/or nipples show
signs of infection (cracked, sore or bleeding
nipples).

This will help to reduce HIV transmission during breastfeeding, but the most effective way to remove all risk is not to breastfeed and to formula feed instead.

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Contraception

You will need contraception if you want to plan when pregnancy happens or if you want to avoid becoming pregnant. There are specific issues for people living with HIV to consider when choosing a contraceptive method.

Male or female condoms can prevent pregnancy, as well as preventing the transmission of HIV and most STIs, when used correctly and consistently.

In addition to condoms, there are many other types of contraception that are more effective, including some hormonal methods such as the pill, injections and implants, and also the intrauterine device (coil).

However, several anti-HIV drugs interfere with the way some hormonal contraceptives work and can reduce the effectiveness of the contraceptive. There are possible drug interactions between some forms of hormonal contraceptive and the anti-HIV drugs efavirenz (Sustiva, also in Atripla), and drugs in the protease inhibitor class, such as darunavir (Prezista, also in Symtuza and Rezolsta) and atazanavir (Reyataz, also in the combination pill Evotaz). If you are taking the integrase inhibitor elvitegravir (included in the combination pills Stribild and Genvoya), you may need to take a higher dose of hormonal contraception or use another method.

The interaction can occur because both the anti-

Several anti-HIV drugs interfere with the way some hormonal contraceptives work."

in the liver by the same enzymes, so the contraceptive is processed faster than usual. As a result, levels of the contraceptive hormones may be too low to always prevent a pregnancy. The anti-HIV drugs will continue to be effective and work well.

You should ask your healthcare team about your options if you are considering a hormonal contraceptive. They may suggest switching to a different HIV treatment or a different contraceptive. You should be provided with the most effective suitable method of contraception that is acceptable for your needs. Intrauterine devices and intrauterine systems are highly effective methods of contraception and do not interact with any anti-HIV medications. For more detailed information on contraception, conception, pregnancy and infant feeding, go to www.aidsmap.com.

Sexually transmitted infections

Although STIs other than
HIV can seem a minor issue,
they can cause unpleasant
symptoms. If left untreated,
some can cause severe health
problems. This section covers
symptoms, vaccinations,
tests and treatment
of common STIs.

Sexually transmitted infections (STIs) can be caused by bacteria, viruses or parasites. More common STIs include:

- Chlamydia
- genital and anal warts (caused by the human papillomavirus, or HPV)
- gonorrhoea
- lymphogranuloma venereum (LGV)
- Mycoplasma genitalium, a bacterial infection
- hepatitis A, B and C
- herpes (caused by the herpes simplex virus, or HSV). This can cause both oral (on the mouth) and genital infection
- syphilis
- parasites such as pubic lice (sometimes called crabs) and scabies
- ☐ shigellosis, an illness caused by the bacteria Shigella, and other illnesses that cause diarrhoea
- ☐ trichomoniasis, an infection caused by a very small parasite.

Most STIs can be easily treated. However, if they are left untreated for many years, some can cause irreversible damage to your health or, in extreme cases, be fatal.

Some sexually transmitted viral infections, such as herpes simplex virus (HSV, normally just called herpes) and HPV, cannot be cured, although their symptoms can be reduced or treated.

Hepatitis A, B and C can all be passed on during sex (hepatitis B is especially infectious). They can all make you seriously ill if they are left untreated (see NAM's booklet *HIV* & hepatitis for more information on hepatitis).

Sexual health check-ups

If you are sexually active, it is important to have regular sexual health check-ups. For people considered to be at high risk of STIs (because they have had sex without a condom with a new partner, have multiple partners, or been diagnosed with an STI), the recommendation is to have a check-up every three months.

Many HIV clinics share a building with a sexual health clinic and many HIV clinics include sexual health screening as part of their routine HIV care. You can choose which sexual health clinic you go to. It does not have to be the one nearest your home or the one linked to your HIV clinic.

Visits to sexual health clinics usually involve seeing a healthcare provider who will ask you about the kind of sex you are having and whether you have any symptoms of an STI before examining you. It is important to be honest about the types of sex you have had, so you can be given the appropriate tests. Sexual health clinics are very used to seeing all the communities affected by HIV in the UK.

Most people are happy with their treatment at sexual health clinics, but if you are not treated in a professional and non-judgemental manner, you have a right to raise this or make a complaint.

Tests and examinations for STIs vary, often depending on whether you have symptoms. They might be done in the clinic. Or they may give you a kit and ask you to take your own swabs and samples which you then post to a laboratory for analysis.



Samples may be taken from the tip of your penis (only if you have symptoms) or from inside your vagina. If you have oral or anal sex, you will be asked for samples from the mouth, throat and anus. You may also be asked for a urine sample and a blood sample. These swabs and samples are then sent to a laboratory to look for evidence of infection and may be examined under a microscope for rapid detection.

Some results can be given to you at your visit, but it may be necessary to wait for a text message, a telephone call from the clinic, or to come back a week or so later for some other results.

All treatment at NHS sexual health clinics is confidential and free of charge (even if you are not normally entitled to free NHS care). The clinic will need a record of your postcode for administration purposes. Your GP will not be informed without your consent.

If it turns out that you have an STI, you may be offered the opportunity to see a sexual health adviser. Sexual health advisers can give you information about STIs and how to avoid them and can help you contact your sexual partners. if this is possible or practical, so they can also be tested and treated. This helps prevent infections from spreading in the wider community and can help reduce the chance of you becoming reinfected.

In the UK, some GPs or practice nurses offer sexual health screens. Free chlamydia testing and treatment is widely available for people under the age of 25. Many pharmacies also work with local sexual health clinics to provide screening and treatment.

STI postal testing kits that can be ordered online and used at home, with samples sent back to a laboratory for testing, may also be available in your area.

Vaccinations against STIs

There are vaccines available for:

- hepatitis A
- hepatitis B
- O human papillomavirus (HPV), which can cause genital and anal warts, as well as several types of cancer

Your clinic can advise you on whether you need vaccination against hepatitis A. Unless you have natural immunity, the hepatitis B vaccine is recommended for all people with HIV.

> The British HIV Association (BHIVA) recommends that the following groups of people living with HIV should have the HPV vaccine: women up to the age of 40, gay and bisexual men up to the age of 40, and heterosexual men up to the age of 26.



Common symptoms

There are some common symptoms of STIs. These include:

- a discharge from your vagina, penis or anus. This may be discoloured – for example, milky, vellowish or like mucus - or may have blood in it
- pain or a burning feeling when you urinate (pee) or needing to urinate more often than usual
- pain while you are having sex
- abnormal stomach pains
- pain or swelling around your anus or testicles
- ogenerally feeling unwell
- of for herpes: numbness, itching and tingling, followed by bumps that become small, fluidfilled blisters
- of for syphilis: small sores, spots or ulcers on the penis or around the mouth, vagina or anus at the site of infection; a rash on your torso, arms, palms or soles of feet

- of for hepatitis A, B and C: symptoms can include jaundice (a yellowing of skin and eyes), nausea and vomiting, and tiredness
- of for genital warts: lumps and bumps around the genital area and anus
- of for parasites, especially scabies: itching around the genitals or in other concealed places, such as between the fingers or toes, or behind the knees
- diarrhoea with blood and rectal pain.

" Many people have no symptoms at all when they first get an STI."

However, many people have no symptoms at all when they first get an STI, or their symptoms are so mild they don't notice them. Regular sexual health checks are important because they can diagnose STIs even if you have no symptoms. Many STIs can go on to cause serious, long-term health problems if they are not diagnosed and treated, including

causing infertility. Hepatitis B and C can become chronic (long-term) conditions and lead to serious liver damage while syphilis can affect organs such as the brain and heart.

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Treatment

Antibiotics can cure bacterial infections such as chlamydia, gonorrhoea and syphilis, and also the parasitical infection, trichomoniasis. Antibiotics may be given as tablets or by injections, depending on the STI you have.

Antiviral drugs can be used to treat (but not always cure) some viral infections. Herpes cannot be cured and the virus stays in nerve cells for life, although most of the time it may not cause symptoms. You may have episodes from time to time, especially if you have a weakened immune system. Your immune system may suppress HPV, the genital warts virus, but this may take a long time and for some people never happens. There are various treatment options to get rid of visible warts.

Drugs to treat hepatitis C can provide a cure, but they don't protect you from being infected again.

Topical treatments, such as lotions, can clear infestations of parasites such as scabies or pubic lice. You should also wash clothing, towels and bedding at high temperatures.

It is important to finish the whole course of any drugs prescribed and to go to any follow-up appointments you are advised to have. You may be advised not to have sex (even with a condom) until any treatment is finished, and sometimes for a while after that. This will ensure you get the correct treatment and are completely cured of the STI, if that is possible.



Transmission and prevention of STIs

STIs can be transmitted through anal, oral and vaginal sex, and by sharing sex toys.

Some can also be passed on through rimming (mouth-to-anus contact), kissing or other close physical contact. Parasites can be passed on by sharing towels or bedding. Some STIs (including hepatitis A) and other infections (for example, gut infections such as giardia) can be caused by contact with infected faeces (excrement, shit), such as during rimming or fisting. Hepatitis A can also be transmitted through contact with infected faeces in contaminated food, for example, shellfish.

Hepatitis B is passed on by contact with the blood, semen, saliva, or vaginal fluids of a person with hepatitis B. It is easily passed on during sex without a condom and to a baby during childbirth. It is many times more infectious than HIV. Hepatitis C is normally passed on through blood-to-blood contact. It is also passed on through sex among gay men having anal sex without using condoms. Other factors that seem to be associated with sexual transmission of hepatitis C are group sex, fisting, sharing sex toys, injecting or snorting drugs, anal administration of drugs and the presence in either person of other STIs, especially syphilis or LGV infection.

"With some STIs, using a condom will reduce the risk of infection, but not protect you completely."

Using condoms during anal or vaginal sex, using a condom or dental dam for oral sex, and not sharing sex toys can protect you against most STIs. If you are fisting, to protect yourself against hepatitis C, wear latex gloves and do not share pots of lubricant. With some STIs, using a condom or dental dam will reduce the risk of infection, but not protect you completely.

For vaccination against hepatitis A, hepatitis B and HPV, (see page 63).

You can read more about these STIs, their transmission, prevention, diagnosis and treatment at www.aidsmap.com.

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Summary

- Living with HIV shouldn't stop you from enjoying sex and physical intimacy. You can take steps to ensure that you protect your health and that of your sexual partner(s).
- Taking effective anti-HIV medication and maintaining an undetectable viral load ensures that you will not pass HIV on to your sexual partners, even if you don't use a condom. This is known as Undetectable = Untransmittable, or U=U.
- There are several ways to prevent the sexual transmission of HIV, including U=U, condoms and PrEP. Knowing that you have a reliable prevention method may help to reduce anxiety around sex.
- You may experience complex and changing feelings about sex in response to your HIV diagnosis. These feelings will probably change over time as you adapt to living with HIV. It's important to recognise that a healthy sex life is part of your overall health and wellbeing.

- Deciding whether to tell sexual partners you have HIV can be difficult. While it may leave you vulnerable to rejection, it also opens up a space where you can talk about U=U and other ways to protect your partner's health.
- Sexual problems can be caused by both psychological and physical issues. Help and support are available for both.
- People living with HIV can have babies who do not have HIV. An undetectable viral load protects your partner and baby from HIV.
- U=U, PrEP and PEP do not prevent the transmission of other sexually transmitted infections (STIs). Condoms are the most effective way to prevent most other STIs; vaccinations are available for some infections.
- Especially if you do not always use condoms, it is important to have regular sexual health check-ups to detect STIs. Most STIs can be treated or cured.

HIV helplines

THT Direct 0808 802 1221

Open Monday to Friday, 10am-6pm. Saturday and Sunday, 10am-1pm. Support, advice and information from the Terrence Higains Trust.

HIV i-Rase 0808 800 6013

Open Monday to Wednesday, 12pm-4pm. For advice on any aspect of HIV treatment.

Positively UK 020 7713 0444

Open Monday to Friday, 10am-4pm. Contact Positively UK about any aspect of your diagnosis, care and living with HIV.

More from NAM

NAM's website is full of useful information resources and the latest news on HIV and related topics: www.aidsmap.com

Subscribe to our bulletins and news feeds, and connect with us on social media:

www.aidsmap.com/about-us/connect-us

All of NAM's booklets and resources for members of our Patient Information Scheme on the clinic portal: clinic.nam.org.uk

NAM's booklets

NAM's booklets are available from HIV clinics which are members of our Patient Information Scheme. Ask for our booklets at your clinic.







Other booklets in the series:

- ☐ A long life with HIV
- Anti-HIV drugs
- CD4, viral load & other tests
- OHIV & hepatitis
- ☐ HIV & sex

- OHIV, stigma & discrimination
- C HIV & women
- Nutrition
- ☐ Side effects

NAM values all feedback which helps us to improve our resources. If you have any comments or feedback about any of our resources, please email us at info@nam.org.uk.

The information in this booklet isn't intended to replace discussion with your doctor about your treatment and care, but it may help you to think about any questions you'd like to ask your healthcare team.



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About NAM

NAM is a charity that works to change lives by sharing information about HIV & AIDS. We believe that independent, clear, accurate information is vital to those living with HIV.

Please help us

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Contact NAM to find out more about the scientific research and information used to produce this booklet.