nam aidsmap

HIV & women

2010 Fourth edition

In collaboration with:

POSITIVELY UK

Fourth edition 2010
This edition revised by Positively UK
(formerly Positively Women)
Due for review in 2012

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

Acknowledgements

NAM is grateful to the funders of this booklet series:
Department of Health
NHS Pan-London HIV Prevention Programme

Thanks to the following for their assistance:

Prof. Janet Darbyshire
Joint Director, NIHR Clinical Research Network

Sarah Ellis
Clinical nurse specialist, HIV women's health, Barts and the London NHS Trust

Sally Farthing
HIV specialist midwife, West Middlesex Hospital

Prof. Frances Gotch
Department of Immunology, Chelsea and Westminster Hospital

Heather Leake Date
Consultant pharmacist, HIV and sexual health, Brighton and Sussex University Hospitals NHS Trust

Sanna Savolainen
Health trainer, Terrence Higgins Trust

Staff and service users at Positively UK

HIV & women

This booklet is about HIV and women. Whether you are newly diagnosed with HIV, or have been living with HIV for a long time, the information here is to help answer your questions on living well with the virus, and on talking to your doctor and others involved in your health care. It is not intended to replace discussion and guidance from your doctor.

The booklet includes information on some of the day-to-day issues involved in living with HIV, as well as information on HIV treatment, sexual health, contraception and pregnancy.

An HIV diagnosis is a life-changing event. It is important to know that a woman with HIV can live a healthy life; have a baby without passing on HIV; work, study, attend school or college; and have emotional and sexual relationships.

In the UK, people with HIV are protected by law against discrimination in employment, housing and the provision of goods and services under the *Equality Act 2010*.

Contents

Living with HIV

We asked a group of women who had been living with HIV for some time how they had felt and responded when they first had their diagnosis.

"This is happening to someone else" and "Why me?" were followed by shock, numbness, disbelief, fear, anger, blame and shame.

"Feelings of isolation, fear of rejection, anxiety about having a sexual relationship and disclosing my status were overwhelming."

But for some women, it was a relief to know what had been causing them to be ill.

We then asked the same group "What has helped you to move into living your life as you are now?"

"Speaking with other women with HIV helped me say I'm HIV-positive and [to] be myself."

"Seeing others with HIV getting on with life and challenging the image of illness and death."

"Making achievable plans, studying, working and not putting life on hold."

"A supportive healthcare team."

"Seeing women with HIV looking well and beautiful was an inspiration."

In practical terms, many women found counselling, peer support and a good healthcare team helped in dealing with their feelings. Being able to disclose HIV status and having supportive and non-judgemental friends and family, being part of a supportive faith community, and personal faith and spirituality all contributed to becoming 'more than a virus'.

"There is life after an HIV diagnosis."

Telling people you have HIV

Many women are fearful of telling their friends and family about their HIV status. They may fear rejection, violence, exclusion or blame. However, many women find acceptance, and relief at sharing a secret that can otherwise seem like a terrible burden. We know that disclosing to just one person can also help you manage to take your HIV drugs regularly and correctly.

It can help to think of disclosure as a process and that you can prepare someone to hear that you are living with HIV. Talk to other women about how to prepare friends, family or partners and get support from your healthcare team and support organisation. See page 39 of this booklet for more on disclosure.

Being vulnerable

Some women with HIV are particularly vulnerable to being sexually or financially exploited because they fear revealing their status. Talk with your healthcare team and support organisation about staying safe and independent if you think this applies to you.

Keeping well

HIV (the human immunodeficiency virus) weakens your immune system. When you become HIV-positive, you might not feel ill or even know you have HIV. Once you have been diagnosed with HIV, the health of your immune system should be regularly measured by looking at your CD4 cell count. If your CD4 count drops below a certain level, you will need to start HIV treatment.

HIV treatment is called antiretroviral therapy (ART). It lowers the level of HIV in your body and allows your immune system to stay strong. The aim of HIV treatment is to get your viral load below 50 copies/ml. This is often referred to as an 'undetectable' viral load because standard viral load tests can't detect such small quantities of virus. Having an undetectable viral load means that HIV is still in your body, but at a much lower level.

HIV treatment helps prevent you from developing certain illnesses, such as some serious infections and types of cancer. Some of these illnesses are known as AIDS-defining illnesses, which means that your HIV has progressed. AIDS stands for:

Acquired – something you get
Immune – affects your body's immune system
Deficiency – weakens your immune system
Syndrome – a collection of illnesses.

With the right treatment and care, many people with HIV may never experience AIDS. It depends on a range of factors, including how well you respond to treatment and lifestyle factors that influence your health, such as diet, exercise and smoking.

Health checks for HIV

To protect your immune system and maintain your health and wellbeing, it is recommended that you have regular medical monitoring. This will measure the health of your immune system and show when it is the best time to start HIV treatment. Once you are on treatment, these checks will show how well the treatment is working and whether you may need to change treatment.

You can play a role in your health care by regularly attending your clinic appointments and thinking about what is working well for you and what is not working well, in advance of the appointment. This way your concerns will be raised and dealt with. It might be a good idea

to note down any questions you have between appointments, so you remember to ask them at your next appointment.

The most important blood tests in monitoring HIV are CD4 cell counts (to measure the strength of your immune system) and HIV viral load tests (to measure the levels of virus in the blood). See NAM's booklet *CD4, viral load and other tests* for more information.

Your CD4 cell count may go up or down with your menstrual cycle. The oral contraceptive pill may lower your CD4 cell count, but not to such an extent that your health could be at risk. Pregnancy can lower your CD4 cell count too; this is due to the effect of having a larger blood volume in your body while you are pregnant.

After the baby is born, the CD4 count usually goes back to the same level as before.

HIV and your body

Periods (your menstrual cycle)

As well as affecting your immune system, HIV may affect your hormonal system. You may experience menstrual changes if you have a low CD4 cell count and/or high viral load, and also if you use (or have used) recreational drugs.

Some of the menstrual changes you may experience include:

- long intervals between periods
- missed periods without pregnancy.

Tell your doctor if you notice any changes to your periods. It could mean that you need to consider starting to take antiretroviral therapy.

Changes in your menstrual cycle can also be a symptom of other health problems. But remember that a missed period might also mean that you are pregnant.

Abnormal bleeding (for example, after sex), bleeding after the menopause, or very heavy periods should also be reported to your doctor. Heavy periods can be caused by several factors, including fibroids (growths that develop from the smooth muscle layer of the uterus). If left untreated, the blood loss from heavy periods could lead to anaemia (a lack of red blood cells).

Fertility and menopause

HIV can affect your body's ability to produce the hormones oestrogen and progesterone. This can affect your fertility (your ability to become

pregnant) or lead to an early menopause (and the ending of your fertility), particularly if your CD4 cell counts are low.

Hormone replacement therapy (HRT) can be prescribed to prevent or lessen some symptoms of menopause, or to treat the early onset of menopause. HRT is generally not used as a long-term treatment because it may increase the risk of developing other conditions such as breast cancer.

HRT can be taken with HIV treatment; ask your doctor if there are any interactions between HRT and the anti-HIV drugs you are on. HIV clinics don't provide HRT, so you will need to have it prescribed by your GP or another doctor.

If you have questions about symptoms of the menopause, or possible interactions between treatments, talk to your healthcare team. You could also ask about attending a menopause clinic.

Osteoporosis

Osteoporosis – weakening of the bones through loss of bone density – is more common in all women who have gone through the menopause, because of the high level of hormonal changes which occur during menopause.

People with HIV tend to have lower than normal bone density. It's not entirely clear why this is, but it seems likely that it is caused both by HIV itself and by the effects of treatment, as research suggests that certain anti-HIV drugs

may cause bone loss. (You can find out more about different types of drugs in NAM's booklet *Anti-HIV drugs*.)

Bone mineral density can be measured painlessly with a scan known as DEXA (for dual energy X-ray absorptiometry). You may have been offered this scan as part of your HIV health monitoring, but if you haven't, and you are HIV-positive and menopausal, ask to have one done.

There are a number of things you can do to reduce loss of bone density and its effects. These include taking some weight-bearing exercise (such as walking, running, or climbing stairs) and having a healthy diet, with plenty of calcium and vitamin D. Oily fish and eggs are a good source of vitamin D (as is sunlight); calcium can be found in dairy products, green leafy vegetables, nuts, soya beans and food made with fortified flour.

You may want to consider taking calcium and vitamin D supplement tablets, particularly if your diet does not include many of the foods containing these nutrients. Taking too much of a supplement can be harmful, so it is a good idea to talk to someone at your HIV clinic, or your GP, before you start. You could also ask to talk to a dietician, to find out if you can adapt your diet to increase the calcium and vitamin D it provides.

Smoking and heavy drinking can increase your risk of osteoporosis.

Your healthcare team can give you more advice on changes to your treatment and lifestyle that may help. There are also some treatments available to improve bone density and they can talk to you about those if necessary.

The *Nutrition* booklet in this series provides information on food, nutrition, exercise and HIV, and could be a good place to start if you have questions about any of these issues.

Reproductive health issues

Some reproductive health (gynaecological) problems happen more often in women with HIV, and can be more severe, or harder to treat.

Regular screening for sexually transmitted infections (STIs) is an important part of your health care. If you have an infection that can be transmitted sexually, your sexual partners will need to have a sexual health screen before you have sex again so that they can also have any infections diagnosed and treated.

Pelvic inflammatory disease (PID) is always a serious condition, especially if you also have HIV. It can be caused by untreated STIs such as gonorrhoea and chlamydia, as well as other bacteria and infections such as tuberculosis. PID can make you infertile (unable to get pregnant).

Symptoms include:

- pain in the lower part of your stomach area
- vaginal discharge
- cramping during sex

- deep internal pain
- fever
- vomiting
- tiredness
- unusual bleeding from the vagina.

A general sexual health check-up will include tests to see if you have gonorrhoea or chlamydia. You may need a scan to see if the PID has caused any cysts or abscesses, or an examination called a laparoscopy. This procedure involves a surgeon making a small cut in the stomach to insert a tube that allows them to see inside the abdomen and the pelvis. It is done under a general anaesthetic.

If you have PID you will be treated with a combination of antibiotics. Getting help and treatment early is important to reduce the risk of long-term pain and recurrence of the PID.

Women living with HIV may be more likely to have abnormal cervical cells caused by the **human papillomavirus** (HPV). Some strains of this virus can lead to cervical cancer. It is possible for your body to clear HPV infection itself, but HIV-positive women are much less likely than HIV-negative women to do so.

Make sure you have regular **cervical screening** (smear test) to check for these cells so that you can receive prompt treatment to remove them. All HIV-positive women should have a cervical screen soon after they are diagnosed with HIV, again after six months and then every year after that. Treatment for abnormal cervical cells is

highly effective, provided they are detected early.

Other strains of HPV can cause genital warts, but these don't always leave visible signs. They can be detected by cervical screening and treated by applying a cream, or by freezing or burning them off.

Genital **herpes** (herpes simplex virus-2, or HSV-2) can last longer and be more painful if you have HIV. The anti-viral drug aciclovir can help shorten the duration of herpes episodes. If you are getting regular episodes of herpes, you may wish to consider taking aciclovir every day to prevent this.

Although there is an increased risk of fungal infections if you are HIV-positive, such as vaginal **candidiasis** (thrush), treatment works well.

Bacterial vaginosis is an overgrowth of bacteria in the vagina that occurs in many women, regardless of their HIV status. It can increase the risk of mother-to-baby transmission of HIV. Its symptoms include a discharge which has a 'fishy' odour. It can be treated with antibiotics. Using scented or strong soaps on the genital area should be avoided to prevent irritation. Excessive washing of the vagina (douching) increases your risk of developing bacterial vaginosis.

Sex and HIV

Many women with HIV experience a temporary loss of libido or find sex painful. You may also experience anxiety about starting a new relationship or transmitting HIV, and fear of rejection on disclosing you have HIV. It is important to acknowledge that these feelings are real and then to seek solutions.

Your healthcare team may include a psychologist or counsellor who could help, but sometimes talking with a close friend or with others who have had similar experiences can be just as helpful.

Sex, desire and pleasure need not stop when you have an HIV diagnosis. You may want help on how best to negotiate safer sex or on how to use male and female condoms. Your healthcare team and support organisation can provide this help.

Preventing transmission of HIV

The risk of passing on HIV depends on many factors such as your viral load and the presence of other sexually transmitted infections.

Using male or female condoms consistently, not having unprotected vaginal or anal sex, not sharing injecting equipment, following the guidelines for a safe pregnancy and birth, and not breastfeeding are the key ways of not transmitting HIV to another person.

The risk of passing on HIV from oral sex is low. If someone is performing oral sex on you (also called 'cunnilingus', which means using the

lips and tongue to stimulate female genitals) they can lower the risk even further by using dental dams (small pieces of latex). If you are performing oral sex on someone else, the only body fluid they have contact with is your saliva, so there is no risk of HIV being passed from you to them. The only possible risk would be if your mouth was bleeding.

Women are often vulnerable in negotiating safer sex for social and cultural reasons. If you have difficulty persuading a partner to use a condom, try using the female condom (*Femidom*), which puts you in control of safer sex and can give heightened sexual pleasure.

Talk to your healthcare team or a support organisation if you are vulnerable to exploitation for financial, social or immigration reasons and they will help you to find ways of managing the situation. See page 44 for contacts.

Sexuality and HIV

HIV-positive lesbians, women who have sex with other women but who don't identify as being lesbian, and transgender people are likely to face stigma based on sexuality as well as HIV status.

The risk of transmitting HIV during sex between women is low, and it can be lowered even further by using dental dams for oral sex. If you and your partner use the same sex toy, you could pass on an infection (including HIV). To avoid this, put a new condom over it or wash it in warm soapy water between each use.

Contraception

Both male and female condoms (*Femidoms*) are highly effective at preventing pregnancy, the transmission of HIV and most sexually transmitted infections. However, they need to be used properly in order for them to be effective. If you are not sure how to use them, you can ask for help from your healthcare team. You can also get help from a range of community-based organisations (see page 44 for contact details); for example, you may be able to attend one of the sexual health and relationship workshops run by the organisation Positively UK to get more information and support around this topic.

In the UK, HIV treatment centres and sexual health (GUM) clinics offer both male and female condoms free of charge.

If a condom breaks during sex, the emergency contraceptive pill is available to buy from chemists. You may also be able to obtain free emergency contraception from a GP, GUM clinic or the accident and emergency department (A&E) of your local hospital. It's important you let the doctor or pharmacist know if you are on HIV treatment, as some anti-HIV drugs interfere with the way the emergency contraceptive pill works, and you will need to take twice the normal dose. You need to take the pill within 72 hours of having sex, ideally sooner.

Having an IUD (see page 16) fitted stops sperm from reaching an egg and fertilising it. It is the most effective method of emergency contraception and prevents up to 99% of pregnancies. It is suitable for women with HIV as it doesn't contain any hormones. You may want to continue to use it as a long-term form of contraception. But remember that this type of contraception doesn't prevent you passing on HIV or other sexually transmitted infections.

If your partner is HIV-negative and a condom breaks during sex, they should visit a GUM clinic or A&E department as soon as possible, and definitely within 72 hours, where they may be prescribed **post-exposure prophylaxis** (PEP), a short course of anti-HIV drugs which may be able to prevent them from becoming infected.

Because of the need for condoms to be used properly every time to prevent pregnancy, you may want to use a back-up form of contraception as well.

Several anti-HIV drugs and antibiotics interfere with the way some hormonal contraceptives work, and the contraceptive may not be as effective as usual. Getting advice on possible drug interactions from your doctor or pharmacist is important.

These hormonal contraceptives are less effective if you're taking HIV treatment:

- the combined pill
- the progestogen-only pill, also known as the mini-pill

- patches – a small beige patch applied to the skin like a sticky plaster that is changed once a week
- implants – a small flexible rod that is inserted under the skin on the upper part of the arm, and works for up to three years
- vaginal rings – a small flexible ring that is inserted in the vagina for three weeks of the month.

Several types of contraceptives are not affected by anti-HIV drugs. They are the intrauterine device (IUD), the Mirena intrauterine system (IUS) and the Depo-Provera injection.

An IUD is a small, T-shaped contraceptive device made from plastic and copper that fits inside the womb (uterus), sometimes called a coil. It releases copper into the body, causing changes that prevent sperm from fertilising eggs. You will be offered a sexual health screen, and any sexually transmitted infection (STI) will be treated before the coil is fitted by a doctor or nurse. It can be easily removed if it doesn't suit you.

The Mirena IUS is a small plastic device also fitted in the womb, which contains hormones that reduce the risk of heavy periods (sometimes stopping them altogether). It is also used by women with heavy, painful periods as an alternative to hysterectomy. It must be fitted by a doctor or nurse, after a sexual health check and treatment of any STI. Once it's fitted, it works for five years.

The most common type of contraceptive injection is called Depo-Provera; it contains the hormone progestogen and each injection lasts for 12 weeks.

None of these methods prevent the transmission of HIV or other STIs.

A number of other medications (e.g. antibiotics) interact with hormonal contraceptives, so getting advice on drug interactions from your HIV doctor or pharmacist is important. During the period you are taking any antibiotics, and for a week after, you are recommended to use an additional form of contraception if you are using a hormonal contraceptive.

Diaphragms and caps are flexible rubber or silicone dome-shaped devices which are placed in the vagina each time you have sex. They are not recommended for women with HIV, as they should be used with a substance called a spermicide that can irritate the vagina.

The National Health Service (NHS) provides free access to contraception; that is, you do not need to pay a prescription charge. Contraception is available from general practitioners (GPs), and from sexual health or contraception clinics. Details of local clinics are available from NHS Direct (tel 0845 46 47 or at www.nhs.uk) or from the FPA (www.fpa.org.uk/helpandadvice/findaclinic).

Conception

All women have the right to make their own choices about fertility and childbirth, regardless of their HIV status, and you should expect and receive the same level of support from doctors and healthcare workers as anyone else.

With effective HIV treatment, reducing viral load to an undetectable level and a managed delivery, the risk of an HIV-positive woman passing HIV on to her baby is very low.

Planning to get pregnant

HIV treatment can reduce the risk of transmitting HIV to your baby. If you are pregnant, or planning pregnancy, it's very important to find out how you can reduce the risk of your baby being infected with HIV and to ensure your drugs are the best ones for pregnancy. Discuss your concerns and options with your doctor.

Talking to other HIV-positive women who have been through the experience can help you to make informed decisions about pregnancy, birth and looking after your baby's health, such as having strategies in place for adhering to your treatment and for not breastfeeding.

You can prepare for pregnancy by making sure your viral load is low and that you and your partner are in good general health with no other infections or STIs. If you are thinking of becoming pregnant, you may be advised to try to conceive at a time when your viral

load is likely to be low, or easily controlled by HIV treatment. If you have an opportunistic infection, you should wait until it has been treated or until you no longer need treatment to prevent you getting such an infection (sometimes called prophylaxis).

UK guidelines on managing HIV infection in pregnant women suggest some things HIV-positive women can do when preparing to conceive, including taking folic acid (a vitamin needed to make new cells in the body). If you are taking a drug called cotrimoxazole (*Septrin*) because of an opportunistic infection or as prophylaxis, you may need to take an increased dose if you are also taking folic acid.

Talk to your doctor if you are planning on getting pregnant to ensure that you are taking or starting the most suitable HIV medication for pregnant women.

You cannot join a clinical trial looking at the effectiveness of new HIV drugs if you are pregnant or thinking of becoming pregnant. See NAM's booklet *Clinical trials* for more information.

Conception for sero-different couples

Getting pregnant through unprotected sex with a sero-different partner (where one partner is HIV-positive and the other is not) is not generally recommended because there is still a risk of transmission of HIV to the negative partner, even when your viral load is undetectable.

For an HIV-positive woman and an HIV-negative man

You can become pregnant safely if your partner is HIV-negative. This can be done through self-insemination, sometimes referred to as 'DIY'. This is a simple process you can do at home. You will need to make sure that neither you nor your partner has a sexually transmitted infection before trying it.

This is best done when you are ovulating (your fertile period). It's best to try the technique several times during your fertile period.

1. Your partner will need to ejaculate into a container. The container doesn't need to be sterile, but it should be clean and dry.
2. Next you'll need a plastic syringe. Your HIV clinic can provide them, or you can buy the kind used to give medicine to babies at a chemist.
3. Wait up to 30 minutes for the semen to become more liquid.
4. Draw back on the syringe once with nothing but air, then push the air out again. Now point the syringe into the liquid and slowly draw it back to suck in the semen.
5. Get into a comfortable position lying on the bed with your bottom raised on a cushion.
6. Either you or your partner can now slowly insert the syringe as far into the vagina as possible.

7. The area to aim for is high up in the vagina, towards the cervix.

8. Slowly squirt out the contents of the syringe. Gently remove the syringe.

9. Try to remain lying down for the next 30 minutes while the sperm makes its way through the cervix. Some semen may leak out but this is normal, and doesn't mean it won't have worked.

An alternative method is for you and your partner to have sex together, using a male condom. After sex, withdraw the penis from the vagina with the condom still on. Then take it off, and use a syringe to transfer the semen to your vagina. If you use this technique, make sure that the condom doesn't contain a spermicide.

The healthcare team at your clinic will be able to provide syringes and information on how to calculate and recognise when you are ovulating.

For an HIV-positive man and an HIV-negative woman

Sperm washing can be used to separate the seminal fluid, which contains HIV, from the sperm, which do not contain HIV. The remaining sperm are placed in a substitute fluid and inserted into your vagina when you are ovulating, the time when you are most fertile.

Although it can't be absolutely guaranteed that no HIV remains, sperm washing is considered very safe.

Sperm washing is not widely available and you may have to pay for this service. Your doctor or GP can give you more information or answer any queries you may have regarding sperm washing.

To be eligible for sperm washing you will need a referral from your partner's doctor with details of his viral load and CD4 count. You may be asked to show that you are in a stable heterosexual relationship.

If you have difficulty in conceiving or if your partner has a low sperm count, you may want to investigate IVF (*in vitro* fertilisation) together with sperm washing. You can ask your doctor for a referral to an assisted conception unit where you should receive the same service as couples who are not HIV-positive.

The success rate for sperm washing varies depending on how the sperm is implanted.

You could also consider the option of using donor sperm.

Conception for couples who are both HIV-positive

If you are both HIV-positive and have unprotected sex, it may result in one or both of you getting reinfected with a different strain of the virus, or a drug-resistant strain, especially if one of you is on treatment and the other one is not.

Sperm washing could be used by couples where both partners have HIV, and want to avoid reinfection.

However, if you are both taking HIV treatment and have an undetectable viral load and no other STIs, and neither of you are having sex with other partners, the risk of transmission is further reduced, but not eliminated. It is therefore extremely important for you and your partner to discuss your options and the risks with your doctor and healthcare team before you make a decision to have unprotected sex.

Other options

Talk to your healthcare team about your situation and other possibilities.

Fertility treatment funded by the NHS currently varies across the UK. The criteria that you must meet to be eligible for treatment can also vary, and in some cases it may depend on what your local health trust will fund. You may want to find out more about your options at a private fertility clinic, but there will be costs associated with this.

Adoption might be another option. Having HIV does not automatically mean you can't adopt, but your health and circumstances would be assessed before you could apply.

Pregnancy and birth

Reducing the risk of HIV transmission to the baby

Antenatal testing for HIV and early diagnosis and taking HIV treatment can help to reduce the risk of passing HIV to your baby.

There are two ways in which HIV treatment reduces the risk of you passing on HIV to your baby.

Firstly, HIV treatment reduces your viral load – the level of virus in your blood – so that your baby is exposed to less of the virus while in the womb and during birth. The aim of HIV treatment is to get your viral load below 50 copies/ml. This is often referred to as an undetectable viral load. Having an undetectable viral load means that HIV is still in your body, but at a much lower level.

Second, some anti-HIV drugs can also cross the placenta and enter your baby's body where they can prevent the virus from taking hold. This is also why newborn babies are given a short course of anti-HIV drugs (this is called PEP, or post-exposure prophylaxis) after they have been born, if their mother is HIV-positive.

A number of factors may make it more likely that you will pass on HIV to your baby. These include:

During pregnancy

- Being ill because of HIV.

- Having a high HIV viral load or a low CD4 cell count.
- Having a sexually transmitted infection. You should have a sexual health screen early in your pregnancy and another one at 28 weeks.
- Having used recreational drugs, particularly injected drugs.

During delivery

- Your waters breaking four or more hours before delivery.
- Having an untreated sexually transmitted infection when you give birth.
- If you have a vaginal delivery (rather than a caesarean delivery) when you have a detectable viral load.
- If you have a difficult delivery; for example, forceps need to be used.
- If you have a premature baby.

After delivery

- To avoid passing HIV to your baby, it is safest to formula feed because breast milk can contain virus. Help should be available with getting formula milk and feeding equipment. Ask your healthcare team about this and how to protect your confidentiality if a friend or family member asks why you are not breastfeeding.

Treatment during pregnancy

If you are in good health

If you have a good CD4 cell count and low viral load, and are not ill because of HIV infection, the UK guidelines recommend that you start taking AZT (zidovudine, *Retrovir*) in the final three months (the third trimester) of your pregnancy. You will also need to have an intravenous injection of AZT during delivery and to have a caesarean, rather than vaginal, delivery.

Another option is to take a short course of combination antiretroviral therapy during the last few months of pregnancy in order to get your viral load down to below 50 copies/ml. You may then have the option of a planned vaginal delivery.

Talk to your doctor or specialist midwife about your options so you can make an informed decision about the best mode of delivery for you.

If you are in good health at the beginning of your pregnancy, but become ill because of HIV later in your pregnancy and have to start taking antiretroviral therapy, then the aim should be to reduce your viral load to an undetectable level. You should continue to take HIV treatment after your baby has been delivered.

Your baby will receive treatment with AZT syrup for four weeks after it is born.

If you have a high viral load

If HIV has significantly damaged your immune system, or if you have a high viral load, then

you are advised to start HIV treatment. This will include two drugs from the nucleoside reverse transcriptase inhibitor class (NRTIs), ideally AZT and 3TC (lamivudine, *Epivir*), and either the non-nucleoside reverse transcriptase inhibitor (NNRTI) nevirapine (*Viramune*) or a protease inhibitor. You can find out more about the classes of drugs in NAM's *Anti-HIV drugs* booklet in this information series.

The higher your viral load, the earlier during your pregnancy you will need to start taking treatment. If you still have a detectable viral load before giving birth, then you need to have a caesarean delivery, but if your viral load is below 50 copies/ml and there are no apparent problems with the pregnancy, you may be able to have a planned vaginal birth.

Your baby will receive treatment with AZT syrup for four weeks after it is born.

If you are already on treatment

If you become pregnant whilst taking effective HIV treatment, you are recommended to continue taking this treatment.

Your baby will receive treatment with antiretroviral syrup (usually AZT) for four weeks after it is born.

If you become pregnant whilst on HIV treatment and your anti-HIV drugs are not suppressing your viral load to an undetectable level, then you should have a resistance test to determine your best drug options and then change to these drugs. The aim should be to

get your viral load undetectable by the time you deliver.

Your baby will receive treatment with an antiretroviral syrup (to which your virus is not resistant) for four weeks after it is born.

If you are diagnosed late in pregnancy

If you are diagnosed with HIV late in your pregnancy (32 weeks or later), then you will need to start taking HIV treatment immediately. A blood test will be used to determine any resistance you have to anti-HIV drugs. The most common drugs used in this situation are AZT, 3TC and nevirapine, as these drugs are able to rapidly pass over the placenta into your baby's body.

Your baby will usually receive treatment with the same combination of three drugs (AZT, 3TC, and nevirapine) as syrups for four weeks after it is born.

If you are diagnosed during delivery or afterwards

If you are diagnosed HIV-positive just before or during delivery, you will usually be given a dose of AZT by injection and oral doses of 3TC and nevirapine. Your baby will also need to take a triple combination of anti-HIV drugs for four weeks.

If you are diagnosed just after delivery, you won't receive any anti-HIV drugs, but your baby will need to take a triple combination of anti-HIV drugs for four weeks.

Safety of treatment to prevent mother-to-baby transmission

There's some evidence of a slightly increased risk of having a premature, or low birth-weight baby if the mother takes anti-HIV drugs during pregnancy, particularly if the mother takes a protease inhibitor. However, this is a controversial issue and other evidence suggests that taking anti-HIV drugs does not cause premature delivery.

A baby's development is most likely to be affected by any drugs you take during the first 14 weeks of pregnancy. AZT is the only drug that has been tested specifically for use during pregnancy and found to be safe. Only two drugs – ddI (didanosine, *Videx*, *Videx EC*) and efavirenz (*Sustiva*) – have caused any concerns about a possible link with birth defects. However, research now suggests that none of the anti-HIV drugs are linked to an increased rate of birth defects.

The anomaly scan pregnant women normally have between weeks 18 and 20 of a pregnancy can check for possible physical problems in your baby's development.

HIV and childbirth

The risk of your baby contracting HIV is reduced if you have a planned caesarean section. This is usually scheduled to take place for the 38th week of pregnancy. If your labour begins early, the surgical delivery will be performed sooner. Taking anti-HIV drugs during a caesarean delivery reduces the risk of you passing on

HIV to your baby to very low levels. However, as with all surgery, caesarean delivery carries some risks. These risks should be explained to you before you agree (give consent) to the procedure.

You are strongly recommended to have a caesarean delivery if you have a detectable viral load, or if the only anti-HIV drug you took during pregnancy was AZT.

If your viral load has been consistently below 50 copies/ml, then you may be able to have an actively managed vaginal birth. This means that your doctors and midwife will monitor you carefully and make sure that your labour doesn't last too long to reduce the risk of you passing on HIV to your baby.

Breastfeeding and HIV

Breastfeeding carries a risk of passing on HIV to your baby. The risk of transmission can be as high as one in eight, depending on your own state of health, how long breastfeeding continues, and whether the baby receives any food or water in addition to breast milk (this seems to make the transmission of HIV more likely).

In the UK and other countries where safe alternatives to breastfeeding are available, you are advised to feed your baby with formula milk from birth.

Detailed advice and support on how to do this is available from your healthcare team, as well as from support organisations (see page 45 for contacts). Ask your healthcare team or support

organisation if you have difficulty meeting the cost of formula and the equipment needed.

For help and support on explaining to others why you are not breastfeeding when you want to keep your HIV status confidential, talk to other mothers with HIV about how they have successfully done this. Your healthcare team or support organisation can also help you with this.

See the British HIV Association guidelines on infant feeding for more information (www.bhiva.org).

Health care during your pregnancy

You are likely to be looked after by a multidisciplinary antenatal team during your pregnancy. Your care will still be offered at your HIV clinic, but as well as your HIV doctor and clinic staff, you are likely to see an obstetrician, a specialist midwife and a paediatrician. Other people you may see, depending on your wishes or needs, could include a peer support worker, community midwife, a counsellor, a psychologist, a social worker or a patient advocate.

Good antenatal care will help support you in reducing the risk of transmission of HIV as well as staying well during your pregnancy. Your healthcare team and support organisation can help you adhere to any treatment you need to take and answer questions you may have about your health and that of your baby. They can provide support and advice on your eligibility for free NHS treatment, as well as help with any other issues you might have, such as housing, finances or alcohol and recreational drug use.

HIV treatment in women

Effectiveness of treatment in women
To find out more about specific types of HIV treatment, or antiretroviral therapy, see the NAM booklets *Anti-HIV drugs* and *HIV therapy* in this series.

Women tend to get higher levels of some anti-HIV drugs in their blood than men. This is probably because men tend to weigh more than women. Having higher levels of a drug in your blood can mean that there's more of it available to fight HIV but, on the downside, it could mean that you might be more likely to experience side-effects.

Gender differences in side-effects may also be due to an interaction between HIV medications and female hormones.

Starting treatment

You may feel anxious about starting and adhering to your treatment. Discuss your concerns with your doctor and talk with other people who are already on HIV treatment. You will find out about how they successfully manage to keep taking the treatment regularly and what strategies they use to minimise any side-effects.

Adhering to your treatment

HIV treatment involves powerful drugs which work very well when your adherence is good. Adherence is a term used to refer to taking your

drugs on the right day and at the right time, every day, as prescribed by your doctor.

Taking your treatments every day, as prescribed by your doctor, and not missing any doses, is one of the most important aspects of managing your HIV. If you are finding it difficult to take your treatment in the right way, talk to one of your HIV healthcare team as soon as possible. You could also talk to other women who are successfully managing their treatment at home and work. Maintaining a healthy lifestyle and having a good support network are other important means of staying well.

You can find out more about taking your HIV treatment properly in NAM's booklet *Adherence & resistance*.

Side-effects of HIV treatment in women

Like any drugs, HIV treatment can cause side-effects. It is important to always talk to your doctor or nurse and let them know whenever you experience any new symptoms that may be due to side-effects, as they may be able to help you deal with them.

Most often, side-effects occur soon after a drug is started and lessen over time. Common side-effects include nausea, diarrhoea, headaches and feeling tired. Your healthcare team should talk to you about what side-effects you can expect and how to minimise their impact. Some drugs can cause a rash on the skin and it's very important that you report rashes to your doctor, in case it is a sign of an allergic reaction.

To find out more about possible side-effects of HIV treatment generally, see the NAM booklet *Side-effects* in this series. Because of possible side-effects, women prescribed certain drugs may need closer clinical and laboratory monitoring in order to avoid potential problems. If you are concerned about any aspect of your treatment, always talk to your doctor, pharmacist, support worker or treatment advocate about this and they will help you to make the treatment choices that suit you best. The side-effects listed below, while not common, are thought to affect women more often than men.

Lipodystrophy: This is where fat accumulates in certain parts of the body, resulting in visible body shape changes. There may also be a reduction in fat in other areas of the body, known as lipoatrophy. Some studies suggest that lipodystrophy may affect women more than men, and that women are more likely to get unusual fat accumulation in certain parts of the body such as the breasts without the fat loss that often occurs in men.

Body changes can be distressing. If this happens, discuss it with your doctor and talk to other HIV-positive women who have had, and dealt with, similar experiences.

Changes in the levels of fat and sugars in the blood are also part of lipodystrophy. These can result in high blood glucose, high blood pressure and increased cholesterol and triglycerides. Regular monitoring of these is

important as high levels are often associated with an increased risk of diabetes, heart disease and stroke.

If you are taking HRT (hormone replacement therapy, for women undergoing the menopause), and HIV treatment, ensure that you discuss the risk factors with your doctor, as HRT can also increase the risk of stroke.

Lactic acidosis: Lactic acidosis is an increased lactate level in the blood (hyperlactatemia). Lactate, or lactic acid, is a by-product of processing sugar in the body, especially during exercise, which causes muscle problems and liver damage. Lactic acidosis is a serious side-effect of treatment with older drugs from the NRTI class, chiefly d4T, but is very rare with the medicines from this group most commonly used in the UK, such as abacavir (*Ziagen*), FTC (emtricitabine, *Emtriva*), 3TC (lamivudine, *Epivir*) and tenofovir (*Viread*). Women seem to be more at risk of developing lactic acidosis than men. You can find out more about the symptoms of lactic acidosis in NAM's *Side-effects* booklet. If you think you are experiencing any of them, it is important to tell your doctor as soon as possible.

Menstrual changes: Menstrual changes, including irregular, heavy and painful periods, are associated with some protease inhibitors. Talk to your doctor if you have any concerns.

Other health checks and care

Breast screening

If you are over 50, you should be called for a breast screen (mammogram) every three years to check for the presence of breast abnormalities and breast cancer. You should also do regular self-examinations of your breasts. Ask for advice on how to do this from your healthcare team.

Human papillomavirus vaccine

If you are aged 13 to 26, it is recommended that you have the preventive quadrivalent HPV vaccine, unless your CD4 count is less than 200 or you have been previously exposed to HPV through sexual contact (a blood test can detect this).

Protection from varicella

Varicella zoster (VZV) is the virus that causes chickenpox and shingles. If you have never had chickenpox or shingles and you are exposed to either illness, you should consult your doctor immediately. If you also test seronegative for the *varicella zoster* virus (that is, you don't have any antibodies to VZV in your blood) you should be given post-exposure prophylaxis with a drug called VariZIG within 96 hours.

If you test seronegative to VZV and your CD4 count is over 200, you could consider being vaccinated against the virus.

HIV and hepatitis co-infection

Hepatitis is a viral infection that affects your liver. Some types – hepatitis B and C – can cause long-term, serious health problems. Many people with HIV also have hepatitis B or C, known as co-infection. However, treatments for both types of hepatitis are available.

Treatment decisions for co-infection are made on an individual basis. The British HIV Association (BHIVA) recommends that the infection that is the greatest threat to your health should be treated first. You can find out more about HIV and hepatitis co-infection and treatment in NAM's booklet *HIV & hepatitis*.

Ribavirin is an important drug in the treatment of hepatitis C. It must not be taken if you are pregnant as it is possible that this could lead to the loss of the baby, or the birth of a baby with deformities or other problems.

Ribavirin can enter the sperm. It is important that sperm from a man on ribavirin treatment is prevented from starting a pregnancy and that ribavirin is not allowed to reach an unborn child. Couples who have been treated with ribavirin should avoid pregnancy (and unprotected sex) for at least six months after the completion of treatment.

Mental health, emotional wellbeing and depression

Women with HIV often report experiencing feelings of isolation, depression, loss of sleep and anxiety on diagnosis. An HIV diagnosis is a life-changing event and these responses are not unexpected. Sometimes support from others with HIV, friends and family is sufficient to help you find a way forward, but you may also want to see a counsellor or therapist at some point, or need some medication to help with depression or other mental health problems.

And don't forget your own health needs even if you have responsibilities for looking after others.

Your HIV clinic or GP may be able to refer you to specialist services. You can contact a support organisation providing these services. See page 44 for contacts.

You can also find out more about emotional and mental health, and get more information on how to access different mental health services and treatments, in NAM's booklet *HIV, mental health and emotional wellbeing*.

Disclosure

Disclosing your HIV status can be frightening. It is important to take time to think about the advantages and disadvantages of doing so. You may fear you will experience rejection or exclusion, or even violence, if you reveal your HIV status to your partner, family, friends or employer.

Many people tell their partners, family, friends and colleagues about being HIV-positive and receive acceptance and support. However, some may become upset or react badly. In some cases, women have been subjected to domestic violence when disclosing to their partners.

There is generally no requirement to tell your employer if you are HIV-positive (unless your work would carry a risk of transmission), or your child's school if your child is HIV-positive.

If you have any concerns about disclosure, support or treatment, advocacy organisations provide specialist services and support to women and families living with HIV. Speak to a support organisation about managing your disclosure, especially to children so they can have a safe, trusted person to talk with about their concerns. See page 44 for contacts.

Confidentiality

Your medical records are confidential and nobody can see them without your consent. If you are worried about telling somebody that you have HIV, or are concerned about somebody finding out, ensure that you make your concerns clear

to the hospital, your GP or any care and support agencies you are in contact with. Your HIV clinic or support organisation can also help and act as an advocate: this means speaking on your behalf with health or social care professionals if you are not comfortable doing so yourself.

Prosecution for transmission of HIV

Some people have been prosecuted for passing on HIV. People have been accused of 'intentional' transmission of HIV (deliberately setting out to infect someone) and 'reckless' transmission. Someone can be considered reckless if they know they can pass on HIV during sex and still go on to take that risk.

If you have unprotected sex with a partner without telling them of your HIV status and, as a result, your partner then becomes HIV-positive, they could try to prosecute you for reckless transmission of HIV. It is not against the law just to have 'unsafe' sex – a prosecution can only happen if your partner did not know you had HIV, you didn't have safe sex and your partner becomes infected as a result.

If someone makes a complaint against you, it is important you seek expert legal advice and personal support as soon as possible. See page 44 for contacts that can help you find the right service.

Scientifically, it is very difficult to prove who may have infected whom, but being investigated, going to court, and having your personal and sexual history made public can be devastating.

If you are thinking about starting a case against someone, it is also a good idea to discuss your situation with your doctor and support network. The process can be long and traumatic.

HIV and your children

Breastfeeding carries a risk of transmitting HIV and the current advice in the UK is to formula feed. If you breastfeed, the law might consider this a danger to your baby. So far no case has been successfully brought against a mother. It may be considered a child protection issue, and your local authority social services department may become involved in considering your child's welfare.

If you have children who were born before your HIV diagnosis, it is recommended that they are tested for HIV, whatever their age. If you are anxious about doing this, ask for the help of your support organisation and healthcare team.

Prison and HIV

Women in prison should have access to health care of the same range and quality as that of the general population. If you are on treatment, it is important that it is not interrupted while you are in prison, and that you receive regular health monitoring. If you are denied access to your treatment or regular check-ups, report it as soon as possible to the prison healthcare team.

Getting specialist help

It is important that you get your HIV care from a specialist HIV treatment centre. There are contacts to help you find a treatment centre at the back of this booklet (see page 44).

You might want to contact a support organisation or a helpline for guidance and advice if you:

- Have difficulty in getting specialist HIV health care.
- Are caring for children and other family members who have HIV.
- Are not a patient at a GP (family doctor) practice and you can't find one.
- Are applying for the right to remain in the UK, facing deportation or are a failed asylum seeker or an overstayer.
- Are experiencing difficulty with taking or adhering to your treatment.
- Are anxious about accessing treatment.

Your local HIV organisation or social services department should also be able to help if you are having problems with issues such as housing, benefits, employment, and asylum and immigration status.

A list of organisations that can put you in touch with other people living with HIV is on page 44.

Summary

- You can live well with HIV.
- Being involved in your own health care can help to keep you well.
- CD4 and viral load tests are key in determining when to start or change treatment.
- HIV treatment works well in women, but there may be some side-effects that affect women more.
- You can have fulfilling emotional and sexual relationships.
- With the right treatment and care, you can have a baby without passing on HIV.
- Getting the right support is an essential part of living well. Your healthcare team, support organisations and other women with HIV can all provide information, advice and support.

Where to go for information, help and support

Positively UK (formerly Positively Women)
Provides a range of support services for women with HIV and their families.
020 7713 0222 (to contact a peer mentor)
www.positivelyuk.org
info@positivelyuk.org

Body and Soul
A charity providing support for children, teenagers and families living with, or affected by HIV.
020 7923 6880
www.bodyandsoulcharity.org
info@bodyandsoulcharity.org

British HIV Association
You can find UK guidelines on HIV treatment and care in a range of situations, including during pregnancy, on the BHIVA website.
www.bhiva.org

Terrence Higgins Trust (THT)
Support and advocacy services throughout the UK. Details of these and services provided by other HIV organisations can be obtained from THT Direct, 0845 1221 200.
www.tht.org.uk
info@tht.org.uk

FPA
Sexual health help and advice.
0845 122 8690
www.fpa.org.uk

Keep yourself up to date – get more from NAM

HIV Treatment Update

NAM's regular newsletter keeps you up to date with the latest news and developments about HIV, to help you talk to your doctor, and make decisions about your health and treatment.

HIV Weekly

NAM's weekly email round-up of the latest HIV news. Sign up today for straightforward news reporting and easy-to-read summaries of the latest HIV research.

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Please complete this form and send to NAM, FREEPOST LON17995 London, SW9 6BR

Under the terms of the Data Protection Act you may advise us at any time if you do not wish to receive further mailings from NAM

What did you think of this booklet?

NAM wants to make sure this booklet is useful to you. We would be grateful if you could take a minute to provide us with some valuable feedback. The questionnaire is anonymous and confidential.

As a result of reading this resource have you learnt anything about HIV, your health and treatment?

☐ I have learnt nothing new

☐ I have learnt something but it's not particularly useful to me

☐ I have learnt something that is useful to me

☐ I have learnt something that seems vitally important to me

Please tell us in your own words what you have learnt:

.....

.....

.....

.....

As a result of reading this resource I am more likely to: (tick all that apply)

☐ Discuss my treatment and care with my healthcare team

☐ Feel more confident talking to my healthcare team

☐ Feel better equipped to take decisions regarding my treatment and care

☐ Feel more informed about HIV treatment and living well with HIV

☐ Find other information and support, if I need it

☐ None of the above

Please tell us if there is anything else you are more likely to do or feel as a result of reading this booklet:

.....

.....

Please tear off this page and post it to: NAM, FREEPOST LON17995 London, SW9 6BR.

We would like to ask you a few more questions. You don't have to answer these, but if you do, it will help us make sure our information is relevant and useful to our readers.

Please circle the description that best describes you

I am: female / male / transgender

I live: in London / in the UK but outside London / outside the UK (please specify).....

My ethnic background is: White / Black – Caribbean / Black – African / Black – other / Indian or Pakistani or Bangladeshi / other Asian or oriental / other or mixed

My HIV status is: positive / negative / unknown

(If positive) I think I got HIV as a result of: sex between men and women / sex between men / injecting drugs / from blood or blood products / mother-to-child transmission / other / don't know / rather not say

I work: in the HIV field / not in the HIV field / I do not work at the moment

I got this booklet from: nurse / doctor / clinic / THT's HIV Health Support Service / support group / friend / family member / NAM / other (please specify) .....

Thank you very much for taking the time to fill in this questionnaire.
NAM really values your feedback. It helps make the information we provide better.
If you have any other comments on the content of this booklet please email info@nam.org.uk

HIV helplines

THT Direct
From the Terrence Higgins Trust
Telephone 0845 1221 200
Opening hours Monday-Friday, 10am-10pm
Saturday & Sunday, 12pm-6pm

African AIDS Helpline
Telephone 0800 0967 500
Opening hours Monday-Friday, 10am-6pm

HIV i-Base Treatment Phoneline
Telephone 0808 800 6013
Opening hours Monday-Wednesday, 12pm-4pm

More from NAM

NAM Information Forums
Free meetings offering an opportunity to hear the latest news, views and research around HIV treatments. Held in the evening at a central London location. **Call NAM for details.**

HIV Health Support Service
NAM supports THT in providing one-to-one and group skills sessions on health and treatments to people living with HIV.
Call THT Direct for details.

NAM information series for HIV-positive people
The booklet series includes: • Adherence & resistance • Anti-HIV drugs • CD4, viral load & other tests • Clinical trials • HIV & children • HIV & hepatitis • HIV, mental health & emotional wellbeing • HIV & sex • HIV & stigma • HIV & TB • HIV therapy • Nutrition • Side-effects

NAM
Lincoln House
1 Brixton Road
London SW9 6DE
UK

Tel: +44 (0) 20 7840 0050
Fax: +44 (0) 20 7735 5351
Website: www.aidsmap.com
Email: info@nam.org.uk
Registered charity no. 1011220

Fourth edition 2010

Print: Lithosphere

This booklet can be viewed in large print as a PDF file using Acrobat Reader.
Call NAM on 020 7840 0050.

About NAM

NAM works to change lives by sharing information about HIV and AIDS. We believe independent, clear and accurate information is vital in the fight against HIV. We produce useful information that you can trust.

Please make a donation by visiting **www.aidsmap.com/donate** or by ringing us on 020 7840 0050.