



information series for hiv-positive people

hiv & women



acknowledgments

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NAM is a charity that publishes information for people affected by HIV and those working with them. We believe information helps people to make decisions about, and be in control of, their lives, health and treatment options.

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hiv & women

This booklet is intended to answer some of the most commonly asked questions about HIV infection in women. It outlines how HIV affects women and the effectiveness of anti-HIV treatment in women. Information on HIV and pregnancy is also included. This booklet also provides information on the day-to-day issues involved in living with HIV.

This booklet has been written to help you decide what questions to ask your doctor. We don't intend for it to replace discussion with your doctor about your treatment.

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1 HIV and women

When HIV was first discovered, it mainly seemed to affect gay men, and very few infections were seen in women in this country or in the USA. Over the years this has changed, and over a quarter of all HIV cases in the UK are in women and more women than men are infected with HIV world-wide.

Because most of the early cases of HIV that were studied were in gay men, doctors learnt more about the way HIV affects the immune system of men than women. Less was also known about the effectiveness of anti-HIV drugs in women than men. However, as the numbers of HIV-positive women have increased, this has gradually changed.

It's now known that:

- HIV causes immune damage in women at the same rate as it does in men.
- Men and women are equally likely to develop AIDS.
- Some key tests used to monitor the effects of HIV on the immune system need to be interpreted differently in women and men.
- HIV can affect a woman's menstrual cycle and reproductive health.
- Women can get some AIDS-defining illnesses which men can't get. These are related to women's reproductive health.

- An HIV-positive woman can pass HIV onto her baby but this can be prevented in nearly all cases.
- Women who breastfeed and are ill with HIV have an increased risk of dying.
- Anti-HIV drugs work just as well in women as men, but the side-effects of some drugs may be different in women.

This booklet provides information on all of these issues, and also includes some general information on living with HIV.

3 HIV and women's health

Without treatment, nearly all HIV-positive women will experience a gradual weakening of their immune systems, and over time, will have such a weak immune system that you are vulnerable to the severe infections and cancers that define AIDS.

It is recommended that everybody who is HIV-positive receive regular medical monitoring.

Monitoring HIV in women

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Two blood tests are of crucial importance in monitoring HIV. These are CD4 cell counts and HIV viral load tests. The booklet *Viral Load and CD4* in this series provides more information on these tests.

In people who are not infected with HIV, CD4 cell counts tend to be higher in women than men.

Your CD4 cell count may go up or down with your menstrual cycle and use of the oral contraceptive pill may lower your CD4 cell count, but not to such an extent that your health may be at risk.

Your viral load may be lower than a man's shortly after you are first infected with HIV, but this does not have any effect on the speed of HIV progression.

5 HIV and your body

Periods

As well as damaging your immune system, you may notice that HIV causes menstrual problems.

You are more likely to experience menstrual changes if you have a low CD4 cell count and/or high viral load or if you use (or used) illegal drugs. Some of the menstrual changes you may experience include:

- Long intervals between periods.
- Missed periods without pregnancy.

It's thought that these changes can occur because the damage to your immune system that HIV is causing can alter your hormone balance. If you have been ill,

have lost a lot of weight, or have anaemia, you may also find that these cause changes to your menstrual cycle.

Make sure that you tell your doctor if you notice any changes to your periods. It could be a warning sign that HIV is damaging your immune system and that you need to consider taking anti-HIV treatment (often called highly active antiretroviral therapy, or HAART for short). Changes in your menstrual cycle can also be a symptom of health problems. But remember that a missed period might also mean that you are pregnant. Abnormal bleeding, for example after sex, after the menopause, or very heavy periods should also be reported to your doctor.

Menopause

It's thought that HIV can interfere with your ability to produce the hormones oestrogen and progesterone and that this can lead to an early menopause (the ending of the ability to become pregnant).

Symptoms of the menopause include:

- Less frequent periods, which then stop completely.
- A dry vagina and vulva.
- Hot flushes.
- Reduced, or lack of, sexual desire.
- Increased frequency of urination.
- Depression and other mood problems.

- Sleep problems.

- Aging skin, dry skin or spotty skin.

Weakening of the bones (osteoporosis) can also be a result of the menopause and this can be of particular concern as HIV, and some anti-HIV drugs, may reduce the amount of important minerals in the bones causing bone weakness. You can help look after the health of your bones by light weight training, by losing weight if you are overweight, and by making sure that you don't drink too much alcohol.

Many women take hormone supplements to replace those they are losing naturally. This is called hormone replacement therapy (HRT) or oestrogen replacement

therapy (ERT) and can relieve the symptoms of the menopause. HRT can have many complications, and long-term risks include heart disease, stroke, and breast cancer, and it is only recommended to relieve menopausal symptoms. If you are thinking about HRT, then talk it over with your doctor. You might also want to ask for a referral to a specialist menopause clinic.

HRT can also be effective if you are HIV-positive. But there might be more risks involved. This is particularly the case if you are taking HAART, as some anti-HIV drugs have been associated with an increased risk of heart disease and stroke.

Reproductive health issues

Some reproductive health (gynaecological) problems can be more common, more severe, or harder to treat if you have HIV.

Pelvic inflammatory disease (PID) is always a serious condition, particularly so if you have HIV. It can be treated with antibiotics, but there is a risk of long-term pain and the recurrence of the condition.

PID can also result in infertility. It can be caused by untreated sexually transmitted infections such as gonorrhoea and *Chlamydia*, as well as other bacteria and infections such as tuberculosis.

Symptoms include long-lasting pain in the lower abdomen, vaginal discharge,

cramping during sex, deep internal pain, fever, vomiting, tiredness and unusual bleeding from the vagina. A general sexual health check-up will include tests to see if you have gonorrhoea or *Chlamydia*. Scans may be needed to see if you have any cysts or abscesses that indicate that you have PID. An examination called a laparoscopy, which involves having a tiny camera put into the pelvic cavity through a small surgical cut below the navel, can be used if you have complicated PID. If you have PID you will be treated with a combination of antibiotics. If it becomes severe, you might need to be admitted to hospital and have treatment with intravenous antibiotics.

Your sexual partners will need to have a sexual health screen so they can have any infections diagnosed and treated.

HIV-positive women may be more likely to have abnormal cervical cells caused by human papilloma virus (HPV) which can lead to cervical cancer, so it's very important that you have regular cervical PAP smear tests to check for these cells so you can receive prompt treatment to remove them. HIV-positive women are much less likely than HIV-negative women to naturally clear HPV infection. However, HPV can cause warts on the sexual organs. HPV can also infect cells in the cervix and cause abnormal cells to develop without

causing any visible sign or symptoms, and can only be detected using a PAP smear that looks for abnormal cells in the cervix. All HIV-positive women should have a PAP smear soon after they are diagnosed with HIV, again after six months and then every year. If you have visible genital warts you do not have increased risk of having an abnormal smear result. Treatment for abnormal cervical cells is highly effective, provided they are detected early.

You may also be more likely to get fungal infections, such as vaginal candidiasis (thrush), a yeast infection, but treatment works just as well if you are HIV-positive. If you are getting fungal infections on a

regular basis, your doctor can give you drugs to prevent them.

Attacks of genital herpes (herpes simplex virus-2, or HSV-2) can last longer and be more painful if you have HIV. The antiviral drug aciclovir can help shorten the duration of attacks, and if you are getting regular attacks of herpes then you may wish to consider taking aciclovir everyday to prevent this.

Bacterial vaginosis, an overgrowth of bacteria in the vagina, 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. Washing the vagina too frequently increases your risk of developing bacterial vaginosis.

11 Mother-to-baby transmission of HIV

This information is also included in the booklet *HIV and Children* in this series.

If you are HIV-positive and pregnant, or thinking about having a baby, it is important to know that you can pass on HIV to your baby during pregnancy, or during delivery, or by breast-feeding.

However, anti-HIV treatment can greatly reduce the risk of you passing on HIV infection to your baby. In addition, many mothers choose to have their babies delivered through an operation (a caesarean birth) as this can further reduce the risk. Exclusive formula feeding is strongly recommended for all babies

born to HIV-positive mothers in the UK. Using these methods it's possible to reduce the risk of mother-to-baby transmission of HIV from about 25% to less than 1%.

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

- Having a high HIV viral load or a low CD4 cell count.
- Your waters breaking more than four hours before delivery.
- Having an untreated sexually transmitted infection or bacterial vaginosis when you give birth.

- Using recreational drugs, particularly injected drugs, during pregnancy.
- Having a vaginal delivery (rather than a caesarean delivery) when you have a detectable viral load.
- Having a difficult delivery, for example if forceps need to be used.
- If you breastfeed.

Preventing mother-to-baby transmission – with anti-HIV drugs

Taking anti-HIV treatment can dramatically reduce the risk of you passing on HIV to your baby.

There are two different ways in which these drugs can act.

First, they reduce your viral load - the level of virus in your blood - so your baby is exposed to less of the virus while in the womb and during childbirth. The aim of HIV treatment is to get, and keep, your viral load below 50 copies/ml. This is often referred to as an undetectable viral load.

Second, the drugs may cross the placenta and enter your baby's body, where they can prevent the virus from ever taking hold. Newborn babies are given a short course of anti-HIV drugs after they have been born when their mother is known to be HIV-positive.

Two drugs have been shown to be very effective at preventing a mother from passing on HIV to her baby in the second of these ways. These are the nucleoside analogue (NRTI) AZT, and the nonnucleoside (NNRTI) nevirapine. It is likely that other drugs are also very effective, but they have not been tested as extensively.

The way in which these drugs are used (AZT on its own, or AZT or nevirapine in combination with other anti-HIV drugs) will depend on how much damage HIV has done to your immune system, and the point in your pregnancy when HIV is diagnosed.

In the UK, and other countries where there is access to a full range of anti-HIV drugs for treatment, nevirapine should not be used by itself (as monotherapy) to prevent mother-to-baby transmission of HIV because resistance to the drug can rapidly develop if it is used in this way. Using it alone might limit your ability to benefit from nevirapine or related drugs in future, when you need them to protect your own health.

In good health?

If you have a good CD4 cell count and low HIV viral load and are not ill because of HIV, then UK guidelines recommend that you start taking AZT in the final three months (third trimester) of your pregnancy. You will also need to have an intravenous dose of AZT during delivery and have a caesarean rather than vaginal delivery. Another option is to take a short course of HAART (three anti-HIV drugs) during the last few months of pregnancy in order to get your viral load down to below 50 copies/ml. You then have the option of a planned vaginal delivery.

Your baby will need to take AZT syrup for four to six weeks after he/she is born.

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 HAART during your pregnancy, then the aim should be to get your viral load undetectable. You should continue to take HAART after your baby has been delivered.

Your baby will need to take AZT syrup for four to six weeks after he/she is born.

High viral load?

If HIV has caused serious damage to your immune system, or if you have a high viral load, then you are advised to take HAART, including two drugs from the nucleoside analogue class (NRTIs), ideally AZT and 3TC, and either the non-nucleoside analogue (NNRTI) nevirapine or a protease inhibitor. 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 you could have a planned vaginal birth.

Your baby will need to take four to six weeks of AZT syrup.

Already on treatment?

If you become pregnant whilst taking HAART which is successfully suppressing your viral load, you are recommended to continue taking this treatment. You will need to have a special scan between weeks 18 - 20 of your pregnancy called an anomaly scan to see if your baby is developing with abnormalities.

Your baby will need to take four to six weeks of AZT syrup.

If you become pregnant whilst taking HAART and your anti-HIV drugs are not

suppressing your viral load to undetectable, then you should have a resistance test to determine your best drug options and then change to these anti-HIV drugs. The aim should be to get your viral load undetectable by the time you deliver. You will need to have an anomaly scan between weeks 18 - 20.

Your baby will need to take four to six weeks of AZT syrup after he/she is born.

Diagnosed late in pregnancy?

If you are diagnosed with HIV very late during pregnancy (32 weeks or later), then you will need to start taking HAART immediately. This will normally include

AZT, 3TC and nevirapine. These drugs are able to rapidly pass over the placenta into your baby.

Your baby will need to take four to six weeks of AZT syrup.

Diagnosed during delivery or afterwards?

If you are diagnosed HIV-positive during delivery, or just after, then you should 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 to six weeks. Not all the licensed HIV drugs are approved for children under three months of age.

Safety of treatment to prevent mother-to-baby transmission

There's some evidence that there is 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.

Preventing mother-to-baby transmission – delivery

The risk of your baby contracting HIV is reduced if you have a planned caesarean

(surgical) delivery. This is called an 'elective caesarean' and is scheduled to take place from the 38th week of pregnancy, but will be performed sooner if your labour begins early. Taking anti-HIV drugs during 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 risk, which should be fully discussed before you agree - give consent - to the procedure.

You are strongly recommended to have a caesarean 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 undetectable (below 50 copies/ml) then you should be able to have an actively managed vaginal birth. This means that your doctors and midwife will make sure that your labour doesn't last too long and can take other steps to reduce the risk of passing on HIV to your baby.

Preventing mother-to-baby transmission – breastfeeding

Breastfeeding your baby carries a risk of passing on HIV to your baby. This risk might 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. In the UK and other countries where safe alternatives to breastfeeding are available, you are strongly recommended to feed your baby with formula feed from birth. Detailed advice and support on how to do this is available from medical services and you should ask for help if you have difficulties meeting the cost.

19 Pregnancy and conception

The positive impact which anti-HIV therapy has had on the health of many people with HIV, and the availability of effective means of reducing the rate of mother-to-child HIV transmission, may have encouraged some HIV-positive women to reconsider decisions about sex and relationships, and about having children. If you would like support thinking through these issues it may be helpful to see a counsellor, or to talk to other HIV-positive women. One option is *Positively Women*, a national organisation providing peer support to HIV-positive women and their children

(tel 020 7713 0222). Another option is *Body and Soul*, a self-help organisation which supports women, heterosexual men, children and families living with or affected by HIV (tel 020 7383 7678).

In the UK, HIV treatment centres and sexually transmitted infections (GUM) clinics offer condoms free of charge. 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 Family Planning Clinics. Details of local Family Planning Clinics are available from NHS Direct on 0845 46 47.

You cannot join a clinical trial looking at the effectiveness of new HIV drugs if you are pregnant or thinking of becoming pregnant. See the booklet, *Clinical Trials* in this series for more information.

If you are planning pregnancy (or are pregnant) it's very important that you tell your doctor so they can, with you, reduce the risk of your baby being infected with HIV and ensure your drugs are the best ones for pregnancy.

Contraceptive choices need to be made on an individual basis. Although condoms are highly effective at preventing both pregnancy and the transmission of HIV

and most sexually transmitted infections, they have to be used properly to work. You may therefore wish to consider a back-up form of contraception, in addition to condoms. Of the alternatives:

- The Mirena Coil includes hormones that reduce the risk of heavy periods and anaemia. Before the coil is fitted, you will be offered a sexual health screen and be given treatment with antibiotics if you have an infection. It can be easily removed if it doesn't suit you.

- Protease inhibitors reduce blood levels of the oestrogen component in oral contraceptive pills, so women taking both the Pill and protease inhibitors may need to use back-up methods of contraception.
- A number of other medications, e.g. ampicillin, may interact with oral contraceptives, so getting advice on drug interactions from your HIV doctor or pharmacist is important.

During the period you are taking antibiotics, and for a week after, you are recommended to use an additional form of contraception.

Effectiveness of treatment in women

Anti-HIV treatment regimens, often called highly active antiretroviral therapy, or HAART for short, work just as well in women as men. To find out more about anti-HIV treatment see the booklets *Anti-HIV Drugs* and *HIV Therapy* in this series.

However, you may be more likely than a man to get higher blood levels of some drugs, probably because men tend to weigh more than women and the doses of anti-HIV drugs were decided after clinical trials that involved many more men than women.

Having higher blood levels of a drug 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 get side-effects. For example, higher levels of the protease inhibitor indinavir in women can cause more side-effects in the kidneys.

Because of the risk of developing severe liver-related side-effects, women who have a CD4 cell count above 250 should not start treatment with the NNRTI nevirapine.

Side-effects of HIV treatment in women

Women may be more likely to get some other side-effects as well. Changes in body shape called lipodystrophy may affect women more than men. It also seems 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 is often seen in men.

Changes in the levels of fats and sugars in the blood – cholesterol, glucose and triglycerides, increasing the risk of heart disease and stroke – are also part of lipodystrophy. The risk of heart disease or stroke from hormone replacement therapy

(HRT) is increased if you have high cholesterol. If you are considering HRT and are taking HAART, or have high cholesterol, you should carefully consider the risks and make sure that the levels of fats and sugars in your blood monitored regularly.

To find out more see the booklet called *Lipodystrophy* in this series.

It's important that you get your HIV care from a specialist HIV treatment centre. If you are not already a patient at one and don't know how to find one, then ring one of the helplines listed at the back of this booklet.

Organisations such as Positively Women and Body and Soul provide specialist services and support to women with HIV.

Your local HIV agency or council should be able to offer help and advice if you are having problems with housing or money.

The booklet in this series, *Nutrition* provides some information on food, nutrition, exercise and HIV infection, and

could be a good place to start if you have questions about any of these issues.

Don't forget your own health needs if you have responsibilities for looking after others. If you are finding it difficult to cope, ask for help from somebody at your HIV clinic, local HIV organisation, council, or an organisation such as Positively Women.

Deciding who to tell that you are HIV-positive can be difficult. Before you decide to tell somebody take time to think about the advantages and disadvantages of doing so. Think how you would respond if a person reacts badly, is upset, or even

threatening. Remember, it is up to you who you tell and when you tell them. But it's equally important to remember that many people tell their partners, family, friends and colleagues about being HIV-positive and receive wonderful support.

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, then ask for help. The chances are that your HIV clinic, HIV support agency or council social services will be able to offer support.

Summary

- HIV can damage the immune systems of women, and without treatment causes illness and death.
- CD4 and viral load tests are the key tests used to monitor HIV in women.
- HIV-positive women should have regular smear tests.
- An HIV-positive woman can pass on HIV to her baby, but this can almost always be prevented.
- HAART works just as well in women and men.
- Women taking HAART might be more likely to experience some side-effects.

anaemia A shortage or change in the size or function of red blood cells. These cells carry oxygen to cells in the body.

cervix The "neck of the womb" at the top of the vagina.

CD4 A molecule on the surface of some cells onto which HIV can bind. The CD4 cell count roughly reflects the state of the immune system.

cholesterol A waxy substance, mostly made by the body and used to produce steroid hormones. High levels can be associated with a hardening of the arteries.

HAART Highly Active Antiretroviral Therapy, a term used to describe anti-HIV combination therapy with three or more drugs.

hormone A chemical which stimulates or suppresses cell and tissue activity.

lipodystrophy A disruption in the way the body produces, uses and distributes fat.

NNRTI Non nucleoside reverse transcriptase inhibitor, the family of antiretrovirals which includes efavirenz, nevirapine and delavirdine.

NRTI Nucleoside analogue reverse transcriptase inhibitor. Family of antiretrovirals which includes AZT, ddI, 3TC, d4T, ddC, abacavir and FTC.

PAP smear A specimen of cells from the cervix, usually obtained in scrapings from the opening, which may be examined under the microscope to look for abnormalities.

protease inhibitor Family of antiretrovirals which target the protease enzyme. Includes amprenavir, atazanavir, indinavir, lopinaivr, nelfinavir, ritonavir, and saquinavir

resistance A drug resistant HIV strain is one which is less susceptible to the effects of one or more anti-HIV drugs because of its genotype.

triglycerides The basic "building blocks" from which fats are formed.

undetectable viral load A level of viral load that is too low to be picked up by the particular viral load test being used.

viral load Measurement of the amount of virus in a sample. HIV viral load indicates the extent to which HIV is reproducing in the body.

Notes

Notes

Notes



free monthly newsletter

AIDS Treatment Update, NAM's free newsletter, gives you regular and up-to-date information on the latest developments in HIV treatment, and is accompanied each month by a one page factsheet providing basic information on key treatment topics.

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- starting and changing treatment
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■ lipodystrophy ■ hiv & mental health ■ nutrition ■ resistance ■ viral load & CD4

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Monthly, free meetings offering an opportunity to hear the latest news, views and research around HIV treatment. Held in the evening at a central London location. Call NAM for details.

NAM information series for HIV-positive people

This booklet is part of an easy-to-read series available free from NAM to people personally affected by HIV. Call NAM for your copies.



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