



information series for hiv-positive people

hiv & children



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 & children

This booklet is intended for the parents and carers of HIV-positive children under twelve. It looks at how babies and children may be affected by HIV and anti-HIV treatment, gives advice about living with HIV and lists organisations that offer support and specialist information.

The booklet also outlines the steps that women who are HIV-positive and pregnant can take to prevent their babies becoming infected with HIV.

A summary is included on page 29 and a glossary of words used is on page 30.

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1 Part 1 — Mother-to-baby transmission of HIV

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 breastfeeding.

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.

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

- Being ill because of HIV.
- Having a high HIV viral load or a low CD4 cell count.
- Your waters breaking four or more hours before delivery.
- Having an untreated sexually transmitted infection when you give birth.
- If you used recreational drugs, particularly injected drugs during pregnancy.

- 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 breastfeed.

3 Preventing mother-to-baby transmission of HIV - treatment

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 may 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 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. This is also why 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 in particular 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 non-nucleoside analogue (NNRTI) nevirapine.

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 the damage HIV has done

to your immune system, and the point in your pregnancy when HIV is diagnosed. Taking a combination of three or more anti-HIV drugs is often referred to as highly active antiretroviral therapy, or HAART for short.

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 (in monotherapy) to prevent mother-to-baby transmission of HIV because resistance to the drug can easily develop if it is used in this way. Using it alone would 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 take an intravenous (injected) dose of AZT during delivery and have a caesarean rather than vaginal delivery. Another option is to take a short course of HAART 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 receive treatment with AZT syrup for four-to-six weeks after it 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 pregnancy, then the aim should be to get your viral load undetectable. You should continue to take anti-HIV treatment after your baby has been delivered.

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

High viral load?

If HIV has damaged 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 (NRTI), 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 will be able to have a planned vaginal birth.

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

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 receive treatment with AZT syrup for four-to-six weeks after it is born.

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 receive treatment with AZT syrup for four-to-six weeks after it 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 should be AZT, 3TC and nevirapine. These drugs are able to rapidly pass over the placenta into your baby.

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

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 treatments 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 of HIV — delivery

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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 for 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 talked through with you before you agree (give consent) to the procedure.

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

If your viral load has been consistently 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 you passing on HIV to your baby.

9 Preventing mother-to-baby transmission of HIV — breastfeeding

Breastfeeding your baby carries a risk of you passing on HIV to your baby which 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 difficulty meeting the cost.

HIV testing in babies

Your baby will be tested at birth using a PCR viral load test which detects the genetic material that makes up HIV rather than the antibodies that the body produces against it. The test will be repeated after six weeks and again after twelve weeks. The babies of HIV-positive mothers often have their mother's antibodies to HIV so the antibody test used for adults has no value for young babies in the first 18 months or so of their lives.

Provided your baby is formula-fed there should be no further risk of infection after birth. It is completely safe to kiss, cuddle, change nappies, and otherwise take care of your baby.

Doctors are currently trying to find out more about the risks of mothers passing on HIV to their babies and which are the best ways to stop this happening, so you might be asked to take part in a clinical trial designed to answer these questions. Participation is voluntary, and completely confidential and it will not affect your treatment or care if you say no. To find out more about clinical trials see the booklet *Clinical Trials* in this series.

11 Part 2: HIV infection in children

The course of HIV infection in babies and children is different to that in adults, and it is important that the monitoring, care and treatment of your child is provided by doctors and other staff at a specialist clinic skilled in looking after young people with HIV.

Babies infected with HIV can experience much faster disease progression than adults, and without treatment many will become very ill and have a high risk of dying within the first few years of life.

HIV-positive children may have a slower rate of growth, and may become sexually mature at a later age.

Monitoring HIV in children

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As in adults, the two key tests used to monitor HIV infection in children are CD4 cell counts and HIV viral load tests. However, because children don't have fully developed immune systems, their CD4 cell counts and viral load are different to those seen in adults.

Normal CD4 cell counts tend to be much higher in very young children than adults. On average the CD4 cell count in a six month old baby is about 3,000 and is about 1,500 in one year olds and often over 1,000 in infants under six. However, CD4 cell counts stabilise at similar levels

to those seen in adults when a child is aged between about six and twelve.

In HIV-positive babies, HIV viral load can rise to very high levels (over 1 million copies/ml) within a few weeks and gradually decline over the first few years of life. The exact reason for this is not known. This contrasts to adults, where viral load normally falls back to relatively low levels (about 20,000 copies/ml) a few months after infection with HIV.

Using CD4 cell counts and viral load to judge the risk of disease progression in children is therefore much harder than in

adults. Doctors calculate the risk of a child becoming ill by taking into account their age, CD4 cell count, and viral load. A 'calculator' is available on-line at this website address:

<http://www.ctu.mrc.ac.uk/penta/hppmcs/calcProb.htm>

To find out more about CD4 and viral load tests, read the booklet, *Viral load and CD4* in this series.

Anti-HIV treatment for babies and children

Anti-HIV drugs are available for the treatment of babies and children. Although the use of anti-HIV drugs has been studied less in babies and children than in adults, there is now a lot of evidence that it works well. However, as in adults it can cause unpleasant side-effects and needs to be taken at the right time and in the right way to work properly.

There are fewer drugs available for the treatment of HIV in babies and children than for adults. Details of the drugs that can be used in babies and children are provided in table 1 on page 18.

The use of combinations of three or more anti-HIV drugs (often called highly active

antiretroviral therapy, or HAART for short) in babies has been shown to prevent illness and death in the first 18 months of life.

HAART has also been shown to be effective in older infants and children, many of whom are living longer, healthier lives thanks to anti-HIV treatment.

The reduction in illness and death in babies and children with HIV in the UK since treatments became available was recently confirmed by a large study that found that rates of illness and death fell by over 80%.

As with adults a decision on when is the best time to start treatment in babies and infants is made on an individual basis.

However, if an infant or child is ill because of HIV, or has a rapidly falling CD4 count and high and rising viral load, then anti-HIV treatment should be started. Using the PENTA calculator mentioned earlier, it's recommended that a baby or child start anti-HIV treatment if he or she has a risk of developing AIDS of 10% or more in the next year.

Anti-HIV treatment should be started in children before their immune system is damaged to such an extent that they are vulnerable to serious, potentially life-threatening illnesses. In adults this is when the CD4 cell count falls to about 200. In children the numbers are

different. In infants aged under 12 months, a CD4 count of 750 is equivalent to an adult count of 200. The figure is 500 for children aged one to five. After the age of six, as in adults, a CD4 cell count of about 200 indicates severe immune damage and treatment should be started. Some centres use the CD4 count percentage as a guide.

The doses of anti-HIV drugs that babies and children receive are different to those given to adults. The dose may increase over-time as doses are often calculated either according to a child's weight or to their surface area (which is looked up on a special chart). Children might also need to

take larger doses of a drug than an adult – this is because babies and children’s bodies process, or metabolise drugs, more quickly than adults.

In some children it may be necessary to use four drugs rather than three when starting treatment because children have very high viral loads. Three NRTIs plus an NNRTI is the usual combination. This means that protease inhibitors can be used if the first treatment fails. NNRTIs are preferable for children because they have liquid formulas that taste okay and don’t upset the stomach and cause diarrhoea.

Side-effects

Anti-HIV treatment can cause unpleasant side-effects in babies and children, including lipodystrophy — changes in blood fats and body shape. Lipodystrophy tends to be more common in older children, probably because of the amount of time they have been taking treatment. For more information see the booklet *Lipodystrophy* in this series.

Side-effects, such as feeling or being sick, generally feeling unwell, and diarrhoea can cause problems in children. As with adults, if HAART is causing severe side-effects, then consideration should be given to

changing the drug or drugs which are causing the problems, if other treatment options are available.

But on the plus side there is also some evidence that side-effects may be less likely to occur in children, and when they do happen children cope better with them than adults. This could be because children are less likely to have lifestyle factors such as drinking or smoking that make side-effects worse.

Table 1 — Anti-HIV drugs available for the treatment of HIV-positive children

Drug name	Approved for	Liquid formula
Nucleoside analogues (NRTIs)		
AZT, zidovudine, <i>Retrovir</i> TM	Infants and children aged three months and over (but also given to babies to prevent mother-to-baby transmission of HIV)	Yes
ddI, didanosine, <i>Videx</i> TM	Infants and children	Yes
3TC, lamivudine, <i>Epivir</i> TM	Infants and children aged three months and over	Yes
d4T, stavudine, <i>Zerit</i> TM	Infants and children aged three months and over	Yes
abacavir, <i>Ziagen</i> TM	Infants and children aged three months and over	Yes
FTC, emtricitabine, <i>Emtriva</i> TM	Infants and children aged four months and over	Available from late spring 2005

Drug name	Approved for	Liquid formula
3TC/AZT combined, <i>Combivir</i> TM	Adults and children aged over 12 years.	No
3TC/abacavir combined, <i>Kivexa</i> TM	Adults and adolescents who weigh over 40kg	No
Non-nucleoside analogues (NNRTIs)		
nevirapine, <i>Viramune</i> TM	Infants and children aged two months and over	Yes
efavirenz, <i>Sustiva</i> TM	Children three years or older or weighing over 10kg	Yes
Protease inhibitors		
amprenavir, <i>Agenerase</i> TM	Children over four years old	Yes
indinavir, <i>Crixivan</i> TM	Children aged four years and over	No
lopinavir/ritonavir, <i>Kaletra</i> TM	Children aged two years and over	Yes

Drug name	Approved for	Liquid formula
nelfinavir, <i>Viracept</i> TM	Infants and children over three years old	Powder to make into a drink, or tablets can be crushed but high rate of diarrhoea reported
ritonavir, <i>Norvir</i> TM	Children aged two years and over	Yes, but unpleasant taste
Protease inhibitors		
T20, enfuvirtide, <i>Fuzeon</i> TM	Children aged six years and over	Administered by injection

Adherence

To work properly, anti-HIV drugs need to be taken at the right time and in the right way at least 95% of the time. Many adults with HIV find this difficult to achieve, and it can be even more difficult in children, who for example might not want to take unpleasant tasting medicines, or who might find it difficult to follow the restrictions on food which some drugs demand.

Essentially, a child will rely on its parents or other adult care-giver to make sure it receives and takes its medicines. To ensure that this happens, it is important to consider how the treatment needs of your child will affect you and your other family

members and come up with plans to manage this. Don't forget that your own health also matters, and if you are also taking anti-HIV drugs, make a plan to ensure that you are able to do so.

There is no single adherence tip that will work for all children. Instead, there may be some strategies that are particularly useful depending on the age of the child.

For children having great difficulty swallowing medicines, it is possible to fit a special tube (gastrostomy tube) into the stomach into which medicines can be directly injected. This means the child does not have to swallow medications with unpleasant tastes and can be especially

helpful for toddlers who cannot understand why they have to take something which does not taste pleasant.

Teaching children to swallow pills is another way to avoid the taste of medicines. Children as young as five can learn a good technique for pill swallowing, and the team at the HIV clinic can help to teach them.

Pills are also much easier to carry than liquid if you are travelling, or if you do not want others to see you are on medications. Children on sleepovers or school trips can carry them discreetly in a little box in their wash bag and swallow them in the bathroom unobserved.

Once daily treatment may be a way of boosting adherence in older children. Seeing other children taking medicine is also likely to be helpful for older children.

Issues regarding adherence can change over time. For example, your child may want to go around to friends for meals or on school trips meaning overnight stays. Making sure that your child takes medicines at these times could be very difficult or impossible. In addition, if your child takes medication in front of friends, then he or she could be asked questions about why they are doing so.

Making plans to deal with these situations can also present problems. For example,

you might ask an adult to make sure your child takes its medicines, but this could lead to pressure to disclose your child's health status.

Your clinic should be able to provide advice on how to deal with problems that you will face in getting your child to take medicines at the right time and in the right way.

To find out more about adherence, see the *Adherence* booklet in this series.

Clinical trials

Trials into the safety and effectiveness of anti-HIV drugs need to include babies and children. If a trial is recommended as being possibly suitable for your baby or child, you

should be given written information to take away and read, and should have the opportunity to talk through the pros and cons of the study with a doctor or nurse involved in the study.

Wherever possible you should involve older children in discussions about whether or not they want to join the trial.

Remember, it is entirely up to you if you want to join a trial. It's perfectly okay to say no. The standard of treatment and care your child (or you) receive will not be affected.

To find out more about trials, see the booklet, *Clinical Trials* in this series.

HIV-positive children can live a normal, and with appropriate treatment, a healthy life. However, as with HIV-positive adults, issues such as stigma, sadness, loss, illness and death may need to be dealt with.

There is no right or wrong way to approach these issues, and the chances are that your HIV clinic or local council will have a specialist social worker who is skilled at working with children and families where HIV is present. Your HIV clinic may also have other staff such as nurses, pharmacists and psychologists who can offer specialist help to HIV-positive children and their parents.

Answering questions

Giving your child information about HIV will be a process.

You're likely to find that even very young children will want to know why they have to go to the clinic, or why they are having tests or taking medicines. You might find it useful to talk about 'goodies' or 'baddies' in the blood, or about bugs or viruses, which may enable you to truthfully talk about illness, without actually naming HIV. This can help build an understanding of health and illness.

By early adolescence, it's important to have a full and frank discussion of HIV.

This will help enable your child to feel involved and more in control of their treatment and care. Talking can also help reduce fear and anxiety, and help build a sense of independence and self-esteem.

It is also possible that your child will be asked by friends why he or she has to go to the doctors, take medicines, or has been unwell. Talking to your child about his or her illnesses, and coming up with some potential answers for questions from other children will be helpful.

By the time your child is about 12 to 13 it is generally thought best if he or she knows that they have HIV, and that they

have to have tests and, if they are taking HAART, need to be taking medicines. You may also find that at about this time your child wants to become more involved in discussion and decisions about his or her treatment and care.

Growing up with HIV

More and more children who were infected with HIV at birth are now growing up and becoming teenagers. Some HIV clinics now have special clinics for adolescents, when medical care is gradually transferred from paediatricians (doctors who care for children) to doctors who are expert in the care of adults with HIV. These clinics are

also designed to help your child adjust to living with HIV as a grown-up and will have services available to help manage the emotional and practical challenges he or she is likely to face.

Immunisations

Talk to your child's doctor about immunisations. Although it's generally safe to give vaccines to children with HIV, they should not be given 'live vaccines.' This means your child should not receive the BCG tuberculosis (TB) vaccine, or yellow fever vaccines. Children with HIV should definitely have the MMR vaccine (measles, mumps and rubella), as they need to be

protected against measles which can be very serious in individuals with a damaged immune system.

Childhood illnesses

Measles and chickenpox can have very severe health implications for HIV-positive children and you should seek medical advice immediately if you think that your child has, or has been exposed to, these illnesses.

Where to go for further information

As well as NAM and the organisations and helplines listed at the back of this booklet, the following organisations provide specialist information and support that you might find useful.

Body and Soul

Body and Soul is a UK charity providing support and services to families, children, and teenagers living with or affected by HIV. You can find out more by visiting their website <http://www.bodyandsoul.demon.co.uk>, by calling them 020 7383 7678, or emailing info@bodyandsoulcharity.co.uk.

Childrens HIV Association (CHIVA)

This organisation of professionals is involved in the treatment and care of babies and children with HIV. Their website <http://www.bhiva.org/chiva> has a lot of information about HIV treatments in children and some tips on pill-taking and other day-to-day issues.

Penta

This is another organisation of doctors and other professionals, but its website <http://www.ctu.mrc.ac.uk/penta> has useful information about HIV treatments and clinical trials for children and a calculator to estimate a child's risk of becoming ill because of HIV without treatment.

Telling people that your child has HIV

You do not have to tell anyone that your baby or child has HIV. You do not have to tell playgroup organisers, childcare workers, schools, or other parents.

If you do feel that you need to tell somebody about your child having HIV think about the reasons you want to do this. Think about how they might react and who else they might tell.

29 Summary

- HIV-positive women can now be almost sure to have an HIV-negative baby by using anti-HIV drugs, having a caesarean delivery and not breastfeeding.
- The course of HIV infection in babies and children is different to that seen in adults and needs specialist monitoring, care, and treatment.
- Infants can have very high viral loads without necessarily being ill, and children under six can have CD4 cell counts higher than those seen in adults and yet still be at risk of serious illness.
- HAART is effective in babies and children and can mean a longer, healthier life.
- All infants and children who are ill because of HIV, or have a rapidly falling CD4 cell count or rising viral load should take treatment.
- HAART can cause side-effects in children which may not always be the same as in adults.
- Adherence is as important in children as it is in adults.
- Children with HIV need appropriate information about their illness.

adherence The act of taking treatment exactly as prescribed, i.e. at the right times, with or without food as needed.

antiretroviral A medicine that acts against retroviruses such as HIV.

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

diagnosis Description of the causes of a patient's medical problems.

disease progression The worsening of a disease.

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

immune system The body's mechanisms for fighting infection and getting rid of cells that are not working properly.

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

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

NRTI Nucleoside reverse transcriptase inhibitor, the family of antiretrovirals that includes 3TC, AZT, ddI, ddC, d4T, abacavir, and FTC.

opportunistic infection Specific infections which cause disease in someone with a damaged immune system.

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

regimen A drug or treatment combination and the way it is taken.

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

undetectable viral load A level of viral load 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 in the blood is checked to see if treatments are working.



free monthly newsletter

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

Issues regularly covered include:

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More from NAM

NAM Information Forums

Monthly, 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.

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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