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hiv & children

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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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This booklet provides information about HIV treatment and care for HIV-positive children. We hope it will be useful if you are the parent or carer of an HIV-positive child. You may also find this booklet helpful if you want to talk to a child about either his or her HIV or that of another family member, in order to help them come to terms with the news and to find ways to stay well in the future.

The information in this booklet isn't intended to replace discussion with a doctor or other professionals. However, it may help you to decide what questions you would like to ask and can be a starting point for discussion.

contents

Children with HIV

Because of improvements in HIV treatment and care, large numbers of children who were born with HIV are now able to live healthy and productive lives as young adults. There are a lot of good reasons to believe that HIV-positive children who get the treatment that they need can now look forward to a long and healthy life.

However, HIV can have a major impact on the health and quality of life of your child and sadly some children, mostly those who do not get the right treatment in time, do still die because of HIV.

Getting the right treatment, care and support is important for the health and wellbeing of your child. There's also support available that can help you to respond to some of the difficult situations and decisions that you may encounter if you are looking after a child affected by HIV.

2 HIV testing

It is very important that children born to HIV-positive women are tested for HIV. Ideally, this should happen at birth (see below). But if this didn't happen, and the child's mother was, or thinks she might have been, HIV-positive at the time the child was born, they should be tested whatever their age because of the risk of mother-to-child transmission. If you are HIV-positive it is very important that your child, or children, are all tested for HIV whatever their age.

Although it can be painful and worrying knowing that a child has a serious illness, potentially life-saving treatment and care can only be provided if it's known that your child has HIV. Once you know about your child's diagnosis, you can be offered support by a variety of services to help your child have a long and healthy life.

The type of test used will depend on the age of your child.

HIV testing in babies

If you and your healthcare team know that you're HIV-positive, your baby will be tested at birth to see if he or she has been infected with HIV. An HIV viral load test will be used. This test looks for the presence of the virus in the blood. This test will be repeated after six weeks and again after twelve weeks.

If there is no trace of HIV after twelve weeks then you can be confident that your baby is not infected with HIV. However, it's important that you bottle feed your baby formula milk, as it's still possible for a mother to pass on HIV to her baby by breastfeeding, because HIV is present in breast milk. Help is available to meet the costs of paying for formula milk.

The HIV antibody test is not used to diagnose HIV in babies and young infants. This is because antibodies can cross the placenta from mother to infant and be present in the baby's blood for up to 18 months after he or she is born. A negative HIV antibody test result for your baby at 18 months of age is the final test that is done to confirm that the baby is not infected.

HIV testing for children aged 18 months and over

By the age of 18 months, if there are any HIV antibodies present in a child, this will be because the child is infected with HIV. Therefore if your child is aged 18 months or older, the test used to diagnose HIV will be the HIV antibody test.

Almost all mothers in the UK will have an HIV test in pregnancy. If for any reason this was not done and a woman or her child is later found to have HIV then if the woman has other children, they should also have an HIV test. It is very important to have older children tested for HIV if you discover that you are HIV-positive. Sadly, there have been cases of children dying of HIV because they were not diagnosed soon enough for life-saving treatment and care to be provided. Do not be afraid of telling your HIV clinic that you would like your children to be tested. HIV services will offer the same confidential service to children who are being tested for HIV as they do to adults and will offer you support regardless of the test result.

HIV care for children

Medical care for HIV-positive children is very specialised. Furthermore, the way HIV develops in babies and children is different to that in adults, especially because HIV progression can be faster in children. It's therefore important that your child is looked after at a clinic that has expertise in the care, treatment and support of HIV-positive children.

It's also important that both you and your child or children are registered with a GP, or family doctor, who will be able to look after your routine healthcare needs. Telling your GP that your child is HIV-positive will help the doctor have a full picture of the child's health to ensure they get the best possible care.

You'll be referred to a specialist clinic at the time your child is diagnosed with HIV. Or your own HIV clinic will be able to arrange an appointment for you. You can also find a clinic by calling the Terrence Higgins Trust helpline, THT Direct, on 0845 12 21 200.

The formal name for a clinic that looks after HIV-positive children is a paediatric HIV clinic. But it's likely that it will have another name (e.g. Family Clinic or ABC Clinic). Names like these don't have HIV in the title to protect the confidentiality of you and your child.

You can expect the clinic to be friendly and welcoming and its decoration and facilities will be non-threatening for children. There are likely to be pleasant activities for your child to help entertain him or her while you are waiting to be seen.

A number of specialist staff will be involved in the care of your child.

HIV paediatrician: The medical care of your child will be looked after by a doctor who specialises in treating HIV-positive children. The formal name for a doctor who specialises in children's medical care is a paediatrician. You'll have regular appointments with this doctor to monitor the health of your child. It's very important that you make sure that you and your child attend these appointments as they are essential to ensuring that your child receives the right treatment and care.

Your child's doctor will conduct physical examinations and arrange any tests. Details of the sorts of tests that may need to be done will be described later in this booklet.

The doctor will also be able to prescribe medicines to treat HIV and other infections. Details of HIV treatment for children will also be described later in this booklet.

Specialist nurses: Your clinic will also have nurses who are dedicated to looking after HIV-positive children. As well as looking after aspects of your child's medical care, they'll also be able to talk through with you other issues involved in looking after an HIV-positive child.

Specialist pharmacists: Medicines will be essential to looking after the health of your child, and to make sure they are used in the right way, your clinic will have specialist paediatric pharmacists. They will make sure that the right drugs and doses are dispensed and will check for interactions with other medicines. They will be able to provide information about how to take medicines properly.

Social workers: Having an HIV-positive child isn't just a medical issue. It can also have a big impact on other aspects of your life. There will be social workers at your clinic who can help you with questions and problems you may have about issues such as support, housing, benefits and schooling.

There's more information in the section on sources of support later in this booklet.

8 Monitoring the health of your child

Your child will have a number of tests to see how HIV is affecting their health and development.

Looking at the results of these tests, you and your doctor will be able to decide on the best course of treatment for your child.

Physical examinations

Every time your child sees his or her HIV doctor, they will have a physical examination to check on their health and development.

Your child will be measured and weighed to monitor their growth. HIV-positive children can have a slower rate of growth. Children with advanced HIV who have not been on treatment, and therefore have damaged immune systems, may enter puberty later than HIV-negative children. Children with good immune systems, including those on successful treatment as well as those not yet requiring treatment, generally enter puberty around the same age as those without HIV.Looking at how alert or happy your child is will help the doctor assess his or her health.

A thermometer placed in the ear for a few seconds will be used to monitor temperature. A high temperature can indicate an infection that requires treatment.

The doctor will check for rashes and dry skin, both of which are common in children with HIV.

By gently pressing down on the stomach, the doctor will be able check for any abnormalities and problems with the internal organs.

The doctor will use an instrument to look into your child's eyes, ears and throat. This isn't painful, and you or the doctor may make a game of it to make it seem less threatening for your child.

A stethoscope will be placed against your child's chest to check their breathing and heartbeat.

Blood tests

Regular blood tests are an essential part of care for everyone living with HIV.

A lot of adults don't like having their blood taken, and children often find it a frightening and distressing experience.

But there are a number of things that can be done to make it less unpleasant.

The skin can be temporarily numbed by applying anaesthetic cream before the blood is taken.

Explaining what is happening, and distracting children from the procedure can help make the experience less frightening. Over time most children gain confidence about blood tests if they have had good experiences and their fears have been calmed. Most children's clinics have specialist blood-taking teams who know how to help children with this.

After the blood has been taken, give your child a hug and congratulate him or her for being brave.

CD4 and viral load

The key tests used to monitor HIV in children are:

- CD4 cell count
- viral load.

The CD4 cell count can give a rough indication of the health of the immune system, and viral load shows how active HIV is in the body.

Because children's immune systems aren't fully developed, their CD4 cell count and viral load are different from those in adults.

CD4 cell counts tend to be higher in young children than adults, but these stabilise as the child gets older.

In babies, viral load can rise to very high levels and only decline very gradually over the first few years of life.

Looking at the results of these tests can help doctors decide when your child should start treatment for HIV, when they may need treatment to prevent infections and to see how effective any HIV treatment is. There's more information on treatment to prevent infections and starting and changing HIV treatment later in this booklet.

Other blood tests

Your child will also have regular blood tests to monitor other aspects of health. For example, tests will look at how organs such as their heart, kidneys and liver are working and can check for anaemia or infections. Looking at the results of these tests, your child's doctor will be able to see if any further investigation or treatment is needed.

Other tests

It may sometimes be necessary for samples of your child's urine, sputum or stools to be checked for infections.

Scans, X-rays and ultrasounds are used to help diagnose some health conditions. They are not painful, but as a new experience for a child they might be unsettling.

There's more information on tests regularly used in the care of people with HIV in NAM's booklet *CD4, viral load & other tests*. Although it is a guide to the medical monitoring of HIV-positive adults, much of the information also applies to the care of HIV-positive children.

12 Symptoms and illnesses

All children get unwell from time to time, but it is especially important to watch out for certain illnesses and symptoms if your child has HIV.

You should contact your child's HIV doctor if any of the following symptoms or illnesses develop:

- A temperature above 38 degrees. It's a good idea to have a thermometer at home so you can monitor your child's temperature if he or she feels hot.
- Pain. Changes in behaviour, restlessness, crying, withdrawal, and not smiling can all be possible warning signs that your child is experiencing pain.
- Weight loss or loss of appetite.
- Rashes and dry skin.
- Feeling or being sick.
- Childhood illnesses like measles, chicken pox, mumps. These can be more serious in children with HIV.

Vaccinations

Many childhood illnesses can be avoided through vaccines or immunisations. Most routine vaccines are safe for children living with HIV and are recommended. Your child should definitely receive the MMR vaccine, which is the combined measles, mumps and rubella vaccination.

'Live vaccines' (where a weakened or killed version of a virus is injected, so that the body builds up an immunity to it – the smallpox vaccine is an example of this) are not, however, generally considered safe.

Flu vaccines, including the swine flu vaccine, are considered safe for children with HIV as they are not 'live' vaccines.

Dental health

Good dental health is important for every child, but especially for children with HIV. Your child's teeth should be gently cleaned twice a day. It's important to keep a look out for any signs of infections, pain or inflammation as these can indicate more serious health problems. Your child should have regular dental check-ups. All dental care for children is free in the UK and your HIV clinic may be able to recommend a dentist.

Make sure your child does not share their toothbrush with anyone else. Brushing teeth can sometimes make them bleed and, although the risk of being infected is very small, good general hygiene means that it is best to make sure everyone has their own toothbrush.

HIV treatment

HIV treatment can mean a longer and healthier life for children with HIV. This treatment consists of taking a combination of three different anti-HIV drugs. If these drugs are taken properly, levels of HIV in the blood reduce to very low levels as no more new virus is being produced and the HIV is 'asleep'. This is called an undetectable viral load and is the aim of HIV treatment.

Having an undetectable viral load doesn't mean that a person has been cured of HIV. If the treatment is stopped new virus will immediately start to be made again. However, on treatment, because there's very little HIV in the blood, the immune system can stay strong and fight infections. This means that your child will have a good chance of staying well.

Available drugs

There are fewer anti-HIV drugs approved for treating children with HIV than there are for HIV-positive adults. Furthermore, some drugs can only be taken by children aged three and above, and the use of others is restricted to children aged six and above. However, you may find that your child is prescribed an anti-HIV drug that hasn't been formally approved for use in children. The use of medicines in this way is guided by current medical opinion and practice.

If you have any worries about your child's medication, always speak to his or her HIV doctor (paediatrician). Never stop giving your child his or her medication without speaking to the doctor first.

Doses

The doses of anti-HIV drugs given to children will depend on either the child's weight or size. These will be regularly monitored by the clinic to make sure your child receives the safest and most effective doses of their treatment.

When to start HIV treatment

All babies, under one year of age, who are infected with HIV should start HIV treatment immediately. This is also the case for babies who become infected with HIV through breastfeeding.

It is also recommended that all children aged over twelve months when they are diagnosed, who are ill because of HIV, should start taking HIV treatment.

Starting treatment at the right time can help reduce the risks of your child becoming ill not only because of HIV but also with some other serious illnesses.

Therefore children aged over twelve months are recommended to start HIV treatment when their CD4 cell count falls to a certain level. The level depends on the age of the child:

Aged 1 to 3 years: CD4 cell percentage below 25%, or a CD4 cell count below 1000.

Aged 3 to 5 years: CD4 cell percentage below 20%, or a CD4 cell count below 500.

Aged 5 years and above: CD4 cell count below 350.

In making a recommendation about starting HIV treatment, your child's doctor may also consider other factors. For example, HIV treatment may be started earlier if your child has a high viral load (above 100,000 copies/ml).

What to start HIV treatment with

The choice of drugs used to treat your child will depend on a number of factors. These include:

- Age
- Availability of formulations
- Your circumstances

If the mother has developed a strain of HIV that is resistant to some anti-HIV drugs, it's possible that this resistance may have been passed on to her child. Therefore all children should have a resistance test when decisions are being made about the most suitable combination of drugs.

A test (HLA B*5701) should also be performed to check for the possible hypersensitivity reaction to the drug abacavir (*Ziagen*, also in the combined pills *Kivexa* and *Trizivir*). If the HLA B*5701 test is positive then the child should **not** receive abacavir.

There are different types, or classes, of anti-HIV drugs. These work against HIV in different ways. To ensure that HIV treatment is successful at suppressing the virus, it is usual to take a combination of three anti-HIV drugs and these will come from at least two different classes of drugs.

The preferred first-line combination comprises two nucleoside reverse transcriptase inhibitors (NRTIs – a type of anti-HIV drug) plus either a non-nucleoside reverse transcriptase inhibitor (NNRTI) or a protease inhibitor (other types of anti-HIV drug).

NRTIs

Abacavir and 3TC (*Kivexa*) is the recommended combination of NRTIs. If your child is HLA B*5701 test positive, then AZT and 3TC (*Combivir*) or tenofovir and FTC (*Truvada*) is recommended.

NNRTIs and PIs

The NRTI drugs are combined with either an NNRTI or a protease inhibitor (PI). For children aged under three, the preferred NNRTI is nevirapine (*Viramune*). For children aged over three, the preferred NNRTI is efavirenz (*Sustiva*).

A PI is an alternative to an NNRTI. This may be a good option if your child is likely to have difficulty taking their treatment exactly as prescribed. This is because it is harder to develop resistance to PIs. PIs usually have their anti-HIV effect boosted by taking them with a small dose of a second PI called ritonavir (*Norvir*).

The recommended boosted protease inhibitor is *Kaletra* (lopinavir/ritonavir). Alternatives for children include: atazanavir (*Reyataz*)/ritonavir; fosamprenavir (*Telzir*)/ritonavir; saquinavir (*Invirase*)/ritonavir; and darunavir (*Prezista*)/ritonavir. *Kaletra* is the only formulation which has both drugs combined in the same tablet or liquid; for all the others the ritonavir booster must be taken separately.

Changing treatment

The aim of HIV treatment is an undetectable viral load. If your child's viral load doesn't fall to undetectable levels within six months of starting HIV treatment, or falls to undetectable and then increases to detectable levels in two successive tests, then his or her treatment may need to be changed. First though, it's important to understand why the virus has become detectable again. If it's because your child is having difficulty taking their medication, then if that can be sorted out and treatment becomes effective again the virus may go back to sleep, and become undetectable again.

Under these circumstances, if the viral load isn't reduced to an undetectable level then your child may develop drug-resistant HIV. This can mean that it is harder to find effective anti-HIV drugs that work to control the virus in the future. A blood test called a resistance test can check for this, and identify which HIV drugs will not work any more.

The choice of the next combination of anti-HIV drugs that your child takes will need to consider the following factors:

- Resistance to anti-HIV drugs.
- Availability of other anti-HIV drugs.
- Likelihood of taking the treatment properly.

Taking HIV treatment

Taking HIV treatment properly is called treatment adherence. Your child will get the most benefit from their HIV treatment if it is taken exactly as prescribed.

This involves:

- Taking all the doses of medication.
- Taking all the pills in the dose.
- Making sure that any food requirements or restrictions are observed.
- Making sure that doses are taken at the right time – taking pills too early or too late can be as bad as not taking them at all.

Missing doses or taking doses incorrectly can mean that viral load increases. This can lead to the development of drug-resistant HIV.

It's therefore important that you, and – as far as possible – your child, are committed to taking treatment.

The clinic will be able to give you some tips about how to give medicines to your child and how to increase the chances of him or her taking them in the right way.

Some useful methods may include:

- Make sure you feel positive about treatment, whether it's for you or your child. Try not to dwell on the downsides of your child being on treatment, but concentrate on the health benefits of it. If you are finding it difficult, talk over your feelings with someone at your child's HIV clinic, or at an HIV support organisation.
- Involve your child. For example, let your child choose the glass used for water to take with the medicines. Or keep a chart, and let your child record each dose of medicine taken, perhaps with a colourful sticker.
- Explain to your child that the medicine is needed to keep them well, it's not negotiable, and make sure they understand the boundaries.
- Establish a routine. If your child takes their medicine at the same time every day, they'll get used to doing it. Make it like cleaning their teeth, just something you do every day to keep strong and healthy for the future.

- Praise your child after each dose is taken.

- Teach your child how to swallow pills. The clinic will show you how to encourage and develop your child's pill-taking technique. For example, placing the pill near the back of the tongue and then washing it down with a good mouthful of water, followed by another good mouthful, can stop it moving around the mouth, which can make people gag or feel sick.

- Your child may need to practise taking pills for a few days or weeks before they start their HIV medication. Training them to swallow small sweets can be a useful way forward.

Make sure that you tell a member of your child's healthcare team if he or she is having problems taking their medicines. Many of the anti-HIV drugs used to treat children are available as either pills or liquid. If your child is having problems taking pills, then it might be possible to switch to a liquid. Or it may be possible to switch to a combination that involves fewer or smaller pills. Everyone has difficulties with medications at some time or another, so don't feel afraid to tell the clinic team how it's going for you – they will understand. If you let them know then you can all work together to try to find another solution.

There's more information on taking HIV treatment in the NAM booklet, *Adherence & Resistance*. Although this is intended for adults, a lot of the information in it is relevant to children.

Side-effects

All medicines can cause side-effects. The side-effects caused by the anti-HIV drugs used today are generally mild and lessen or go away completely over time. Children tend to cope with HIV treatment very well and have few side-effects.

Common side-effects

Before your child starts treatment with a new drug, the doctor or pharmacist will provide information about possible side-effects and some tips on how to cope with them.

Common side-effects of the drugs used to treat HIV are diarrhoea, feeling or being sick, and headache.

Many of these side-effects will only last for a week or two, so try to encourage your child to keep taking their medication until they notice the side-effects reducing. The clinic may give you anti-sickness or anti-diarrhoea medication when starting HIV treatment so you can give them to your child if needed.

If your child vomits within an hour of taking his or her medication, there will not have been enough time for the pill/liquid to be absorbed into the body, so the dose should be repeated.

If you have any concerns when your child is starting medication, speak to a specialist nurse or your child's doctor at your clinic for advice; don't wait or worry. Do not stop giving your child their HIV medication without talking to the clinic team.

Hypersensitivity reactions

Before starting treatment with abacavir (*Ziagen*, also in the combination pills *Kivexa* and *Trizivir*) your child should have the HLA B*5701 test to see if he or she has the gene associated with reactions to the drug. If the test is positive, then abacavir should definitely not be taken. If the test is negative it's probably safe to use abacavir, but you should still watch your child closely to see if they develop symptoms of hypersensitivity.

Symptoms of hypersensitivity include: rash, fever, diarrhoea and stomach pain, feeling generally unwell, cough, muscle pain, headache, feeling or being sick or sore throat.

Symptoms of reaction to abacavir usually develop within the first two to three weeks of treatment with the drug. The symptoms steadily get worse. If you think your child is reacting to abacavir, contact the HIV clinic immediately, or go to casualty (A&E) if your clinic is closed. Don't stop treatment with abacavir until the doctor advises you to.

If your doctor advises you to stop giving your child abacavir, make sure you never give it to your child again as this can be very dangerous.

Rash is also a symptom of reaction to nevirapine (*Viramune*). In most cases this goes away over time and isn't anything to worry about. But in rarer cases it can cause serious health problems. It's important that you mention this to your child's doctor if it develops so it is properly monitored.

A third drug, etravirine (*Intelence*) has also been linked to rare, but very serious, allergic reactions, which also involve a severe rash. Etravirine is not currently licensed for use in children.

Longer-term side-effects

Some anti-HIV drugs can cause longer-term side-effects. These include increases in blood fats, and liver and kidney problems. Although these may not be an issue yet, factors such as family history may affect which treatment is most suitable for your child.

Part of your child's HIV care will involve regular blood tests to see if these problems are developing. It's usually possible to do something about them.

Lipodystrophy

Treatment with some anti-HIV drugs such as AZT (zidovudine, *Retrovir*) or ritonavir (*Norvir*) have been linked to body fat changes including gradual fat loss from the face, limbs and buttocks (this is called lipodystrophy). This isn't dangerous, but it can affect the way a person looks and can affect their self-confidence.

Body fat changes can be very distressing in young people who are often very conscious of their body image. If your child needs to take drugs which may cause lipodystrophy, he or she will be closely monitored to see if they are experiencing fat loss.

Treatment is available to help restore fat loss from the face. It's been widely used in adults and has been shown to be safe and effective. Your clinic will be able to tell you if it's a suitable option for your child.

Talking to a child psychologist or a counsellor about this may also be helpful for your child.

Changing treatment because of side-effects

HIV treatment is meant to make people better, so side-effects aren't something that have to be endured if they are quite severe or if they don't reduce after the first few weeks. If your child isn't coping with a side-effect you should mention this at the clinic. Something can usually be done about side-effects.

Changing treatment might be appropriate in some cases. You'll need to consider the pro's and con's of this – for example, the side-effects of new treatments and how easy they are to take.

The NAM booklet *Side-effects* provides more information on the range of side-effects that anti-HIV drugs can cause and how to cope with them. Although it's been written with adults in mind, much of its content also applies to children.

Living with HIV

Children with HIV can have a happy, normal and, thanks to HIV treatment, long life.

However, your child will grow up with some different experiences from other children, and this could affect how they feel about themselves, as well as leading to a feeling of being different or alone.

Stigma and discrimination may be experienced, as might sadness, illnesses, or even the loss or death of loved ones.

Loving and supporting your child will provide the foundation for living through these issues. Helping them recognise that planning their days, developing a routine around their medication and talking to someone they can trust, will help them to adjust to the diagnosis and management of the condition. It's also good to know that a lot of support is available to you and this will be outlined later in this booklet.

Day-to-day life

Children often get cuts or grazes whilst playing. These should be washed thoroughly and sticking plaster or another form of dressing should be applied. If somebody else has come into contact with your child's blood, it should be washed off with soap and hot water.

The risk of being infected with the virus through open cuts and abrasions is extremely small. It's impossible to contract HIV through intact, healthy skin.

Similarly, the risk of HIV being passed on by biting is extremely low.

It's probably a good idea not to let your child share objects which may have had contact with their blood such as toothbrushes, although HIV transmission this way is highly unlikely.

HIV cannot be passed on by sharing cutlery, plates or cups, because HIV cannot be transmitted in saliva. Nor can it be transmitted by social contact, through the air or by touching objects handled by an HIV-positive person.

Giving your child information about HIV will be an ongoing process. What you say at any one time will depend on the child's age, their level of understanding, and their readiness to know.

It's important to think about how and when you'll give your child information about their own HIV infection or, if relevant, yours or other people's. It's important that you use language your child will understand. Be honest and consistent. Hiding the truth can mean that you encounter problems later.

A psychologist, social worker or nurse at the clinic may be able to give you some tips about how to talk to your child about HIV and illness. Other parents and carers of HIV-positive children may also be able to share their experiences with you. It's a good idea to prepare yourself for possible answers to questions and have some support lined up to turn to if you need to.

Providing information as your child grows up

You're likely to find that even very young children will want to know why they have to go to the clinic, have tests or take medicines. Explanations can initially be provided without having to mention HIV. This can help build up an understanding of their illness. For example:

- We went to see the doctor today because you have an illness that can sometimes make you unwell.

- The doctor and nurse wanted to see how you are doing.
- The medicines you need to take can help you get better and/or stay well.

As your child gets older, you'll need to provide more information. For example, you might want to say something like:

- The reason you need to go to the clinic is because something in your blood isn't working as well as it should do.
- The tests you have look at your blood and what we learn from them helps us to keep you well.
- You take medicines to make sure that your blood is working properly and this can stop you from getting ill.
- Your medicines are working very well, keeping your white blood fighter cells very strong so you don't get sick from any infections.
- Your medicines are working very well, keeping the virus in your blood asleep so you don't get sick.
- I am also taking my medicines, and my virus is asleep too; we are both doing very well together.

Most children are ready to learn about HIV at about eleven or twelve years old – around the time they go to secondary school. The information you provide should therefore mention HIV.

Think about what you need to tell your child. They don't need to have lots of detail about HIV or know everything straight away. Giving too much information may only complicate things for them and make them confused and worried.

If your child starts asking questions about why they need to take medication or go to hospital, you should provide an explanation of why monitoring needs to happen and why treatment is important. For example:

- You were born with a virus in your blood called HIV.
- You go to the clinic to see how HIV is affecting your health.
- The medicines you take stop HIV from damaging your body and keep you well.

Talking to your child may be difficult or even painful for you. But it can help your child to feel involved and give them a sense of control over their treatment and care. It can also help build a sense of independence and help reduce fear and anxiety.

Be prepared to answers questions. The questions you might be asked include:

- How did I get it?
- How long will I live?
- Am I going to die?
- What will happen to me?
- Do you have HIV as well?
- How did you get HIV?
- Can I give it to someone else?
- Can I tell my friends I have it?
- Will the HIV ever go away?

You can probably think of lots of other questions that your child might ask. The questions will vary depending on how old your child is and how much they understand.

It's a good idea to think about answers. Try practising a roleplay in your mind or with someone you can trust, where you can act out the scene when you tell your child about HIV. Try to think about some of the questions they might ask you: some of these questions might be awkward, difficult or embarrassing, but if you have thought about what they are you can feel prepared if and when they happen.

Many parents find it very difficult to name HIV to their child. Your clinic team can help you with doing this for the first time, and support you and your child afterwards in dealing with this new knowledge. For children who are well, and have learnt the story bit by bit over the years, this process is often not as worrying or problematic for the child as parents fear.

Many parents fear that their children will then tell others that they have HIV. You can be reassured that children rarely do this: they almost always feel that this information should be kept private. If your child does want to tell someone, you need to help them think carefully about this (see *Telling other people that your child has HIV* below). This may become more of an issue as your child gets older.

Older children may have worries that they feel uncomfortable talking to their parents about. For example, they might want to know about how not to spread the virus to boyfriends or girlfriends. Talking about safe sex and using condoms can be uncomfortable for lots of parents as well. Don't be afraid of asking your clinic for help with this. They may have, or can refer you to, health advisers whose job it is to advise about preventing HIV and other sexually transmitted infections.

Many parents fear that their child will be very angry that they have been 'given' HIV. Again this is a very rare reaction: most children and parents actually get closer together, and feel more strongly connected in trying to support each other with their condition.

Many parents want to put off telling their child about HIV. Young people who have been born with HIV have told us that they think the best time to know about the virus is between ten and twelve years. Those who found out later than this often feel quite angry that important information about their body and their health was not shared with them, and this did not help their relationships with their parents.

So remember:

- Many children with HIV cope extremely well with the knowledge that they are HIV positive.
- Take things slowly. Keep messages about your child's condition and treatment simple so that they can remember instructions easily.
- Write things down if you think it will help them.
- Encourage them to ask questions – if you give them any leaflets or booklets to read, make time to ask them what they think about the information and whether they understood it.
- Let them know that you are there to support them – this will help them feel that HIV is something they can cope with in the future.

- Speak to staff at your child's clinic – find out if there is someone like a nurse, health adviser, social worker or psychologist they can call if they need to ask a question or if they would like to talk to someone outside the family.

- If your child asks you questions that you are struggling to answer, you can also call their clinic for advice. Staff at the clinic will help you prepare and will be able to talk to your child and provide more information if needed.

Talking to your child about your own or other family members' HIV

If you, or other members of your family, are HIV-positive as well, then this is something that you'll eventually need to discuss with your child.

Although it will be probably upset them to learn that someone close to them has an illness, knowing could build a greater understanding of events that they may actually already be aware of to some degree and give a sense of involvement and control.

When you tell them, offer reassurance but do not lie to them. Help them feel prepared for the fact that they might witness you or someone else falling ill and consider telling them how they can help (e.g. you may want to let them know when you have to take your tablets).

Some parents find it helpful to write down a list of instructions of what people in the family should do if you or someone else falls ill. Although this may be uncomfortable to do, many children are glad to know they can be of help and this reduces fear and anxiety. The instructions may include:

- Details of the HIV clinic and names of doctors
- The name of the family GP
- How to use 999 emergency services in case an ambulance is needed
- The names and telephone numbers of friends or relatives who can help.

The instructions should be kept somewhere safe where they can be found easily. Even though they may not be needed, having the instructions available can help everyone who knows about HIV in the family feel less worried and give them a sense of control. And they can be useful in all sorts of situations – not just those to do with HIV.

Telling other people that your child has HIV

It's up to you who you tell, and when you tell them, that your child has HIV.

You don't have to tell playgroups, schools or other parents. Illnesses, absence, and medicines can all be explained without reference to HIV.

If you do plan to tell someone else about your child's HIV, think carefully about your reasons for doing this. Does the person really need to know? Will it make a positive difference to the wellbeing of your child? Who else might this person tell? What will the consequences be if other people find out?

There can be benefits from telling people about your child's (or your own) HIV status. Most importantly, it can open sources of love and support, or make services easier to obtain. It's good to know that many people have had very good experiences after telling others about their child's HIV or their own, and have found that loved ones, friends and professionals have done their best to help.

Staff at the clinic and at HIV support organisations will be able to talk through the pro's and con's of telling people about your child's health and HIV.

It is possible, even likely, that your child will be asked by friends at school about their time off for things like clinic visits and illness, or why he or she needs to take medicines. When you talk to your child you can tell them that their illness is nothing to be ashamed of, but that it's private. You can also think of some potential answers to give to other children about absences or taking medicines. It's often useful to keep these answers vague.

As your child gets older, they may want to tell more people about their HIV status (and this may become more important once they start thinking about having sexual relationships; see *The future*, below). You will need to help them think through the impact of telling more people, how they might do it and the best time to do it.

38 Education

At the age of four or five your child will start going to school. This is initially an unsettling experience for a lot of children, but most soon settle in, make friends, and enjoy the stimulation that school provides. Schools are not allowed to discriminate against children because they have HIV. Children with HIV should be allowed to take part in all school activities, depending only on how well they are at any time.

Hospital appointments and illness may mean that your child has more frequent absences from school, which means they can miss out on lessons. You don't have to mention HIV when you provide an explanation to the school. However, regular or lengthy absences can have an impact on your child's learning. If children are doing well on treatment, they only need to have about four visits to the clinic per year and at least half of them can be in the holidays, so children really do not need to miss much time from school.

Research has shown that some children with HIV have slower educational development than other children. There are likely to be a number of reasons for this, including both the child's physical health and their family history and circumstances. Support from a child psychologist or specialist educational support workers may be helpful and can be accessed through your child's HIV clinic or the school. If discussing this with the school, you don't have to mention HIV.

It's good to know that schools are not allowed to discriminate against children because they have HIV.

More and more children who were infected with HIV at birth are growing up and entering their teenage years and adulthood.

Some children's HIV clinics now have special clinics for adolescents. These help to gradually transfer their treatment, care and support to adult HIV services. Adolescent HIV clinics can help your child adjust to living with HIV as a grown-up. They have services that can respond to the emotional and practical issues they are likely to encounter.

If there isn't a specialist adolescent clinic, your child will be gradually introduced to an adult HIV clinic. This is likely to happen when your child is around 16 to 18. The first appointment will be a joint consultation with the paediatrician who has been looking after your child and the doctor who will be taking over their care.

Adult HIV clinics have a different environment to those offering services to children. Obviously, the other patients will all be grown-ups aged from their late teens to advanced old age.

The literature on display will be targeted at adults: there will certainly be information available about sex and how to avoid passing on HIV to sexual partners.

As HIV-positive children approach adulthood, it's very important that they are provided with information about safe and enjoyable sex. This should include a discussion about the physical development of their body, their feelings about intimacy and relationships, and their sexual desires. It's also important that there is a discussion of ways of preventing the transmission of HIV especially safer sex but also through other transmission routes such as drug use.

Many parents find it difficult to talk to their children about sex, and judging the right time to do this is often tricky.

Don't be afraid to look to the clinic staff for advice about how to talk to your child about safer sex and sexuality – they are used to discussing these issues. Also, just talking to your child about these issues will not make them have sex, but it will help them prepare themselves for sex when the time is right.

It's good to know that staff at your child's HIV clinic will be able to talk through the issues with you. They may be willing to discuss sex and sexuality with your child if you feel this would be helpful.

THT Direct

0845 12 21 200
10am to 10pm Monday to Friday
12 noon to 6pm at weekends

THT Direct staff can provide information, support and advice, and can help you to find other relevant health and support services.

African AIDS Helpline

0800 0967 500
10am to 6pm Monday to Friday

Helpline staff can answer questions and provide referrals for support if needed.

Body and Soul

020 7923 6880
www.bodyandsoulcharity.org
info@bodyandsoulcharity.org

Body and Soul is a charity providing support for children, teenagers and families living with, or affected by HIV.

Children's HIV Association (CHIVA)

www.chiva.org.uk

CHIVA is the professional organisation for all clinic staff involved in the treatment and care of children with HIV. Their website has a lot of useful information about HIV treatment for children and some tips on pill-taking and other day-to-day issues.

Children with AIDS Charity (CWAC)

020 7033 8620

www.cwac.org

info@cwac.org

CWAC has three main ways of helping children and families infected and affected by HIV/AIDS. It provides direct financial support through a hardship and respite fund, assistance with transport and transport costs and aims to educate people about HIV and how to prevent its spread.

Summary

- If you are an HIV-positive woman, it's very important that your children are tested for HIV.
- The course of HIV infection in children is different to that seen in adults and needs specialist monitoring, care and treatment.
- Treatment for HIV is very effective, and HIV-positive children who get the treatment they need can look forward to a long, healthy life.
- Your child's health should be monitored regularly at a specialist clinic.
- Taking treatment properly is very important and the clinic can suggest ways of helping with this.
- Children with HIV need appropriate information about their illness.
- It's up to you whether you tell other people that your child has HIV, and it's a good idea to think carefully about this before making a decision.
- There is lots of support available to help you and your child live well with HIV.

Glossary

adherence Taking treatment as prescribed - at the right times, with or without food, as needed.

antiretroviral A type of medicine that acts against retroviruses like HIV.

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

immune system The body's mechanism for fighting infections.

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

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

side-effects An unwanted secondary effect of a treatment.

viral load The measurement of the amount of virus in a sample. HIV viral load shows the extent to which HIV is reproducing in the body.

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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:

....

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....

Please tear off this page and post it to: NAM, FREEPOST LON17995 London, SW9 6BR. Alternatively you can complete the questionnaire at www.aidsmap.com/feedback, where you can also try our HIV treatment and health knowledge quiz, which will help ensure you have all the information you need to get the best out of your health care or treatment.

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: male / female / 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: unknown / negative / positive
- (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 & hepatitis ■ hiv & mental health ■ hiv & sex ■ hiv & stigma ■ hiv & women ■ hiv therapy ■ hiv & tb ■ nutrition ■ side-effects

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