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EDITORIAL

Dear parent/guardian

Finding out that your child or a child in your care is HIV infected can be one of the most difficult and traumatic experiences of your life. You may feel quite overwhelmed and have little time to process all the new information coming your way. A lot of the information that is given to you in the clinic might simply seem confusing and can be quickly forgotten. This booklet seeks to provide some basic information about HIV infection and children that you can read at your own pace and at a time that suits you.

There is a lot to learn about HIV infection. Although we do not have a cure yet, treatment has dramatically improved the outlook for infected children. Over the years The Rainbow Clinic Team has learned a lot about HIV infection, about preventing complications that can arise, and how to slow down the gradual weakening of the immune system that can progress to AIDS.

This booklet has been put together by The Rainbow Clinic Team, parents and other healthcare workers. It is based on their experiences and experiences gained through working with families like you. We hope it will benefit you by explaining how HIV infection affects children and what help is available for you and your child.

This booklet is just a beginning. With your help and feedback we can learn how to make it better. Certainly, let us know the parts that are useful, but please let us know that parts that aren't clear enough or that haven't answered your questions. Together we can make it better.

The Rainbow Clinic Team, based at Our Lady's Hospital for Sick Children, Crumlin, and The Children's University Hospital, Temple Street, would like to take this opportunity to thank all their colleagues in the Paediatric Units, Paediatric Hospitals, Maternity Services and Adult HIV services throughout the country for their unfailing support and assistance, and to Bristol-Myers Squibb for the financial support which has enabled production of this booklet.

Finally and most sincerely, we would like to thank all the children and their families who teach us so much.

Yours,

Dr Karina M. Butler.

A NOTE FROM PARENTS OF A CHILD WITH HIV INFECTION

Four years ago, in 1998, my son and I were diagnosed with HIV. When I was first told, I felt that there was very little future for either of us. I wanted to drive over a pier and end it all for both of us. But four years on, we are both very healthy and very happy.

In the beginning it was difficult to deal with the diagnosis. There were my own confused feelings and emotions as well as the usual problems that come with looking after a demanding toddler.

We have had only one stay in hospital, for a week, when my son had chicken pox. Apart from that, he leads a very normal life, with the usual illnesses that are common in children his age - colds, coughs, earache, etc.

He is doing very well in school and really enjoys sport, especially badminton, soccer and swimming. He eats very well and is growing at a normal rate for his age. We visit the dentist regularly and he has had several fillings with no problems.

Life for us now is generally very good and we have travelled a long distance since the early days of the diagnosis. I have only told two close family members about the diagnosis and I still feel very wary about telling any other family and friends. Sometimes this can be lonely and frustrating, but it is a decision I made four years ago and I am very happy with that.

I still have many fears and worries about the illness - namely how my son will react when he finds out his diagnosis and how he will cope with it in his adolescent years. My greatest fear is that if something should happen to me, who will take care of my son. It is during these times that I rely on the support available to me from my family and from the Rainbow Team.

I know that I could never come through all of this had it not been for the support given to us by the Rainbow Team, who have always been at the other end of a phone in times of illness, or worry, or just for a chat. I have also had great support from my GP who always has time to listen and talk.

In these past few years I have learned that this illness does not go away, it is always there, but I have learned to live with it and cope with it in the best way I can. Things do get better.

Emer (parent of a 7 year old HIV positive boy)



COPING WITH A DIAGNOSIS OF HIV

If you have been told that your child is HIV positive you may well be in a state of shock, distress and disbelief. You may have also learned that you too have the virus. Fear, anger, guilt, denial, helplessness and grief are all very powerful and normal reactions to such a crisis. Information that is given to you can be difficult to take in and understand. It may need to be repeated several times. Do not be afraid to ask questions, however basic and simple they seem to you. Many parents find it helpful to write out a list of questions at home to bring to the hospital. Some questions and answers included in this booklet may be helpful to you.

WHAT IS HIV AND WHAT DOES BEING "HIV POSITIVE" MEAN?

HIV or **H**uman **I**mmunodeficiency **V**irus is a tiny virus that attacks the immune system. The immune system is the body's natural defence against disease.

A person infected with HIV can feel well and appear healthy for many years. Eventually as HIV attacks the body's immune system, one or more serious illnesses can develop and the person is diagnosed as having **AIDS** (**A**cquired **I**mmune **D**eficiency **S**ndrome).

Most children who are infected with HIV live normal lives for many years but are more prone to infections than uninfected children.

HOW IS HIV TRANSMITTED

HIV lives in body fluids such as blood, semen, breast milk and vaginal fluids. The virus is passed on when any of these infected body fluids enter another person's body. HIV is a very fragile virus and is therefore not easy to transmit.

The different ways that HIV can be transmitted are:

- Having unprotected sex with a person who is infected with HIV
- Receiving a transfusion of an infected blood product
- Sharing needles or syringes with a person who is infected with HIV
- From mother to baby, during pregnancy, at delivery, or through breastfeeding.

TRANSMISSION FROM MOTHER TO BABY

Vertical transmission is the transmission of HIV from an HIV positive pregnant woman to her baby, either during pregnancy or at the time of delivery. The risk of this happening is around 25%. However, if anti HIV therapy (including Zidovudine) is taken during pregnancy, during delivery and by the infant for four weeks, the risk can be reduced from 25% to < 2%.

HIV has also been found in breast milk and babies have become infected with the virus through breast feeding.

- HIV cannot be caught from everyday activities.
- HIV is not transmitted through hugs, cuddles, kisses, saliva, sweat or tears.
- HIV is not transmitted through faeces and urine

SHOULD OTHER CHILDREN IN THE FAMILY BE TESTED FOR HIV?

As HIV is transmitted from mother to child, it is important that all children in the family be tested for HIV. This can be organised through the Rainbow Clinic or your GP.

EVERYDAY LIFE WITH HIV

You, your child and your family can carry on with every day life as normal. Your child will be able to go to childcare, a playgroup, or a school that is appropriate for his/her age. Children with HIV can be involved in all the usual activities such as swimming and sports, school excursions and outings with family and friends.

Choosing a Doctor

It is important that your child sees a local GP and a paediatrician regularly. Your GP will look after day to day problems like colds, ear infections and immunisations. Your child will be reviewed on a regular basis by the Rainbow Team at Our Lady's Hospital for Sick Children or The Children's University Hospital, Temple St. (Your GP and the Rainbow Team will communicate with each other on a regular basis).



THE RAINBOW TEAM

The Rainbow Team provides care to children with HIV and other infections. It includes doctors, nurses, a social worker, a dietician, administration staff, a pharmacist and a psychologist. The effects of HIV infection on you and your family are not only physical, but also financial, social and emotional. You will need support from different members of the team at different times. You will be allocated a nurse specialist who will help co-ordinate the care your child requires.



If you are concerned about your child's health at any time, you should always seek advice from your doctor or nurse.

HOW CAN I HELP MY CHILD STAY WELL?

General Hygiene

All children (and adults) need to understand the importance of hand washing before touching and eating food and after toileting - regardless of their HIV status. If there is an animal in the house, remember to ask the children to wash their hands after playing with it. Personal items such as toothbrushes, razors or tweezers should not be shared. This is basic hygiene needed to protect everyone from a variety of germs.



Mouth and teeth

Children with weakened immune systems are more prone to getting infections in the mouth. These sores can be uncomfortable and can prevent your child from eating. Regular tooth brushing should be encouraged so that the mouth can be kept as clean as possible. Your child should also be seen by a dentist regularly.

Sharing toothbrushes or razors is not recommended, as these objects may cause bleeding during use.

Contact with common childhood diseases

It is really important if your child comes into contact with a child with chicken pox, measles, whooping cough or indeed any childhood illness, to seek advice as soon as possible from your nurse or doctor. Your child may need an injection to help boost the immune system. This measure may either prevent the disease, or stop your child from getting a severe form of the disease.

Immunisations

It is important that children with HIV receive normal childhood immunisations at the appropriate ages this includes the 'five in one' (tetanus, diphtheria, pertussis, polio & Hib), meningitis C and MMR. BCG should not be given. It is also recommended that children with HIV receive some additional vaccinations including a flu vaccine every autumn and pneumococcal vaccine.

Diet

For normal childhood growth and development and in order to stay well, children with HIV should eat a well balanced and nutritious diet.

The dietician on the Rainbow Team will be able to advise you on a healthy diet if your child is not growing normally or is having problems eating. He/she may recommend changes to the diet and try to tailor these changes to fit into your family routine.

INTELLECTUAL DEVELOPMENT

Because the HIV virus can affect your child's development, your child should be seen by a child psychologist from time to time. If any problems are highlighted, he/she will advise you on how to help your child. This information may also be useful in assisting your child's teacher to address your child's learning needs. Of course information will only be provided to teachers with your consent and need not contain any direct reference to HIV status.



WHAT KINDS OF ILLNESS SHOULD I LOOK OUT FOR?

It is advisable for your child to see or contact the doctor if any of the following problems occur.

Fever

This is a temperature of 38°C or higher. Rigors (uncontrolled shaking) can occur when a child has a high fever. It is useful to have a thermometer at home so that you can check your child's temperature if he/she is unwell. Paracetamol (calpol) or Ibuprofen (nurofen) can be given as required.

Ear infections and/or sinusitis

If small children and toddlers pull at their ears constantly, it could mean that they have an ear infection. Older children may complain of an earache. The child may not hear normally, turn the TV up loud, or appear to be naughty (because they have not heard you). Occasionally fluid can drain from the ear canal.

Sinusitis is an infection of the sinuses. Children may have a runny nose for several days and sometimes a cough and fever.

Swollen glands

Some children with HIV have swollen glands, particularly around their face and neck. Anti HIV medicines can reduce the size of these glands. If the glands become painful, you should contact your doctor or nurse as they could be infected. Infections can be treated with antibiotics.

Breathing difficulties

This is breathing that is faster or more difficult than usual. It is sometimes accompanied by a cough.

If your child appears to have difficulty in breathing, contact your doctor or nurse as soon as possible. If your doctor or nurse is unable to be contacted, bring your child to the nearest hospital emergency department to be checked out by the doctors there.

Skin problems

Some children with HIV have very dry skin. We recommend using silcocks base instead of soap in the shower or bath. It provides moisture protection for the skin. If you notice

that your child's skin is very dry, use emulsifying cream as a moisturiser as frequently as necessary. Both these creams can be obtained at any pharmacy.

The appearance of sores, rashes, lumps, itching, redness, swelling on any part of the body (including severe nappy rashes) should be examined by your doctor.

Children with HIV have a higher incidence of a rash called "eczema". This can result in extremely dry skin and/or open sores on the skin. Consult your doctor if you think your child has eczema. A special steroid cream may be necessary for a while.

Pain and/or discomfort

In children who are too young to tell you where their pain is, watch for pulling on ears, holding arms or legs in awkward ways, drawing up of legs towards the stomach, general irritability, and change in sleeping patterns. Other indicators of pain may include, a change in behaviour such as mood swings, sleeping for longer periods, less responsive, not wanting to play, not talking, not smiling, limping or not walking. If you are worried that your child is in pain, contact your doctor or nurse for advice.

Vomiting and/or diarrhoea

If your child is vomiting and/or has diarrhoea, speak to your doctor or nurse for advice. Your child may need to have his/her stools examined for infectious organisms, or they may need extra fluids if they are dehydrated.

Loss of appetite and/or weight

Growth problems may be the first indication that a child's health is starting to be affected by HIV. Self esteem needs to be encouraged, particularly if they are shorter than their younger siblings or friends. A dietician will provide you with dietary advice.

Chicken pox & Measles

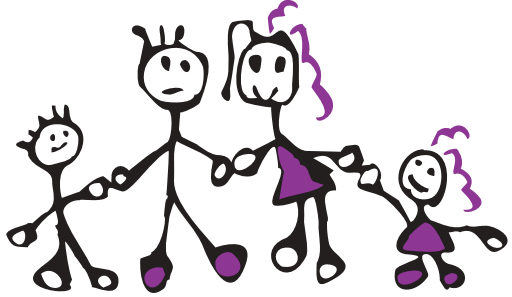
If your child comes into contact with chicken pox or measles it is important to contact your nurse specialist immediately. Protection can be offered to your child to try and prevent him/her getting either disease.

'At times of illness or a change in medications it is great to talk with another parent about the up's and downs'

Sarah (parent of a 10 year old HIV positive child)

WHO WILL I CONTACT IF THERE IS ANY PROBLEMS WITH MY CHILD?

You should contact the Rainbow Team or your Nurse Specialist on **01 409 6100** between 9 a.m. and 5 p.m. After these hours please contact your GP or nearest Accident and Emergency Department.



THE BLOOD TESTS - WHY ARE THEY NEEDED?

There are several common blood tests that are done on a regular basis to see how your child is doing. These are:

Full blood count (FBC)

This test measures the amount of blood cells in the circulation system.

T-cell count - also called CD4 count

This test measures the number of T-cells in the blood. The T-cells help fight infection and are specifically damaged by HIV. A T-cell count can tell how healthy the immune system is. A high T-cell count is good.

Electrolytes and Liver Function Tests

There are several tests which measure the chemical balance of the body and how well the liver and kidneys are functioning. Some of the medications that your child may be taking have the potential to affect the kidneys and/or liver.

Viral load test

This test shows the amount of HIV in the blood. A low or preferably an undetectable result is desirable. The aim is to keep HIV from damaging T-cells so that your child can protect him/herself from infections. If the viral load is high your doctor may recommend starting or changing treatment.

Other common tests

These may include X-rays, CT and ultrasounds scans of body parts (e.g. the tummy). These are often done in order to find out the reason why your child has a particular problem with a part of their body e.g. chest X ray for a persistent cough, a CT scan of the brain for loss of developmental skills, or ultrasound scans for unexplained tummy pains.

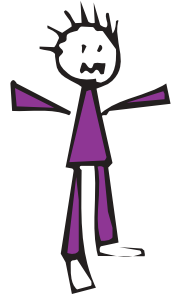
'HIV is just like an army inside your body, the red army is the good army and the black army is the bad army. This is HIV. Before I knew I had HIV I only had 80 red soldiers and a lot more black ones. But now I have 500 red soldiers and not too many black ones. But how I got so high is a bit of a secret. But I'll tell you. I take special tablets'.

Aaron (10 year old HIV positive boy)

FEAR OF NEEDLES

Everybody hates needles and children are no different. Ametop or EMLA cream, often called "magic cream" by the children, should be available to all children having blood tests. This cream is a local anaesthetic, which means that it actually numbs the area where the needle is inserted (a small number of children may be allergic to one or other of the creams). The procedure for taking blood tests is then explained to your child. This is to provide your child with an understanding of the process and hopefully lessens fear and anxiety levels.

The next thing to do is to help your child through the actual blood testing procedure. Your nurse can help you to distract your child, like getting them to count or sing a song, blow bubbles, scream but not move, or story telling. Some children like to look away; others need to watch the needle go in. Talk to your child before blood is taken to see what they would like to do. There is nothing worse than breaking into a song that your child hates!!



If your child is too young to do any of the above, just be there for your child and comforting can help. With children under 2 years of age it can be difficult to distract them, but they soon learn that the process is not actually very painful. Rather, it is a frightening process that becomes easier with time. It probably hurts you much more than your child. Give your child a big cuddle afterwards and tell them how good they were.

'I go to the hospital every month and get my bloods done. It is only a little prick and I usually laugh'.

Aaron (10 year old HIV positive boy)

DRUG TREATMENT FOR HIV

After testing positive, will my child require medicines?

When your child tests positive for HIV he/she will be examined thoroughly by your doctor and this will include some more blood tests. Depending on the results, your child at this time may or may not require medication. Some children will not need to start taking medication for some time after diagnosis. If this is the case, your child will be closely monitored to see how he/she is doing. Alternatively some children will require medicines soon after diagnosis. The Rainbow Team will discuss this with you and talk to you about the drug options available. Your child will start medicines when you, your child and the Rainbow Team feel happy that the time is right.

Clinical Trials

Clinical trials are research studies that closely monitor the effectiveness of anti-HIV medicines in people with HIV. They are important if we are to find new and better ways to treat HIV. If your child needs treatment for his or her HIV, a member of the Rainbow Clinic Team may talk to you about enrolling your child into a trial. Whether or not you decide to participate in a trial is your decision and will not effect the care and treatment your child receives.

PCP prophylaxis

Pneumocystis Carinii Pneumonia (PCP) is an opportunistic infection. An opportunistic infection means that a normally harmless germ attacks the body once the immune system has been severely weakened by HIV infection.

PCP is the most common and most worrisome opportunistic infection in HIV positive children. It can cause coughing, fever and breathing problems. Children who are infected with HIV and who have a low T-cell count (a low T-cell count means a weakened immune system), should take co-trimoxazole (also called Bactrim or Septrin) as directed by the doctor to reduce the risk of developing PCP. This preventative measure is called prophylaxis (pro-fill-axis). Co-trimoxazole is an antibiotic.

Anti-HIV medication

The goal of the treatment for HIV is to slow down the rate at which the virus makes copies of itself. This process of copying is also known as replication.

Drugs that are used in the treatment of HIV infection are known as **ANTIRETROVIRAL AGENTS** (antiviral or anti-HIV medicines) and there are three separate groups. Each group works on the virus at a different stage of its replication.

The three groups are:

Nucleoside Reverse Transcriptase Inhibitors (NRTI's), Non-nucleoside Reverse Transcriptase Inhibitors (NNRTI's) and Protease Inhibitors (PI's). If your child needs to take these, your doctor and nurse will explain how and when to give them.

Three or more of these medicines are used together to treat children (and adults) infected with HIV. This is known as **COMBINATION THERAPY**. It has been found that using a combination of three medicines is more effective than one medicine alone or a combination of two.

The benefits of using a combination of medicines for your child are:

- The medicines working together are more effective than a medicine working on its own
- The viral load will be decreased significantly
- It is less likely that the virus will become resistant to the medicines

The ultimate goals of anti-HIV treatment are:

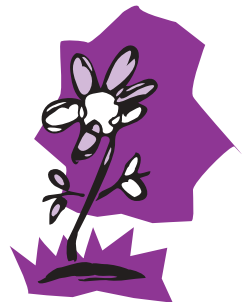
- To promote or restore normal growth and development
- To prevent complicating infections and cancers
- To improve quality of life
- To prolong survival

Common side effects

The most common side effects of antiretroviral agents are nausea, diarrhoea, headaches and feeling tired. However they vary from person to person and from adult to child. It is rare to experience all of these side effects. These symptoms can appear shortly after the medication has been started but gradually disappear after a few weeks. It is important that you tell the doctor about any side effects that your child develops. The doctor will monitor your child closely at first, usually monthly. Once your child is stable or settled on the medicine, your doctor may wish to see you and your child about every three months.

Lipodystrophy

Protease inhibitors have been linked with a syndrome called lipodystrophy, which is the abnormal distribution of fat in the body. If you notice a change in your child's physical appearance, particularly thinning of the face or limbs or abnormal accumulations of fat on the back, tummy or other areas, you should inform your doctor.



Natural/complementary therapy

These are natural medicines usually extracted from plants and are reported to boost the immune system and reduce the side effects caused by antiviral medicines. Some natural therapies may interact with the medicines your child is already receiving. It is very important to discuss with your doctor or pharmacist before starting your child on natural therapies.

Adherence to medication

It is very important that the medicines are taken at the same time each day and that no doses are missed. There is a greater risk of viral resistance developing when doses are missed. Resistance means that the medicines become less effective at slowing down the activity of the virus. It also means that the medicines will not work as efficiently and the length of time for which they will be of benefit to your child will be much shorter. When starting medications it is important that you and your child are ready to commit to a regimen that requires taking medicines twice a day, or more, at the right time, in the right way and with no missed doses. Regular blood tests can tell how well the medicines are working for your child and can indicate if changes are required to the current treatment.



You must let the doctor, nurse or pharmacist know if your child is having difficulty taking or tolerating any of the medicines or is experiencing any side effects. Most of the medicines that are available for use in children come in preparations that are relatively easy to take, that is in liquid form. Not all medicines taste nice. The Rainbow Team will advise you on how to give the medications to your child and tips on the best foods to give them with.

GIVING MEDICINES TO CHILDREN

Before giving any medicine to your child it is essential that you know what the medicine is and what the correct dose should be. It is also a good idea to write down the medicines that your child takes and when they are taken, just in case someone else has to look after your child when you cannot be there.

There will be times when giving medicine to your child will be an extremely difficult task, regardless of his/her age. Generally speaking, after a few weeks of taking medicines most children become very good at it. It is worth having a bit of patience initially, as it pays off in the long run. Children respond better when they have some control of the situation. Maybe you can involve your child in taking the medicines from the beginning.

If your child decides to have a screaming attack and throws a tantrum let him/her continue with it. Do not attempt to give the medicine while your child is in that state as it will probably

be spat back at you. Wait until your child has calmed down, give a cuddle and then try giving the medicines again. Do not hold the child down and force the medicine in their mouth. If you do this, your child may well refuse to take any further medicine for days. Of course how you deal with your child very much depends on his/her age. With babies and toddlers you really do have to sit down and put the medicine in their mouth. After all, you cannot reason with this age group. It is the older children who often need encouragement. If none of this helps, talk to your nurse about it she may be able to come up with some more strategies to help you help your child. Sometimes children can be referred to the clinical psychologist at the hospital who can help your child to take the medicines. Whatever you do, be consistent in your approach, and try and make medicine taking part of your child's everyday routine.

"the frustrations of foul tasting medicines and the anxiety of persuading a young child to take them when he doesn't understand how important it is, is difficult. But my son learned very early on to swallow capsules and the problems have now passed"

Emer (parent of a 7 year old HIV positive boy).

FEAR OF INFECTING OTHERS

There is no evidence to suggest that your child can infect other children or adults from everyday activities. People cannot catch HIV by attending the same school or childcare centre, or by living in the same house as a child or adult with HIV.

The important issue is what to do if your child has an injury which results in a bleeding wound or a nose bleed. Extra care is required in these situations. Whenever possible wear gloves when dealing with blood or body fluids. If these are not available use a tissue or cloth to prevent blood coming into direct contact with your skin. Cover the sore, cut or graze with a Band-Aid or other form of waterproof dressing. The dressing should stay in place until a scab has formed. A dressing will also protect your child from any infections entering the wound. Hand washing is very important after contact with blood or body fluids and we recommend the use of liquid soap and hot water.

If you or anyone else gets blood splashed into the mouth or eyes, rinse well with lots of water. If blood splashes onto the skin, wash off immediately with soap and water.

Members of the family should exercise particular care when handling blood or body fluids if they have eczema, psoriasis or severe contact dermatitis as their normal defence against infection is impaired (that is, the skin). Gloves should be kept readily available.



Any spills of blood or other body fluids should be mopped up using disposable paper towels or tissues and bleach (e.g., Domestos). Cover the spillage with paper towels and pour diluted bleach (roughly 1 part bleach to 9 parts water) over the towels and leave for 2 minutes. If no bleach is available, use very hot, soapy water. Wipe up the spillage and discard the paper towels. These can then be disposed of by placing them in a plastic bag before throwing in the rubbish bin. Clothes stained with blood or other body fluids should be first washed in a cold wash with 'napisan' and then washed in a hot wash in the usual way. Household gloves should be worn when handling such items.

These precautions are called standard precautions and mean that everybody is treated as though they are potentially infectious. Standard precautions should be practised by everybody - including child care workers, health professionals, teachers, volunteers and the general community. Some people forget that HIV is not the only blood borne infection; in fact both hepatitis B and C are much more easily transmitted than HIV.

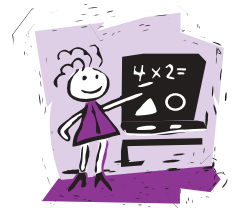
NAPPIES can be disposed of in the usual manner, by placing in a plastic bag, securing and disposing in a rubbish bin.

WORRIED ABOUT BITING?

People often express concern with regard to biting as a possible source of infection. For HIV to be transmitted in this way, the biter would have to be HIV positive, be bleeding from the mouth and bite the other child sufficiently deeply for blood to flow. Blood from the HIV positive child would then have to enter the bloodstream of the other person in order to pass on the virus, i.e. both would have to be bleeding when the bite occurred. This is a very unlikely scenario.

CHILDCARE AND SCHOOL CARE ISSUES

It is not a legal obligation in Ireland for you to disclose your child's HIV status to the school or childcare centre. This is in place to protect your child and family's right to privacy and confidentiality.



It is often recommended that a partial disclosure takes place. This is so that the child's best interests are protected. In this situation the school principal or director of the childcare centre are informed of the situation along with selected members of staff. By doing this, periods of absence from school due to hospital appointments or illness are accepted as normal for your child. It also means that the school or childcare centre will inform you of

a chickenpox or measles outbreak. It is essential that you are aware if your child comes into contact with these usual "childhood illnesses" so that you can inform your child's nurse or doctor immediately.

In any case a disclosure will depend upon the readiness of everyone involved. It should be a controlled process and the Rainbow Team can help you with this. This programme is very successful and has been running for many years now.

TELLING YOUR CHILD ABOUT HIV

Talking to your child about HIV very much depends upon their age and how much you think he/she understands and of course your readiness to do it. You need to decide when to do it, how to say it, and how much to tell them. It will not be easy; in fact it is possibly one of the hardest tasks that a parent/guardian has to face.

It is a process that takes a lot of time and thought and it is often a gradual one. You may require help from a social worker or nurse. Whatever you tell your child, it is important that you are honest and use language that they will understand. Try to give simple answers to all their questions. Be consistent with the information and answers that you give them. As children get older they start asking more questions. Hiding the truth from them at this stage starts to become more difficult.



When a child does ask questions, try to listen carefully, take seriously what they say, answer at their level and be as honest as possible.

BROTHERS AND SISTERS

Do not forget to include the other children in your family. They may well have many questions and concerns regarding the health of their sibling, even if they are not infected with HIV themselves. They still have to cope with disclosure issues and the fact that their sibling and/or parent may be unwell. They may also have feelings of jealousy - jealous that their sibling appears to get all of the attention.

Children are perceptive and will often have an idea that "something is happening" either to themselves or to someone else in the family. They will sometimes make up their own explanations about what is happening, without telling you. They may believe that it is their fault that they or another member of the family is sick. You may notice a change in their behaviour. This is common when children are not given the opportunity to talk about their anxieties. It is important that children feel secure and safe in their home environment so that they can confide in you.

Please let us know if you are planning to disclose your child's HIV status to a school or your child so that we can support you through this.

COPING WITH A HIV DIAGNOSIS

People do not grieve only when someone dies. Grieving is a process that occurs in many other life situations that are often harder to deal with than an actual death. Being told that you and/or your child are HIV positive is an example of this. Emotions associated with grief can make you feel totally overwhelmed in such a way that you may be left feeling that you simply cannot cope.

It is important that you recognise these feelings and get support if you feel you need it at this time. The situation is often more complicated in the case of HIV because you may want to keep it a secret from other family members and friends. This can make it more difficult to cope with, as you cannot share the burden.

Many people get support from HIV/AIDS organisations, clinics and hospitals. Some people like to talk to other families affected by HIV. Some people find it difficult to talk to anybody. Take time deciding who you want to tell.

Remember, everyone develops their own coping strategies. What works for one family does not necessarily work for another. Learning to live one day at a time is an important and helpful strategy to implement in the early days, after diagnosis. Never be afraid to ask for

help or support from your child's health care team. Social workers, nurses and doctors can sometimes help you through the most difficult of situations.

Guilt, blame and powerlessness are very strong emotions that you may be feeling at this time, particularly if you are infected with HIV. What is important is that you continue to show your love for your child and care for him/her as you always have done.

'When I look back over the last few years I don't know how I coped with the pressure, the not knowing and the loneliness. I feel I have become stronger in myself now and I know a lot more about the virus through attending support groups. I guess what I'm trying to say is that if you can find one person to talk to, or to call, who can understand what you are feeling...I promise you, you will not feel as alone anymore'

Margaret (mother of a 10 year old HIV positive girl)

CARING FOR YOUR CHILD

Caring for a child can be a tiring, demanding and draining job. You may find that at times you will need a short break from the stress of parenting, especially if you, your partner, or child, becomes sick. Childcare, before and after school care, clubs and camps are a great idea for giving you a break whilst allowing your child to participate in child designed and focused activities. Please ask your nurse for details of services that are available.

One of the biggest concerns for parents who are HIV positive is "who will care for my children should I become sick or die". Care plans that are made when you are well will ensure that your wishes and desires for your child are known and respected and you are not forced to make important decisions at a time of crisis. Keeping children with their natural family is the preferred option. This is something you can discuss with a member of the Rainbow Team.

FINANCIAL MATTERS AND ENTITLEMENTS

Medical Card

All children with HIV are entitled to receive a medical card regardless of your income. Speak to your social worker about getting one for your child.

Domiciliary care allowance (DCA)

Domiciliary care allowance is a monthly allowance administered by Health Boards. It is payable to the parent of a sick child who requires extra care. Application for this allowance will be supported by The Rainbow Team and each case is assessed individually by the Area Medical Officer in your relevant health board.

Travel expenses

Travel to and from the hospital can be expensive. In some situations you can apply for support from your local Community Welfare Officer.



SUPPORT AGENCIES

There are support services which are run throughout the year for families in Ireland living with HIV. The Rainbow Team will inform you of where they are. A list of contact numbers may also be found at the back of this booklet.

OTHER SERVICES

You may need the help of additional services that are not listed here. Sometimes there seems to be so many services involved that it's hard to keep a track of them all. Each family will be allocated a clinical nurse specialist who will be responsible for co-ordinating the services provided to you. All of the services meet up regularly to assess your child's needs and any changes will be discussed with you.

FURTHER READING

Ciaras Story, published by the Irish Health Promotion Unit and explains how HIV affects a child. ISBN 0-86387-032-5.

Jimmy and the EGGS Virus, by Mary Tasker 1994.

This is a book for children and explains how HIV/AIDS affects them.

Come sit by me, by Margaret Merryfield, published in 1990 by Women's Press, Toronto, Ontario, Canada. An educational storybook about HIV and AIDS for small children ages 4 to 8.

You and HIV, A day at a time, by Lynn Baker, MD, published by W.B. Saunders Co. This is a book for children and explains how HIV/AIDS affects them.

How can I tell you? Secrecy and Disclosure with Children When a Family Member has AIDS, by Mary Tasker, published in 1995 by the Association for the Care of Children's Health, Bethesda, Maryland, USA.

When I go to Hospital, by Michael Dugan. Published in 1994 by CIS Publishers, Carlton, Victoria, Australia. A book for children which helps to ease the fear associated with a hospital admission.

WEB SITES

www.pedhivaid.org/news

www.kidsconnect.org

HOSPITAL ADDRESS

The Rainbow Clinic

Our Lady's Hospital for Sick Children
Crumlin
Dublin 12
Ireland
01 4096100

The Rainbow Clinic

The Children's University Hospital
Temple St
Dublin 1
Ireland
01 8748763

SUPPORT ORGANISATIONS

ACET(AIDS Care Education and Training) CAIRDE

PO Box 3400
Dublin 14
01 8787700
ACET@indigo.ie
www.acet.ie

19 Belvedere Place
Dublin 1
info@cairde.ie
www.cairde.org
01 8552111

Grandmas Ireland

PO Box 7276
Dublin 5
086 8041858

Dublin AIDS Alliance

53 Parnell Sq
Dublin 1
01 8733799

Open Heart House,

2 St. Mary's Place
Dublin 7
01 8305000

Friend for Friends

9 Guilford Rd
Dublin 4
01 2604050

NATIONAL HIV HELP LINE

1800 459 459

REGIONAL SUPPORT ORGANISATIONS

AIDS Help West,

Ozanam House
St. Augustine St
Galway
091 566266

The Red Ribbon Project

94 Henry St
Limerick
061 314354
rrp@indigo.ie

AIDS Help North West,

Mount Southwell
Letterkenny
Co Donegal
074 255500

My Rainbow Team

	Name	Phone No.
My Doctor		
My Nurse Specialist		
My Pharmacist		
My Social Worker		
My Psychologist		
My Dietician		
My Clinic		