

## Patient Advice and Liaison Service (PALS)

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## Patient information

# Testing your child for HIV

## Why should I test my child for HIV?

We now have very effective treatment – anti- retroviral therapy (ART) – which means that if a person knows they have HIV, their health can be monitored and this medication can keep them well.

The most dangerous thing for an HIV-positive child or adult in the UK is not knowing they have HIV. If you don't know your child's diagnosis and they do have HIV, they could become very ill. If you, and we, know their diagnosis, we can start their treatment and keep them well.



## **How do children get HIV?**

The main way children become infected with HIV is through mother-to-baby transmission during pregnancy, delivery or breastfeeding, if the woman is HIV positive at that time.

Other than that, HIV can be transmitted through sexual contact, sharing of needles or contact with infected blood. It does not get passed on through ordinary household contact.

## **My child is healthy – why should I worry – surely it would have shown up by now if they are infected?**

Both adults and children with HIV can remain well with no outward signs for years, until the HIV weakens their immune system. (The immune system is the body's defence against illness and infections.) When the immune system becomes weak, the person becomes very vulnerable to HIV related disease, so they can suddenly have dangerous, or potentially fatal illnesses.

Although most children born with HIV will start to show signs of illness before the age of 5, there are a number of children who remain perfectly healthy up to the age of 10, 15 or even occasionally 20 years. Therefore the only way to be sure that a child born to parents with HIV is not infected, is to have a test.

## **I don't know when I became HIV infected**

If a child's mother has tested HIV negative in a later pregnancy (subsequent to this child) then she was not HIV positive during pregnancy or breastfeeding of this child. However, unless that fact is clearly established, then this child and any siblings need to be tested by the paediatric team.

## **I don't want my child to know about my HIV infection. How can they be tested without finding out?**

This is a concern for many parents. If the child is young, then those doing the test simply need your permission. Talk to the paediatrician about the test and you may want to talk to a health advisor or your doctor about what a positive test result will mean to you. If the child is older and can give their own permission for blood tests, you will need to work out with the paediatrician a way in which the test can be undertaken, where you feel comfortable about what your child is told, but at the same time your child knows what they are being tested for.

This is a difficult time, but the people supporting you have done this many times before and can help you through it. Talk to a health advisor or your doctor about what can be said, and also what you will say to your child if their test is positive.

## **Why is this really important? Can't we wait until they show signs of infection before testing them?**

This is important, and we shouldn't wait. There have been a number of cases where children have become very ill, or have actually died, because they were not diagnosed with HIV in time. HIV testing of all children born to HIV-positive parents, and in particular mothers with HIV, can be a lifesaving action and should be done in every case.

Therefore these children, even if they look healthy and feel healthy and however old they are, should have a test to make absolutely sure that they are HIV negative.

Most children tested in this way will be HIV negative. Those who are HIV positive need to be diagnosed as soon as possible. The medication really works, but if we don't know, we can't use it to keep them well.