



Children in Need and Blood-borne Viruses: HIV and Hepatitis

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Summary

This document replaces guidance on prevention and testing in *Children and HIV – Guidance for Local Authorities* (1992) and includes advice about hepatitis B and C.

In summary, the document covers:

- the legislative framework;
- transmission of HIV, hepatitis B and hepatitis C;
- preventing blood-borne virus transmission;
- testing for blood-borne viruses and the provision of information, advice and support to children with blood-borne virus infections and their families;
- useful sources of information and advice.

It is intended to assist local authority social services departments, NHS and Primary Care Trusts and other local service providers in promoting and safeguarding the welfare of children in need in relation to blood-borne viruses. The information may also be of interest to local education authorities. The guidance is for NHS Foundation Trusts' information only.

The emphasis within this guidance is on ensuring that the particular circumstances of children and their families at risk of, or affected by, blood-borne viruses are addressed sensitively and positively. The aim is to encourage professionals involved with children and their families to work in partnership with them.

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1. Introduction

Purpose and scope of guidance

- 1.1 This guidance document is intended to build on existing relationships and assist local authority social services departments, NHS and Primary Care Trusts and other local service providers in promoting and safeguarding the welfare of children in need in relation to blood-borne viruses. It will also be of use to local education authorities and proprietors providing services in schools and in early years and child care settings. It provides advice about preventing the transmission of blood-borne viruses and the circumstances in which testing children in need for blood-borne viruses might be considered. The guidance has been developed following consultation with local authorities and their representative organisations, health service interests, voluntary organisations and the Department of Health's Expert Advisory Group on AIDS and Advisory Group on Hepatitis.
- 1.2 The document replaces the guidance on testing in *Children and HIV: Guidance for Local Authorities* (1992), and includes advice about hepatitis B and C. The treatment and care of children infected or affected by HIV is a very specialised field. A Children's HIV National Network Review (CHINN) has been established, as part of the *National Strategy for Sexual Health and HIV*, to review current provision of services for children with HIV in England. CHINN will report its findings to the Department of Health and National Specialised Commissioning Group in 2004 with recommendations for the future structure of paediatric HIV specialist care, based on the model of managed service networks.
- 1.3 The emphasis within this guidance is on ensuring that the particular circumstances of children and their families at risk of, or affected by, blood-borne viruses are addressed sensitively and positively. The aim should be for all professionals involved with children and families to work respectfully and in partnership, sharing information with them and explaining the implications of any decisions they need to make. In most circumstances, parents and carers want what is best for their children and are best placed to decide this. Working in partnership is therefore key to achieving optimum outcomes for most children. The *National Service Framework for Children, Young People and Maternity Services* sets

standards for the NHS and social services for children to help ensure better access and smoother progression in services for children.

- 1.4 In accordance with the spirit of the Children Act 1989, the interests and welfare of the child must always remain the paramount consideration for all those working with children and their families in whatever capacity. Children who are infected with blood-borne viruses will be affected in varying degrees. Some will be considerably incapacitated by their condition and may need continuing care and support to manage it and to enable them to live as normal a life as possible. Others will be much less affected. It is important that children with blood-borne virus infections and their families are given appropriate information, advice and support.
- 1.5 When parents or carers are infected with these viruses, this can have a considerable impact on their children. When parents or carers are significantly affected by their illness, this may limit their capacity to care for their child or they may increasingly depend on the child for help and support.
- 1.6 When support is necessary, the needs of children affected by blood-borne viruses should be assessed by local authorities in accordance with the *Framework for the Assessment of Children in Need and their Families* (2000) and arrangements made to address these needs. It is important that adult and children's services work closely together to ensure that they are meeting the needs of children and parents/carers.
- 1.7 The cultural, racial and linguistic backgrounds of children and families should be positively and specifically addressed when services are provided. For example, many of the families and children affected by HIV are from African communities, and it is particularly important that cultural considerations and views are fully appreciated and taken into account.
- 1.8 The main role for local authorities in relation to children affected by blood-borne viruses will be to support families in caring for children. This may include respite care and family placements for children. Support should also be given to children/adolescents acting as young carers and to those children/adolescents orphaned by the death of a parent(s). However, in certain circumstances, the local authority's role may shift to protecting children because there will be a small number of families who, unrelated to their medical condition, will neglect or abuse their children.

Blood-borne viruses

1.9 Blood-borne viruses are infectious agents that some people carry persistently in their blood. They can cause severe disease in some cases, and few or no symptoms in others. The virus can be spread to another person and this may occur whether the carrier of the virus is ill or not.

1.10 The main blood-borne viruses of concern are:

- human immunodeficiency virus (HIV) which causes acquired immune deficiency syndrome (AIDS), affecting the immune system of the body;
- hepatitis B virus (HBV) and hepatitis C virus (HCV), which cause hepatitis, a disease of the liver, which in a proportion of cases can lead to cirrhosis and liver cancer.

1.11 Blood-borne viruses are spread by direct contact with the blood of an infected person. Certain other body fluids may also be infectious e.g. semen, vaginal secretions and breast milk. The risk of blood-borne virus infection from body fluids or materials most likely to be encountered in the home, child care, early years or school environment (e.g. urine, faeces, saliva, sputum, sweat, tears and vomit) is minimal unless they are contaminated with blood. However, the presence of blood is not always obvious in these fluids.

1.12 It should be noted that blood-borne viruses are not spread by normal social contact and daily activities e.g. coughing, sneezing, kissing, hugging, holding hands, or sharing bathrooms, swimming pools, toilets, food, cups, cutlery and crockery.

Related Department of Health guidance

1.13 Related Department of Health guidance is cross-referenced in the text, and a list of useful publications and sources of advice is contained in Annex 1.

Local advice on blood-borne viruses

- 1.14 Local advice on blood-borne viruses may be sought from the Consultant in Communicable Disease Control who can be contacted via the local Primary Care Trust or the Health Protection Agency. In addition, where appropriate, advice may be sought from a microbiologist, virologist or a genito-urinary medicine (GUM) or infectious diseases physician.

2. Legislative framework: duties of local authorities under the Children Act 1989, the Health and Safety at Work etc. Act 1974 and other legislation

The Children Act 1989

- 2.1 The Children Act 1989 provides the statutory context for supporting and protecting vulnerable children and their families within local authority areas.
- 2.2 The general duty (section 17, Children Act 1989) is to safeguard and promote the welfare of children in need and, so far as is consistent with their welfare, to promote the upbringing of these children by their families, by providing an appropriate range and level of services. The definition of a child in need is set out in section 17(10) of the Act. If a young asylum seeker falls within that definition, social services departments have the same responsibilities to provide services to them as to other children.
- 2.3 Some children are in need because they are suffering or likely to suffer significant harm. Local authorities are required to make enquiries and to consider whether action should be taken to protect such children where they have reasonable cause to suspect they are at risk (section 47, Children Act 1989 and *Working Together to Safeguard Children* (1999)).
- 2.4 The *Framework for the Assessment of Children in Need and their Families* (2000) provides a systematic methodology for the analysis and evaluation of the circumstances of children in need and their families.

- 2.5 Local authorities are required to consider how best to promote the health and development of children in their care or for whom they provide accommodation, particularly those for whom permanent placement, including adoption, is part of their care plan. The Department of Health's guidance, *Promoting the Health of Looked After Children* (2002), is relevant here. Where children may have been in contact with blood-borne viruses or are themselves infected, there will be a particular need to refer to the guidance in this document.
- 2.6 Local authorities and local child health services will need to work closely together to ensure that the needs of any child in their area who is affected or infected by blood-borne viruses are appropriately assessed and support provided. The *Government's Objectives for Children's Social Services* (1999) sets out clearly the requirements for social services and what they are expected to achieve together with other agencies in the community for disadvantaged families and vulnerable children. Within the *Government's Objectives*, emphasis is placed on ensuring that the needs of ethnic minority children and their families are sensitively and appropriately considered and met, and this is a key principle of current policy.

The Health and Safety at Work etc. Act 1974

- 2.7 Under the Health and Safety at Work etc. Act 1974 and the Management of Health and Safety at Work Regulations 1999, local authorities have a legal duty to ensure, so far as is reasonably practicable, the health of their employees at work, and a duty not to expose to health risks any non-employees who may be affected by their work. Local authorities should have a health and safety policy and ensure that employees are familiar with it.
- 2.8 Specific legislation on controlling biological hazards, such as blood-borne viruses, in the workplace is covered by the Control of Substances Hazardous to Health (COSHH) Regulations 2002. Under COSHH, local authorities have a legal duty to assess the risk of infection for employees and others affected by their work. When a risk is identified, local authorities should take suitable precautions to protect the health of their employees and others affected by their work. Employees should also be given adequate information, instruction and training on any risks to their health that they may face in the course of their work.

The Public Health (Control of Disease Act) 1984

2.9. The Public Health (Control of Disease) Act 1984 gives local authorities certain powers and duties in relation to the control and prevention of infectious disease, and requires members of the public and others not to expose others to the risk of infection of some infectious diseases in the circumstances specified. Regulations made under the Act (the Public Health (Infectious Diseases) Regulations 1988) apply some of the provisions of the Act to viral hepatitis and a smaller number, with some modification, to AIDS. In particular, there is a requirement for registered medical practitioners to notify the local authority proper officer (e.g. the Consultant in Communicable Disease Control) of new cases of viral hepatitis.

The Carers and Disabled Children Act 2000

2.10 The Carers and Disabled Children Act 2000 which came into force in relation to England on 1 April 2001, gives local authorities the power to supply certain services direct to carers following assessment.

The Disability Discrimination Act 1995

2.11 Currently, a person with a progressive condition is regarded as a disabled person for the purposes of the Disability Discrimination Act 1995 if they have a physical or mental impairment that has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities. The Act modifies this general definition for people with a progressive condition such as HIV. They do not have to show that the effects of the impairment are substantial. They will be treated as disabled if the impairment produces any effect on their ability to carry out normal day-to-day activities, provided that the condition will result in impairment having a substantial affect in the future.

2.12 The Government has announced that, subject to the approval of Parliament, the definition of disability in the Disability Discrimination Act 1995 will be extended to include people with asymptomatic HIV infection. The necessary legislation to do this was published in draft form as the Draft Disability Discrimination Bill in December 2003.

The Race Relations (Amendment) Act 2000

- 2.13 The Race Relations (Amendment) Act, which has its origins in the Stephen Lawrence Inquiry, became law on 1 December 2000 and outlaws race discrimination in all public functions. The Act amends the Race Relations Act 1976 to place a general duty on public authorities, including local authority social services departments, to have due regard to the need to eliminate unlawful racial discrimination and to promote race equality and good race relations between people of different racial groups.
- 2.14 Although local authorities have been under a legal obligation since the 1976 Race Relations Act not to discriminate on grounds of race, the new Act extends this requirement to all the functions of the authority, including those carried out by independent sector organisations contracted to the authority. All local authorities have a duty to publish a Race Equality Scheme and this should include details of how the social services department is taking active steps to promote race equality.

The Human Rights Act 1998

- 2.15 The Human Rights Act 1998 came into force on 2 October 2000. It gives effect in the United Kingdom to most of the rights under the European Convention on Human Rights. It means that public bodies must have human rights principles in mind when they make decisions affecting people's rights. Article 8 (right to respect for private and family life) will have a particular bearing on this guidance.

3. Transmission of HIV, hepatitis B and hepatitis C

HIV

- 3.1 HIV (human immunodeficiency virus) is a virus that attacks the body's immune system making it vulnerable, over time, to infections that a healthy immune system would fight off. However, people with HIV do not necessarily have symptoms or feel unwell. Adults may experience a short illness soon after they become infected (termed seroconversion illness) with symptoms ranging from mild and 'flu-like to more severe symptoms such as prolonged fever, aching limbs, skin rash, sore throat, diarrhoea, severe headaches and aversion to light. These symptoms are not specific to HIV infection and could have other less serious causes.
- 3.2 When a person with HIV infection develops certain tumours or contracts a so-called 'opportunistic infection' (i.e. an infection caused by bacteria, viruses or fungi that takes the opportunity to infect a person with a damaged immune system), they may be diagnosed as having AIDS (acquired immune deficiency syndrome). There is as yet no cure for AIDS or a vaccine that can protect against HIV infection. There are, however, anti-retroviral drugs that can improve the quality of life and extend the lifespan of people with HIV. However, such treatments may have debilitating side effects. In addition, people with HIV infection may take prophylactic drugs (e.g. certain antibiotics) to prevent them from acquiring opportunistic infections and to keep them in good health.

HIV in children

- 3.3 The vast majority of HIV-infected children in this country have acquired HIV infection through mother to child transmission. Infection may pass from the mother to the unborn child in the womb during pregnancy, during delivery of the baby or after birth through breastfeeding. Around 1 in 4 infants exposed to HIV infection in this way will become infected in the absence of measures to reduce transmission (see Chapter 4). Infants infected through mother to child transmission show few symptoms of acute HIV infection in the first weeks of life, but progression to serious

disease or death is rapid, and up to 25% of these infants will progress to serious disease or death by their first birthday. Children with HIV should be referred to a specialist HIV paediatrician for assessment.

How is HIV spread?

3.4 HIV infection is spread by blood-to-blood contact with an infected person's blood. Certain other body fluids may also be infectious e.g. semen, vaginal secretions and breast milk.

3.5 The main routes of infection are:

- by sexual intercourse with an infected person without a condom (i.e. unprotected sex);
- by sharing blood-contaminated needles or other equipment for injecting drug use;
- from an infected mother to her baby during pregnancy, while giving birth or through breastfeeding.

Other less common routes by which the infection may be spread are:

- by unprotected oral sex with an infected person;
- through a blood transfusion in a country where blood donations are not screened for HIV (all blood donations in the UK are screened for HIV);
- by invasive medical/dental treatment abroad using non-sterile instruments/needles;
- by tattooing, cosmetic piercing (e.g. ear and body piercing) or acupuncture with unsterilised needles or equipment;
- by sharing razors and toothbrushes (which may be contaminated with blood) with an infected person.

3.6 HIV infection is not spread by social contact and daily activities e.g. coughing, sneezing, kissing, hugging, holding hands, or sharing bathrooms, swimming pools, toilets, food, cups, cutlery and crockery.

Distribution of HIV

3.7 HIV is endemic world-wide. The number of people living with HIV infection (the prevalence) in the UK is relatively low (about 0.17% of the adult population) compared with some of our European neighbours. This is attributed to the early introduction in the mid-1980s of wide-ranging health promotion campaigns and needle-exchange schemes for injecting drug users. However, there is wide geographical variation in levels of HIV infection (prevalence) in the UK, with the focus of the epidemic being in London and other large cities. Among pregnant women giving birth in 2002, the prevalence of HIV infection was 0.38% in London compared with 0.06% in the rest of England. Prevalence is much higher in some other parts of the world, particularly sub-Saharan Africa. This is reflected in the 80-fold higher prevalence of HIV infection in women born in sub-Saharan Africa (2.47%) who gave birth in the UK in 2002 relative to women born in the UK (HIV prevalence of 0.03%).

Hepatitis B

3.8 Hepatitis B is a viral infection that may damage the liver and cause serious long-term consequences. People with acute hepatitis B infection do not necessarily have symptoms or feel unwell, but some do get a short 'flu-like illness, often with jaundice (yellowing of the skin and eyes and dark urine), nausea, vomiting and loss of appetite. Infection without symptoms, and illness without jaundice, occurs particularly in children. Very rarely, hepatitis B infection may cause acute liver failure. Hepatitis B infection is preventable by immunisation (see paragraphs 4.14–4.16, 4.42–4.48 and 4.53).

3.9 Most adults infected with the virus recover fully and develop lifelong immunity. However, a small proportion – about 1 in 20 – may remain persistently infected. This is sometimes referred to as chronic infection or carriage. Babies infected at birth from their mothers have up to about a 90% chance of becoming persistently infected and children infected aged 1-10 years have about a 25% chance of becoming persistently infected. About 1 in 5 of those infected with hepatitis B in infancy or childhood may develop serious liver damage later in life such as cirrhosis (scarring of the liver) and primary liver cancer. Children with persistent hepatitis B infection should be referred for assessment by a specialist clinician. Drug treatments may be available.

3.10 The UK has a relatively low prevalence of hepatitis B; it is estimated that about 0.2-0.3% of the general population are persistently infected with hepatitis B. Hepatitis B is more common in other parts of the world such as South-East Asia, the Indian sub-continent, the Middle and Far East, Africa, South America, parts of Eastern Europe and Southern Europe.

How is hepatitis B spread?

3.11 Hepatitis B infection is spread by blood-to-blood contact with an infected person's blood or certain body fluids e.g. semen, vaginal secretions. The hepatitis B virus is highly infectious and more easily transmitted than HIV by blood-borne routes. The main routes by which infection is spread are:

- from an infected mother to her baby usually at birth (many people with hepatitis B from countries in which hepatitis B infection is highly endemic will have been infected by this route themselves);
- by sexual intercourse with an infected person without a condom;
- by sharing contaminated needles or other equipment for injecting drug use;
- through a blood transfusion in a country where blood donations are not screened for hepatitis B (all blood donations in the UK are screened for hepatitis B);
- by invasive medical/dental treatment abroad using non-sterile instruments/needles.

Other less common routes by which the infection may be spread are:

- by tattooing, cosmetic piercing (e.g. ear piercing or body piercing) or acupuncture with unsterilised needles or equipment;
- by sharing razors and toothbrushes (which may be contaminated with blood) with an infected person.

3.12 Like HIV, hepatitis B infection is not spread by normal social contact and daily activities e.g. coughing, sneezing, kissing, hugging, holding hands, or sharing bathrooms, swimming pools, toilets, food, cups, cutlery and crockery.

Hepatitis C

- 3.13 Like hepatitis B, hepatitis C is a viral infection that may damage the liver. Many people with hepatitis C infection have no symptoms and are often unaware that they have been infected. Some people will experience tiredness, nausea, loss of appetite, abdominal pain and 'flu-like symptoms. They may also develop jaundice (yellowing of the skin and eyes and dark urine), but this is unusual.
- 3.14 About 20-40% of people with hepatitis C infection will clear the virus and recover completely. The majority of people who get hepatitis C infection may remain persistently infected (this is sometimes referred to as chronic infection or carriage), many of whom will have only mild liver damage. About 5-20% of people with persistent infection develop severe scarring of the liver (cirrhosis) after 20-30 years. A small number of those patients who develop cirrhosis may go on to develop liver cancer. The majority of patients who get hepatitis C infection are likely to live out their normal lifespan. Children with persistent hepatitis C infection should be referred for assessment by a specialist clinician. Drug treatments may be available.
- 3.15 The UK has a relatively low prevalence of hepatitis C. It is estimated that about 0.4% of the general population are persistently infected with hepatitis C. Hepatitis C is more common in other parts of the world e.g. Egypt, some other parts of Africa, South-East Asia and Southern Europe.

How is hepatitis C spread?

- 3.16. Hepatitis C infection is spread by blood-to-blood contact with an infected person's blood or other body fluids if they are contaminated with blood. Before the introduction of measures such as the heat treatment of blood products (1985) and screening of blood donations (1991), hepatitis C infection was occasionally transmitted by blood and blood products. As a result of the comprehensive measures now in place, the chance of being infected with hepatitis C through blood transfusion and blood product use is now very low. However, there may be a risk of hepatitis C transmission in countries where safety measures for blood and blood products are not in place. Currently, the main way in which hepatitis C infection is passed on in the UK is through the sharing of contaminated equipment by injecting drug users.

3.17 Other less common ways in which the infection may be passed on are:

- from an infected mother to her baby at birth (This risk is increased if a mother is also infected with HIV. Currently there is no proven association between breastfeeding and hepatitis C transmission, and hepatitis C positive mothers should not be advised against breastfeeding.);
- by sexual intercourse with an infected person without a condom;
- from unsterile equipment used for tattooing, cosmetic piercing (e.g. ear and body piercing) or acupuncture;
- by invasive medical/dental treatment abroad using non-sterile instruments/needles;
- by sharing razors and toothbrushes (which may be contaminated with blood) with an infected person.

3.18 Hepatitis C infection is not spread by normal daily contact and activities e.g. coughing, sneezing, kissing, hugging, holding hands, or sharing bathrooms, swimming pools, toilets, food, cups, cutlery and crockery.

Are other body fluids infectious?

3.19 Urine, faeces, saliva, sputum, tears, sweat and vomit are not considered to pose a risk of HIV, hepatitis B or hepatitis C infection, unless they are contaminated with blood. However, some of these may be risky for other reasons (e.g. faeces may contain bacteria that cause gastro-intestinal infections).

4. Preventing blood-borne virus transmission

- 4.1 The major routes of transmission of blood-borne viruses have been well characterised and are described in detail in Chapter 3. Preventing transmission means avoiding exposure to the viruses (e.g. through unprotected sexual intercourse or sharing of injecting drug equipment). Children and young people looked after by local authorities need age-appropriate information and advice on preventing blood-borne virus transmission, particularly as some older children and young people may be at particular risk of HIV, hepatitis B or hepatitis C (e.g. because of injecting drug use, involvement in prostitution or unprotected sexual intercourse with frequent partner change). It is also important that local authority staff and carers are given appropriate information, advice and training. Local advice on blood-borne viruses may be sought from the Consultant in Communicable Disease Control who can be contacted via the local Primary Care Trust or Health Protection Agency. In addition, where appropriate, advice can be sought from a microbiologist, virologist or a genito-urinary medicine (GUM) or infectious diseases physician.
- 4.2 For some children, such as those who are looked after by local authorities, there are particular issues to consider. The Department of Health's guidance, *Promoting Health for Looked After Children*, provides information about how best to ensure these children receive appropriate access to health care and advice about health promotion. Local authorities should ensure that all those working with and caring for children, including foster carers, are provided with information and training about child health issues, including blood-borne viruses.
- 4.3 *The Teenage Pregnancy Strategy* and *The National Strategy for Sexual Health and HIV* are initiatives that are geared to ensuring that prevention of infection is actively promoted by all those who work with children and young people. There is an emphasis on identifying the most vulnerable children, including those who are looked after, those who are offending and those who are involved in substance abuse.

- 4.4 As part of *The Teenage Pregnancy Strategy*, best practice guidance designed to improve access to advice and contraception for all young people has been issued to local teenage pregnancy co-ordinators. Guidance has also been issued on developing contraception and advice services for boys and young men, and for people from black and minority ethnic communities.
- 4.5 Research has shown that looked after young people and care leavers are at particular risk of teenage pregnancy, and guidance for social workers and youth workers has also been issued which makes clear that they can, and should, direct young people to seek advice and contraception if it appears that they are, or are planning to become, sexually active.
- 4.6 Every local authority area (social services boundaries) has produced a ten-year local teenage pregnancy strategy, beginning in 2001. The strategies outline how health and local authorities will work with other local agencies to take forward the aims of the national *Teenage Pregnancy Strategy*. Details of local strategies are available from local teenage pregnancy co-ordinators.
- 4.7 Existing *Quality Protects* guidance asks local authorities to set out activity and future plans for reducing teenage pregnancy amongst looked after young people, for supporting teenage parents who are looked after and for staff training.

Preventing mother to baby transmission

- 4.8 Blood-borne viruses may be transmitted from an infected mother to her baby during pregnancy, childbirth or via breastfeeding, although the risks differ depending on the particular virus. Interventions are available that can reduce the risk of transmission of HIV and hepatitis B, but only if the pregnant woman knows that she is infected before giving birth. All pregnant women should now be offered and recommended screening for HIV and hepatitis B as part of their routine antenatal care and babies born to infected mothers should be followed up to ensure that they have not been infected.

HIV

4.9 In this country, most children with HIV are infected as a result of transmission of HIV infection from their mothers during pregnancy, childbirth or via breastfeeding. The Department of Health has asked NHS and Primary Care Trusts to ensure that all pregnant women are offered and recommended a test for HIV as an integral part of their antenatal care (Health Service Circular 1999/183 *Reducing mother to baby transmission of HIV*), together with appropriate information about the implications of the test result. Those found to be positive can then be offered advice and treatment during antenatal care. The risk of transmission of HIV from an infected mother to her baby during pregnancy, while giving birth or through breastfeeding can be reduced from about 1 in 4 to around 1 in 50 by interventions such as:

- anti-retroviral drug treatment for the mother during the late stages of pregnancy and the infant for the first weeks of life;
- careful obstetric management during pregnancy and birth such as an elective caesarean section;
- avoidance of breastfeeding.

Breastfeeding

4.10 Breastfeeding, in particular exclusive breastfeeding, is the ideal way to feed infants and should be promoted and supported. Its benefits go beyond sound nutrition in that it protects against common childhood infections. However, as it is one of the routes of mother-to-child HIV transmission, HIV-infected women in the UK are advised not to breastfeed. For the latest guidance, see *HIV and Infant Feeding: Guidance from the UK Chief Medical Officers' Expert Advisory Group on AIDS* (September 2004). In cases of financial hardship, where purchasing infant formula milk is a barrier to avoidance of breastfeeding, a range of social and health care agencies may be able to provide free or low-cost infant formula milk for infants born to HIV-infected mothers.

- 4.11 The majority of HIV-infected pregnant women take up the offer of interventions to reduce the likelihood of passing on HIV to their infants, including choosing not to breastfeed. Rarely, however, an HIV-infected mother may feel unable to avoid breastfeeding entirely. For example, women from a background where breastfeeding is the norm may fear deductive disclosure of their HIV status (if they do not breastfeed) because of the adverse social consequences that may follow disclosure such as violence, stigma, ostracism or abandonment. Women may also be under pressure to breastfeed from 'Breast is best' campaigns.
- 4.12 In cases where women feel unable to avoid breastfeeding, their fears should be recognised and extra support provided to overcome these difficulties. Input from an expert professional, usually a midwife, may be helpful to explore the reasons for and implications of choosing to breastfeed. If, after considering all the alternatives, an HIV-infected mother chooses to breastfeed, she should be provided with information about measures that may help reduce the risk of transmission of HIV to her baby. Local arrangements between health and social services can provide a positive way of resolving any practical difficulties and ensuring that all related matters are considered. Solutions should be sought, where possible, putting the best interests of the baby first.
- 4.13 There have been several high-profile child protection cases involving mothers with HIV. These have questioned whether informed choice can be sustained under circumstances where not accepting interventions (to reduce mother to child transmission of HIV e.g. avoiding breastfeeding or refusing consent for antiretroviral treatment of a newborn baby) might constitute a child protection issue. As yet, however, there has been no judgment directly on this point and clarification is only likely to come from a future court ruling. In the interim, it should be borne in mind that, under the Children Act 1989, the welfare of the child is paramount.

Hepatitis B

- 4.14 All pregnant women should be offered a test for hepatitis B as part of their antenatal care (Health Service Circular 1998/127 *Screening of Pregnant Women for Hepatitis B and Immunisation of Babies at Risk*). The risk of hepatitis B transmission from an infected mother to her baby at or around the time of birth can be minimised if the baby receives a full course of immunisation starting shortly after birth. Immunisation of babies born to infected mothers commencing at birth is 90-95% effective in

preventing persistent infection with hepatitis B. Babies acquiring infection at this time have a high risk of becoming persistently infected, and are also at increased risk of developing chronic liver disease. Some will die prematurely from cirrhosis or primary liver cancer, as well as being infectious to others.

- 4.15 Babies born to mothers infected with hepatitis B should be immunised with the accelerated immunisation schedule. This will mean an initial dose at birth, with further doses at one and two months of age and with a booster dose at twelve months. A blood test to check that the vaccine has prevented the baby becoming infected should also be carried out at this time. It is important that arrangements are in place to ensure that babies born to infected mothers receive a complete course of vaccine. For babies born to mothers who are considered to be highly infectious, an injection of antibodies against hepatitis B (hepatitis B immunoglobulin) is recommended at birth or shortly afterwards for additional protection. There is no reason why mothers with hepatitis B should not breastfeed if the baby receives a complete course of vaccine starting at birth.
- 4.16 If a pregnant woman is found to have hepatitis B infection, then arrangements should be made to offer her husband/sexual partner and any existing children a hepatitis B test. Results of these tests will indicate if further actions are needed such as immunisation of those who are non-immune and referral of the mother and any others shown to be infected.

Hepatitis C

- 4.17 The risk of transmission of hepatitis C from an infected mother to her baby is lower than for HIV or hepatitis B. However, this risk increases when the mother is also infected with HIV. Currently, there is no vaccine, drug treatment or other well-established method to prevent mother to baby transmission of hepatitis C infection. Breastfeeding is not thought to play a significant part in mother to baby transmission of hepatitis C. However, where a mother is known to have hepatitis C infection or may have been exposed to hepatitis C in the past (e.g. because of injecting drug use), it may be appropriate to consider testing the child for hepatitis C. If tests show that the child has hepatitis C infection, referral for specialist medical assessment is advised.

Preventing sexual transmission

4.18 Sexual transmission of blood-borne viruses and other sexually transmitted infections can be reduced significantly by the use of condoms. Condoms are available free from family planning clinics, Brook Centres, NHS Walk-in Centres and NHS sexual health (GUM) clinics. Condoms should carry the European CE mark. Advice on how to use a condom is available on the playing safely website (www.playingsafely.co.uk). The Department of Health's guidance *Effective Sexual Health Promotion Toolkit* includes good practice and practical guidance on sexual health promotion and HIV prevention for a number of groups, including young people, black and minority ethnic groups and men who have sex with men.

Preventing transmission associated with injecting drug use

- 4.19 Any equipment used for injecting drug use – including needles, syringes, filters, spoons, water, cups or pots – may transmit infection if shared with other people. Therefore injecting equipment should not be shared. Needles should be discarded into a sharps container (conforming to UN 3291 and BS 7320 standards) at the point of use or discovery. Containers must not be over-filled and those sited in public areas should be located in a safe position.
- 4.20 Prevention of transmission associated with injecting drug use involves a range of measures including the active promotion of information and advice about the risks of sharing injecting equipment, the provision and use of needle-exchange schemes, outreach services and the availability and access to specialist drug treatments and services.
- 4.21 Key messages about hepatitis C for those working with drug users (contained in Department of Health guidance) apply equally for other blood-borne viruses and are set out below:

Hepatitis C - guidance for those working with drug users (2001)

The key messages to drug users are:

- **Do not start injecting**
- **If currently injecting then stop**
- **If unable to stop injecting then reduce harm**
- **Use safer injecting practices (this includes paraphernalia)**
- **Avoid initiating others (or as a minimum provide them with harm reduction advice)**
- **Use needle exchange schemes**

- 4.22 People at risk of beginning to inject are usually initiated into injecting by existing injecting drug users (IDUs), so measures should be aimed at raising awareness of the risk of acquiring infection (both to new and to existing drug users).
- 4.23 IDUs should be encouraged to use sterile syringes and needles and to avoid sharing needles and syringes. In addition, those who inject drugs should be encouraged to adopt hygienic practices. This includes cleaning the injection site with alcohol, never sharing any injecting paraphernalia (such as filters, tourniquets, mixing bowls), and washing hands before and after injection.
- 4.24 Needle-exchange schemes provided through drug agencies and by pharmacies have a key role to play in reducing infections as these services are likely to be in contact with more injectors than any other. Good practice should also be followed in the safe disposal of used needles and syringes.
- 4.25 Encouraging enrolment in treatment services may be important for harm reduction. This has been shown to have an overall positive effect, reducing injecting and sharing behaviour and hence risk of infection by blood-borne viruses.

Cosmetic piercing (ear piercing and body piercing) and tattooing

- 4.26 Blood-borne viruses may be transmitted via unsterilised equipment used for cosmetic piercing or tattooing. Sterile piercing instruments and jewellery should be used on each customer. Local authority environmental health departments are a useful source of advice as they regulate such businesses under specific legislation and Health and Safety at Work legislation and work with the businesses to promote safe and hygienic practices.
- 4.27 In choosing a reputable piercer, potential customers visiting a cosmetic piercing business should check that both the premises and the operator are clean, and that sterile piercing instruments and jewellery are used on each customer. The piercer should discuss fully the type of piercing requested and possible risks, ask about any health conditions that the customer may have and, if necessary, advise them to contact their GP before proceeding. After-care advice should be provided on looking after the piercing until it heals.
- 4.28 It is an offence to tattoo a person under the age of 18 years – Tattooing of Minors Act 1969.

Hygienic procedures to reduce the risk of blood-borne virus transmission

Local authority staff and carers

- 4.29 The following hygiene precautions are recommended as safe practice for all local authority staff and for all those who care for children. These are common-sense precautions that will protect against blood-borne viruses and other infections that may be transmitted via blood and body fluids. They should be incorporated as standard practice in all settings at all times. Guidance on the management of occupational exposure to HIV, hepatitis B and hepatitis C is contained in paragraphs 4.57-4.59. Carers and staff may require training on standard infection control precautions.

Standard infection control precautions

- Always keep cuts or broken skin covered with waterproof dressings;
- Avoid direct skin contact with blood or body fluids;
- If blood is splashed onto the skin, it should be washed off immediately with soap and water. Splashes of blood into the eyes or mouth should be washed immediately with plenty of water;
- If a sharps injury is sustained or blood is splashed into the eyes or mouth, or on to non-intact skin (e.g. eczema) medical advice should be sought promptly (see paragraphs 4.57-4.59);
- Wear disposable gloves when contact with blood or body fluids is likely;
- Always wash and dry hands after removing gloves;
- Always wash and dry your hands before and after giving first aid;
- Never share toothbrushes and razors as they might be contaminated with blood;
- Teach children about avoiding contact with other people's blood as soon as they are able to understand how to protect themselves;
- Teach children to wash and dry their hands before meals and after using the toilet.

Local education authorities and proprietors providing services in schools and in early years and childcare settings

4.30 The Department for Education and Skills has provided general information for schools on the TeacherNet website at: <http://www.teachernet.gov.uk/management/atoz/index.cfm?component=topic&id=239&part=1>. The Hints and Tips section also recommends that infection control precautions are adopted as standard practice for handling accidents involving external bleeding. This follows the principles of universal infection control precautions, whereby all blood is treated as potentially infectious regardless of source, and recommends the use of disposable gloves.

4.31 Regulations under the Children Act require early years and childcare providers to meet the 14 standards as set out in the national standards

for under 8s day care childminding documentation. Standard 7 (Health) states that the registered person promotes the good health of children and takes positive steps to prevent the spread of infection; also, that staff are informed and kept up to date with hygiene precautions.

Spillages of blood or body fluids

4.32 It is recommended that spillages are dealt with in the following ways:

- Household grade gloves and a disposable plastic apron should be worn when cleaning splashes or spillages. Eye protection should be considered if there is a risk of splashing. Gloves should be washed with neutral detergent and hot water after use. Hands should always be washed and dried on removal of gloves.

Spillages of blood

- Small spills or splashes of blood on floors or other hard surfaces should be cleaned with neutral detergent and hot water.
- Large spills should be covered with sodium dichloroisocyanurate (NADCC) granules for two minutes. The spillage and granules should be removed with paper towels, which should be disposed of carefully into a waste bag. The area should be cleaned with hot water and neutral detergent.
- NADCC granules should not be used on metal, wood or fabric as they may damage these surfaces.
- Chlorine fumes will be released when NADCC granules are used, therefore it is important that the area is well ventilated. These granules should not be used on spillages of urine.

Spillages of body fluids

- Small spills or splashes on floors or other hard surfaces should be cleaned with neutral detergent and hot water.
- Large spillages should be covered with absorbent paper towels and the area then cleaned with hot water and neutral detergent. Paper towels should be disposed of carefully into a waste bag.

Carpets and upholstery

- Remove the spillage as far as possible using absorbent paper towels, then clean with a fresh solution of neutral detergent and water. Carpets and upholstery can then be cleaned using cleaner of choice. Steam cleaning may be considered.

Crockery and cutlery

4.33 Crockery and cutlery can be cleaned in the normal way either by hand washing with hot soapy water or in a dishwasher.

Linen

4.34 Linen and clothing contaminated with blood and body fluids can be washed in a domestic machine and should be washed at the highest temperature the fabric can withstand. Household gloves and cold running water should be used to remove soil prior to washing if necessary, and any solid matter (i.e. faeces and vomit) should be flushed down the toilet. Care should be taken to avoid splashing body fluids into the mouth or eyes. In residential/day care/special schools it is recommended that an industrial washing machine is used. Soiled linen/clothing does not need to be sluiced in this instance with a sluice pre-wash programme.

Disposal of waste

Child's own home, foster placements and small group homes

4.35 Paper towels, together with gloves and aprons, should be put into a plastic waste sack prior to disposal, the top tied and placed in a household waste bag for collection.

4.36 Waste such as sanitary towels, nappies, tampons and incontinence pads should be wrapped adequately in newspaper to soak up excess fluid prior to disposal in a household waste bag.

4.37 Vomit, urine and faeces should be flushed down the toilet. Potties and nappy changing mats should be washed with neutral detergent and hot water, and dried with paper towels after each use.

- 4.38 It is important that standard infection control precautions, such as hand-washing and the use of gloves, are followed when handling body fluids (see paragraph 4.29).
- 4.39 In some individual cases, a child's general practitioner may identify a specific infection risk associated with their medical condition and may make additional arrangements for disposal of waste via the local authority. This should be discussed with the general practitioner and local infection control team or paediatric community nursing service.

Residential settings, day care settings, schools, early years/nurseries and childcare settings

- 4.40 Waste contaminated with body fluids should be regarded as clinical waste and disposed of appropriately. This should be via a designated clinical waste collection service. Potties and nappy changing surfaces should be cleaned as described in paragraph 4.37.
- 4.41 Further information is set out in the Health and Safety Commission (HSC) booklet on safe disposal of clinical waste. Although primarily aimed at those who are dealing with clinical waste in the health care sector, the guidance is also intended to be helpful to others, such as people managing care homes, who are responsible on a day-to-day basis for ensuring the risks from clinical waste are minimised. If you are unsure about arrangements for disposal, contact your employer. (See Annex 1 for details of how to obtain this booklet and other relevant guidance and information on clinical waste disposal.)

Immunisation against hepatitis B

- 4.42 Hepatitis B infection can be prevented by immunisation. Immunisation is recommended for individuals at risk of infection because of their lifestyle, occupation or other factors such as close contact with a case or person who is persistently infected (see *Immunisation against Infectious Disease* 1996. UK Health Departments). In the context of this guidance document, it is appropriate to mention the following groups for whom immunisation is recommended:

Groups for whom hepatitis B immunisation is recommended

- Babies born to mothers who are chronic carriers of hepatitis B virus or to mothers who have had acute hepatitis B during pregnancy (see paragraphs 4.14-4.16);
- Injecting drug users;
- Household or close family contacts of a case or carrier, particularly sexual partners and young children;
- Individuals who change sexual partners frequently, particularly gay and bisexual males, and men and women who are sex workers;
- Families adopting children from countries with a high prevalence of hepatitis B (particularly some countries in Eastern Europe, South East-Asia and South America);
- Staff and residents of residential accommodation for those with severe learning disabilities;
- Individuals with haemophilia;
- Patients with chronic renal failure;
- Short-term foster carers and family members in the household.

Immunisation of looked after children

4.43 The need for a child to be tested for, or immunised against, hepatitis B should be considered in the light of the guidance above as part of the medical assessment of a child before placement. It is important to ensure that children receive the full course of vaccine. Guidance on testing for blood-borne viruses is in Chapter 5.

Immunisation of foster carers

4.44 Some children being placed with foster carers may have been exposed to hepatitis B infection and may have become persistently infected (e.g. through mother to child transmission, through household contact, as a result of their parents' lifestyle, or through sexual abuse by parents or others). However, there is not yet evidence to justify a recommendation that *all* foster parents and other family members in the household, including other looked after children, should be offered immunisation, as many will care for children who would not have been exposed to

hepatitis B infection. Immunisation is recommended for short-term carers because they are more likely to foster children from the risk groups whose hepatitis B status may be unknown, at very short notice. Immunisation should also be offered to other family members in the household. The need to offer immunisation to other foster carers should be based on a risk assessment by the local authority making the placement.

- 4.45 In making foster care placements, local authorities have a duty to arrange for a medical examination and written health assessment of a child before placement or as soon as is practicable after placement. As part of the foster placement agreement between the local authority and the foster carers, and under the Fostering Minimum Standards, local authorities are required to provide a written health record for each child placed in their care, which should be updated during the period of the placement. In addition, before a placement begins, the local authority has a duty to pass on to the carer as full a description as possible of the health needs of a child and any relevant information about the child's state of health and need for health care and clear procedures governing consent for the child to receive medical treatment.
- 4.46 Therefore, if a local authority is intending to place a child known to be, or at higher risk of being, persistently infected with hepatitis B (e.g. who was born or raised in an area of high prevalence for hepatitis B or who was the child of injecting drug misusers), this should be discussed with the foster carers before the placement is made. The carers should be advised about the risk of infection, informed about precautions to avoid the transmission of infection (including protection through immunisation) and the implications for the child and their health care. It is understandable that such information may not be available before an emergency placement is made.
- 4.47 The local authority should assist the foster carers and members of their household in obtaining immunisation against hepatitis B if warranted on risk assessment. Foster carers looking after a child with hepatitis B are included in the recommendation of immunisation for close household contacts of a person with acute hepatitis B infection or person persistently infected with hepatitis B.
- 4.48 Similar procedures should be followed by the local authority or an adoption agency working on behalf of prospective domestic adoptive parents.

Intercountry adoption issues

- 4.49 It is a legal requirement for placements in the UK that information is provided about the health and development of children proposed for adoption. For the latest guidance, see *Intercountry Adoption Guide*, May 2003 issued under the cover of LAC (2003)12: *New arrangements for Intercountry Adoption and Adoption Support Services*.
- 4.50 Many children available for intercountry adoption have been abandoned or placed for adoption by parents who provide little background or medical information about themselves or the child. Prospective adopters should seek medical advice from their GPs to establish which medical conditions are endemic in the child's country of origin. They should be advised to have any necessary immunisations before travelling to pick up the child. (See also the British Association for Adoption and Fostering Practice Note 46: *Health Screening of Children Adopted from Abroad*.)
- 4.51 Prospective adopters of young children (under 18 months old) should be made aware that standard (antibody-based) screening tests for infection with HIV and hepatitis C may give rise to misleading positive results. (Tests for hepatitis B infection based on detection of hepatitis B surface antigen provide a reliable indication of infection at an earlier age.) This is because infants born to infected mothers acquire antibodies via the placenta and these maternal antibodies may persist for 18 months or more. Additional tests may be needed in such cases, over a period of time, to determine definitively an infant's infection status. In older children, an initially negative test result may give false reassurance on two counts: firstly, because a recent infection may go undetected if testing occurs in the interval before antibodies develop; and secondly, because of the questionable accuracy of tests performed in some countries from which children may be adopted, and the fact that tests have been falsified in some cases. (The latter two points would also apply to antigen tests for hepatitis B.) It has also been suggested that the child could be put at risk of acquiring blood-borne virus infection through unsafe practices (e.g. re-use of needles for drawing blood), as a result of being tested in the child's own country.
- 4.52 The local authority or agency working on behalf of the applicants should make them aware that neither the Department of Health nor the Department for Education and Skills is in a position to verify the quality of medical information contained in any medical report received from abroad. Applicants should also be made aware that there is no guarantee that the child will be free of serious health and development problems.

4.53 Before proceeding with the adoption, information on the child's health should be discussed with the doctor (usually a community paediatrician) acting as medical adviser to the local authority or agency and with the applicants' GP. It may be recommended that, after arrival in the UK, the child should be tested or immunised. The advice of a consultant in communicable disease control or an infectious diseases paediatrician should be sought or, if the child has HIV or hepatitis, he/she should be referred for a full assessment by a specialist clinician. Where prospective adopters decide to accept a child who is infected, or has a high risk of being infected with hepatitis B, they should be advised to arrange for a course of immunisation for themselves and their families. The course may take up to six months to complete, so arrangements need to be made as soon as possible.

Vaccines

4.54 There is currently no vaccine for HIV or hepatitis C.

Carers with blood-borne viruses

4.55 Individuals known to be infected with a blood-borne virus should not be barred from consideration as carers, but a medical report on the prospective carer (and members of the household) is required as part of the recruitment process for residential staff and of the approval process for foster carers. As with other serious illnesses, there should be consideration of the likelihood that the carer's life expectancy may be reduced and how this might affect the child. A child placed with a carer with hepatitis B should be immunised to minimise the risk of household transmission of infection. Carers with HIV should receive ongoing monitoring for co-infections such as tuberculosis.

Information, training and advice

4.56 The fostering service should make clear to the carer(s) what their role is in helping to promote the health of the child in their care. It is important that all carers receive information, advice and training on measures to reduce the risk of blood-borne virus transmission in household and residential settings.

Post-exposure prophylaxis for HIV

4.57 Post-exposure prophylaxis (PEP) (in the form of combination anti-retroviral drug treatment) is available to health care workers who may have been exposed to HIV infected blood or body fluids in the course of their work. This treatment reduces the risk that they will acquire HIV infection. In social care settings, there may be rare circumstances when a child or carer is exposed to the blood or potentially infectious body fluids of a person known to have HIV or considered to be at high risk of HIV infection, but where the result of an HIV test is not available. Local policies should be in place for urgent referral to a designated health professional for risk assessment, advice and possible provision of PEP. Where indicated, PEP should be started as soon as possible after the exposure incident for maximum efficacy, and ideally within the hour. However, if a longer interval has elapsed since possible exposure, PEP may still be worthwhile. Where PEP for a child is being considered, advice should be sought from a specialist HIV paediatrician and the child should be accompanied by someone with parental responsibility to avoid delays in starting PEP. Guidance on HIV PEP for children is available from the Children's HIV Association website (<http://www.bhiva.org/chiva/index.html>).

Post-exposure prophylaxis for hepatitis B

4.58 As for HIV, there is post-exposure prophylaxis (PEP) for hepatitis B. This involves immunisation with hepatitis B vaccine and/or immunoglobulin (antibodies), as indicated. PEP may be indicated when a child or carer is exposed to the blood or body fluids of a person known to be infected with hepatitis B or considered to be at high risk of hepatitis B infection. Where the infection status of the source individual cannot be determined (e.g. following an injury from a discarded needle), the local authority or carer should seek medical advice urgently (e.g. from their local accident and emergency department or general practitioner). PEP may be indicated even if the individual exposed has received hepatitis B vaccine previously. Ideally, PEP should be given within 48 hours, and no later than 7 days after exposure. Information about hepatitis B vaccine is contained in the UK Health Departments *Immunisation against infectious diseases (1996)* 'The Green Book', which is available on the Department of Health website at: <http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/GreenBook/fs/en>

Management of exposure to hepatitis C

4.59 There is no PEP for hepatitis C. However, there should be careful management and follow-up of blood exposure incidents and early referral for specialist assessment if infection has been transmitted. Guidance on the investigation and appropriate management of occupational exposure to blood and specifically in relation to hepatitis C has been published by the Department of Health and the former Public Health Laboratory Service (see Annex 1). This guidance is directed mainly at health care workers, but others who may have been exposed to infected blood should be managed in the same way as exposed health care workers.

5. Testing for blood-borne viruses

- 5.1 Testing for blood-borne viruses provides the opportunity for reassurance if the test is negative. If the test is positive, the child and family should receive appropriate information, advice and support, and be referred for specialist assessment and treatment, if indicated. Testing should not be undertaken either routinely or without careful consideration of whether it is justified and what the implications of a positive test result might be for the child concerned. A positive test could also have implications for a birth parent where it is thought that the child acquired the infection vertically and the birth parent was not aware that they themselves were infected. There should be pre-test discussion with a trained health professional and an independent person or advocate should also be available for the child to ensure that the child's wishes have been appropriately determined. In any decision whether or not to offer a test, the welfare of the child must be the paramount consideration. Relieving the anxiety of carers, whether they are temporary or permanent, should not in itself be a reason for testing.
- 5.2 Initial tests will generally show if a person has been exposed to infection and developed antibodies to it. If exposure to infection has only recently occurred, it may be necessary to carry out a further test as antibodies may take up to 3-6 months to develop. Specialised tests will be used to determine whether the person is carrying the particular virus for which the test has been carried out. Tests for antibodies in young children under the age of 18 months will not necessarily indicate whether the child has been infected, as the antibodies may have been acquired from their mother during pregnancy. The specialised tests referred to above will detect infection earlier than antibody tests and may be used.

Suggested indicators for considering testing

- 5.3. Where a child may have been exposed to HIV, hepatitis B or hepatitis C, the decision to test should be based on careful consideration of the information available for each child, on a case-by-case basis. The child's best interests should be the primary consideration. The list below summarises suggested indicators for considering testing for HIV, hepatitis B or hepatitis C.

- a child or young person born to an infected mother, or a mother considered to be at risk of infection with a blood-borne virus – unless it is already established by previous testing that the child is not infected;
- a child or young person who may have shared contaminated needles, syringes and other equipment while injecting drugs, or who has been injured by such a needle;
- a child or young person who may have had vaginal, anal or oral sex with an infected person;
- a child or young person who has received blood or blood products where measures to screen donors or treat blood products are not in place, or who has undergone invasive medical or dental treatment in countries where infection control precautions may have been inadequate;
- a child or young person with clinical symptoms suggestive of infection (e.g. weight loss and oral thrush (HIV), jaundice (acute hepatitis B or C¹)). Specialist advice may be necessary.

Advantages of testing

5.4 As mentioned above, there are considerable benefits for the child of knowing whether or not they have HIV, hepatitis B or hepatitis C. If the child is not infected, this knowledge can remove doubt and prevent unnecessary stress and anxiety. If the child tests positive, this too can cause stress and anxiety, but early diagnosis allows for the child to be referred for specialist clinical assessment, treatment, if indicated, and care and support. More effective drug treatments for HIV and hepatitis C, in particular, have been developed over recent years and new treatments for hepatitis B are emerging. Treatment for HIV may slow progression of HIV disease, improve quality of life and extend the lifespan of people with HIV. Drug treatment for hepatitis C has an overall success rate of around 55% and up to 80% in some cases.

1. A child with clinical symptoms of acute hepatitis such as jaundice is more likely to have acute hepatitis A infection, which is spread by the faecal-oral route and does not cause chronic infection. Immunisation of close contacts is advisable and advice should be sought from the Consultant in Communicable Disease Control. Blood tests can differentiate between hepatitis A, B and C infections. As well as viral hepatitis, there are other infectious and non-infectious causes of jaundice so that clinical assessment of the child is needed.

Disadvantages of testing

- 5.5 A positive diagnosis may impose a significant psychological burden on the individual child, particularly as they grow older. Treatment for all these viruses may also cause considerable side effects.
- 5.6 There is still stigma and fear associated with HIV, and to a lesser extent with hepatitis B and C. There will therefore always be concern that disclosure of the child's status will lead to prejudice, rejection and even harassment by relatives, friends, neighbours and peers. A positive test can lead to a woman and her child/children being rejected by their families and ostracised by their communities. The process of having the test may be stressful in itself, whether or not the result is positive.
- 5.7 In the longer term, it is likely that a positive test may need to be disclosed if applying for a mortgage or insurance. As with other potentially serious health conditions, having a blood-borne virus may affect such applications. The Association of British Insurers (ABI) has recommended that insurance companies should not ask whether an applicant for insurance has taken an HIV, hepatitis B or hepatitis C test, had counselling in connection with such a test, or received a negative test result. Doctors should not reveal this information when writing reports and insurance companies will not expect this information to be provided. Insurers should ask only whether someone has had a positive test result, is awaiting a test result, or is receiving treatment for HIV/AIDS, hepatitis B or hepatitis C. Further information can be obtained from the ABI website at: <http://www.abi.org.uk/>.

Consent to testing

Children aged 16 or 17

- 5.8 A young person aged 16 or 17 may give their own consent to medical tests (see paragraph 5.1 regarding pre-test discussion), examination or treatment. To help them reach a decision, young people should be given age-appropriate information and advice so that the nature of the test and the implications of a positive test are well understood. However, if a child aged 16 or 17 lacks capacity to make the decision, consent may be given by a person with parental responsibility. If the child does have capacity, but refuses, the refusal can be overridden in exceptional cases by either a person with parental responsibility or the courts. In such circumstances if the outcome may have

serious implications for the child, it may be appropriate to seek a ruling from the court rather than proceeding on the basis of consent from a person with parental responsibility. The legal position on this is discussed in the Department of Health's 2001 *Reference Guide to Consent for Examination or Treatment* (chapter 3, paragraphs 8-8.4).

Children under 16

5.9 Children under the age of 16 may give consent to or refuse testing, examination and treatment, if they are capable of understanding the reasons for and the nature and implications of the test. The child should be given information and advice appropriate to their age and understanding. Where the child lacks capacity, consent may be given by a person with parental responsibility or the courts. If the child has capacity but does not give consent, their refusal may be overruled in the circumstances described in paragraph 5.8 above. It is for the doctor concerned to decide about capacity. Where parents oppose testing and either the child lacks capacity to consent, or has capacity and refuses, it is possible that the courts may overrule parental opposition if testing is regarded as being in the child's best interests. This was done in the case of *Re C (HIV test)* (CP 1204 of 1999). However, this does not mean that testing is always in a child's best interests, as each case must be considered on its own facts.

Parental responsibility

5.10 Under the Children Act 1989, several parties may have parental responsibility for the same child. Parental consent should be sought where the child is not capable of giving informed consent. Although consent may be given by one person with parental responsibility, caution should be exercised if there is evidence of disagreement between two parents. Further advice should be sought and it may be necessary to involve the courts. The local authority does not have full parental responsibility even with a care order. Responsibility is shared with parents, and the parents and any other person with parental responsibility should always be consulted, unless the local authority has decided that such consultation would not be in the best interests of the child. When a child is not in the care of the local authority and the parents refuse consent to testing, the local authority may apply for an appropriate court order (e.g. a section 8 specific issue order) to make the case for testing, if they judge that it would be in the child's best interests.

5.11 Information about the suggested need for testing should be non-directive and sensitive to the child's and family's ethnic background, culture and

language. Similarly, any sensitive issues relating to the sexuality of the child will need to be addressed.

Information and advice for children with blood-borne virus infections and their families

5.12 It is important that children with blood-borne virus infections and their families are given appropriate information, advice and support. Information about further sources of advice and support may also be helpful e.g. from voluntary and community sector organisations.

Confidentiality

5.13 Social services and other local authority departments will already have procedures in place to protect the confidentiality of their clients. Information about the health or medical history of an individual is confidential to the person concerned and should be protected by these procedures. The protection of client confidentiality is particularly important in relation to blood-borne viruses because HIV, and to some extent hepatitis B and hepatitis C, carry a stigma which may lead to discrimination against individuals with disease, sometimes leading to social isolation and harassment.

5.14 The question of whether to disclose information about blood-borne viruses to other local authority departments or outside agencies may arise following a detailed assessment, where there is a need to access specific services for the child and/or family, and these can be gained only by disclosing details of the assessment. Before disclosing information about blood-borne viruses to any agency or individual, local authority officers should be satisfied that all of the following criteria are fulfilled:

- the child and/or the child's parents have given their written consent to the transfer of information (for guidance on steps to take when consent is not given, see paragraphs 5.16-5.20);
- the disclosure of the information would be in the best interests of the child and would benefit the welfare of the family in a specific way, or the disclosure would protect an individual at risk of infection;

- the person(s)/agencies receiving the information are aware of its confidential nature and are able to maintain the confidentiality of the information provided.

5.15 The child's consent to disclosure of information about their blood-borne virus status should be sought whenever the child is of an age and understanding to provide it. Parental consent should be sought where the child is not capable of giving informed consent. Where the local authority has parental responsibility, the birth parents and any other person with parental responsibility should always be consulted, unless the local authority has decided that such consultation would not be in the best interests of the child. Local authorities will need to liaise closely with other agencies to ensure that their procedures for maintaining confidentiality are appropriate, so that they can advise clients accordingly.

5.16 The local authority should provide full age-appropriate information in terms which the recipient can understand, describing both the advantages and disadvantages of disclosing infection status. As with consent to testing, information about the suggested need for disclosure should be non-directive and sensitive to the child's and family's ethnic background, culture and language. Information to discuss includes:

- what are the specific advantages and disadvantages for the child and/or family which may result from the disclosure or non-disclosure;
- who will have access to the information if disclosed;
- what confidentiality procedures are in place to protect the information before, during and after transfer.

5.17 If consent to disclosure is withheld, the decision of the child and parents should be followed wherever possible. If the child opposes disclosure, the parents' consent should generally override the child's wishes only if the child is not of an age and understanding to consent. If the local authority officer is concerned that the welfare of the child and/or family is diminished because of their objection to disclosure, further discussions with the family may be appropriate.

5.18 Social services staff will wish to identify the child's and/or family's concerns and reassure them if possible. If the child or family clients are still

opposed to disclosure, their wishes should generally only be overruled if any of the following apply:

- the child is at risk of significant harm if disclosure is not made;
- there is a legal requirement for the information to be disclosed;
- public interest requires disclosure, for example in order to prevent others being put at serious risk.

5.19 If it is considered necessary to go against the wishes of the child or parents, they should be told that the information is to be disclosed and to whom, and should be given a full written explanation of the reasons for overruling their wishes. Social workers should always discuss their decision with senior officers and seek legal advice before taking action to disclose. Similarly, disclosure of information about HIV, hepatitis B or hepatitis C without having sought the consent of the person concerned should take place only in exceptional circumstances and after consultation with senior management and legal advisers.

5.20 A sensitive approach will be needed in exceptional cases when a young person may want information kept confidential from their parents. If a young person does not consent to information being disclosed, their wishes should be overruled only if the circumstances described in paragraph 5.17 apply.

Local education authorities and proprietors providing services in schools and in early years and childcare settings

5.21 In schools, early years and childcare settings there may be reasons why the proprietor/person in charge should be informed. These reasons include if the child is frequently absent due to ill health or to attend hospital appointments and may need additional educational support. If the child is on medication, arrangements may be needed to manage the medication safely.

5.22 Where the education setting is informed, every effort should be made to safeguard the child's confidentiality and right to privacy. Those who are made aware should be strictly confined to those who need to know in order to ensure the proper care of the child and for any additional pastoral and educational support that may be required. Local advice on blood-borne viruses may be sought from the Consultant in Communicable Disease Control, who can be contacted via the local Primary Care Trust

or Health Protection Agency. In addition, where appropriate, advice can be sought from a microbiologist, virologist or a genito-urinary medicine (GUM) or infectious diseases physician.

- 5.23 Information should not be disclosed to carers or in schools solely on the basis that it might help protect those involved in the care or treatment of a child with blood-borne virus infection. Standard hygiene precautions (see Chapter 4) should be in use to protect against infection and it is a requirement under COSHH for risk assessments to be done in all settings to assess the risk and to control and minimise the risk of infection.
- 5.24 Under the Disability Discrimination Act 1995, schools have duties not to discriminate against students on grounds relating to a disability in admissions, education and associated services, and exclusions from school (see paragraphs 2.11-2.12 for discussion of HIV and disability). In exceptional circumstances, where a child's behaviour is thought to pose a serious risk of infection to others, disclosure of the child's blood-borne virus status may be warranted (e.g. if a child is deliberately trying to harm other children by activities involving the direct exchange of fresh blood).

Child protection issues

- 5.25 As far as testing for infection is concerned, the court may require the testing of a child for HIV infection against the wishes of the parents, but only if this procedure is in the child's best interest. This will depend on all the circumstances of each particular case. If parents refuse consent against medical advice, then child protection processes and legal action may be considered.
- 5.26 If a parent were to refuse appropriate treatment for a child and this was likely to result in the child suffering significant harm, there may be grounds for following child protection processes and considering legal action. This has been tested in relation to other medical conditions and the need for treatment but not yet in relation to HIV, hepatitis B and hepatitis C.
- 5.27 Wherever possible, every effort should be made to work in partnership with parents and carers to explain the available options and the possible consequences for their child's health of withholding consent.

Annex 1

Useful publications and sources of advice

Publications²

Blood-borne viruses in the workplace: guidance for employers and employees. HSE Books 2001, ISBN 0 7176 2062X. Free single copies or priced packs of ten can be ordered online at <http://www.hsebooks.com/Books/> or by writing to HSE Books, PO Box 1999, Sudbury, Suffolk, CO10 2WA, Tel: 01787 881165 or Fax: 01787 313995. Alternatively download the free leaflet <http://www.hse.gov.uk/pubns/indg342.pdf> (PDF document on HSE website).

Control of Substances Hazardous to Health Regulations 2002 Approved Codes of Practice (ACOP) (L5) (fourth edition). HSE Books 2002, ISBN 0 7176 2534 6.

Drug Misuse and Dependence – Guidelines on Clinical Management. UK Health Departments, TSO 1999, ISBN 0 11 322277 7.
http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4009665&chk=k9LrB5

Effective Sexual Health Promotion Toolkit, Department of Health, 2003.
<http://www.dh.gov.uk/assetRoot/04/07/96/03/04079603.pdf>

Exposure to Hepatitis B Virus; Guidance on Post Exposure Prophylaxis. PHLS Hepatitis subcommittee. *CDR Review*1992: 2; R97-R101.
<http://www.hpa.org.uk/infections/publications/guidelines.asp?topic=14>

Framework for the Assessment of Children in Need and Their Families. Department of Health, Department for Education and Employment, Home Office 2000.
http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4003256&chk=Fss1ka

2. Websites were accessed on 31 August 2004, unless otherwise stated.

Guidance for Field Social Workers, Residential Social Workers and Foster Carers on Providing Information and Referring Young People to Contraceptive Sexual Health Services. Teenage Pregnancy Unit . Department of Health, 2001.
<http://www.info.doh.gov.uk/tpu/tpu.nsf>

Guidance for Youth Workers on Providing Information and Referring Young People to Contraceptive and Sexual Health Services. Teenage Pregnancy Unit. Department of Health. 2001. <http://www.info.doh.gov.uk/tpu/tpu.nsf>

Guidance on the Investigation and Management of Occupational Exposure to Hepatitis C. Public Health Laboratory Service (Ramsay, M E). *Commun Dis Public Health* 1999; **2**: 258-262.
<http://www.hpa.org.uk/infections/publications/guidelines.asp?topic=14>

Hepatitis C: Essential Information for Professionals and Guidance on Testing. Department of Health, 2004
http://www.hepc.nhs.uk/pdf/HepC_Information.pdf

Hepatitis C – Guidance for Those Working with Drug Users. Department of Health, 2001. <http://www.dh.gov.uk/assetRoot/04/01/96/49/04019649.pdf>

Health Service Circular 1998/127: Screening of Pregnant Women for Hepatitis B and Immunisation of Babies at Risk. Department of Health, 1998.
<http://www.dh.gov.uk/assetRoot/04/01/18/40/04011840.pdf>

Health Service Circular 1999/183: Reducing Mother to Baby Transmission of HIV. Department of Health, 1999.
<http://www.dh.gov.uk/assetRoot/04/01/21/28/04012128.pdf>

HIV and Infant Feeding: Guidance from the UK Chief Medical Officers' Expert Advisory Group on AIDS. Department of Health, 2004. Accessed on 29 September 2004. <http://www.advisorybodies.doh.gov.uk/eaga/pdfs/hivinfantsep04.pdf>

HIV Post-exposure Prophylaxis: Guidance from the UK Chief Medical Officers' Expert Advisory Group on AIDS. Department of Health, 2004.
<http://www.advisorybodies.doh.gov.uk/eaga/PDFS/prophylaxisguidancefeb04.pdf>

Immunisation against Infectious Disease. UK Health Departments, HMSO 1996, ISBN 0 11 321815 X.
<http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/GreenBook/fs/en>

The National Service Framework for Children, Young People and Maternity Services webpage.

<http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/ChildrenServices/ChildrenServicesInformation/fs/en>

The National Strategy for Sexual Health and HIV. Department of Health, 2001.
http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4003133&chk=/iTv%2BN

Promoting the Health of Looked after Children. Department of Health, 2002.
http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4005321&chk=jkfnxm

Protection against Blood-borne Infections in the Workplace: HIV and hepatitis. Advisory Committee on Dangerous Pathogens. HMSO 1995, ISBN 0 11 321953 9.

Reference Guide to Consent for Examination or Treatment. Department of Health, 2001.
<http://www.dh.gov.uk/assetRoot/04/01/90/79/04019079.pdf>

Safe Disposal of Clinical Waste (second edition). Health and Safety Commission's Health Services Advisory Committee. HSE Books 1999, ISBN 0 7176 2492 7.

TeacherNet, A to Z of School Leadership – HIV and AIDS, Department for Education and Skills
<http://www.teachernet.gov.uk/management/atoz/index.cfm?component=topic&id+239&part=1>

Teenage Pregnancy. Social Exclusion Unit, Cabinet Office. London: the Stationery Office; 1999 (Cm 4342).
http://www.dfes.gov.uk/teenagepregnancy/dsp_showDoc.cfm?FileName=teenpreg.pdf

Working Together to Safeguard Children. Department of Health , Home Office, Department for Education and Employment, 1999.
<http://www.dh.gov.uk/assetRoot/04/07/58/24/04075824.pdf>

Sources of advice

British Agencies for Adoption and Fostering

Skyline House
200 Union Street
London
SE1 OLX
Tel: 020 7593 2000

The British Liver Trust (specialises in adults with liver disease)

Portman House
44 High Street
Ringwood BH24 1AG
Tel: 01425 463080
Fax: 01425 470706
Information line: 0808-800-1000
E-mail: info@britishlivertrust.org.uk
Website: www.britishlivertrust.org.uk/content/home/default.asp

Brook (Advisory Centre)

421 Highgate Studios
53-79 Highgate Road
London
NW5 1TL
Tel: 020 7284 6040
Fax: 020 7284 6050
E-mail: admin@brookcentres.org.uk
Website: www.brook.org.uk/content/

Children First

Website: www.childrenfirst.nhs.uk/index.php

Children's Liver Disease Foundation (specialises in children with liver disease)

36 Great Charles Street
Birmingham B3 3JY
Tel: 0121 212 3839
Fax: 0121 212 4300
E-mail: cldf@childliverdisease.org
Website: www.childliverdisease.org/

The Children's HIV Association

Website: www.bhiva.org/chiva

Contact a family (for families with disabled children)

209-211 City Road,
London
EC1V 1JN

Tel: 020 7608 8700

Fax: 020 7608 8701

Helpline: 0808 808 3555 or

Textphone: 0808 808 3556 **Freephone** for parents and families (10am-4pm, Mon-Fri)

E-mail: info@cafamily.org.uk

Website: www.cafamily.org.uk/

Drinkline (provides confidential advice and guidance about ways to control or avoid alcohol and related problems)

Helpline: 0800 567 123

Environment Agency Office (clinical waste disposal enquiries)

Tel: 0845 9333111

The Fostering Network (formerly the National Foster Care Association)

87 Blackfriars Road
London
SE1 8HA

Tel: 020 7620 6400

Fax: 020 7620 6401

E-mail: info@fostering.net

Website: www.thefostering.net/

Fpa (formerly the family planning association)

2-12 Pentonville Road
London
N1 9FP

Tel: 020 7837 5432

Fax: 020 7837 3042

Helpline: 0845 310 1334 (Open Monday to Friday 9am-6pm)

Website: www.fpa.org.uk/

The Haemophilia Society

Chesterfield House, 385 Euston Road,
London
NW1 3AU

Helpline: 0800 018 6068 (9am to 5pm, Monday to Friday)

E-mail: info@haemophilia.org.uk

Website: www.haemophilia.org.uk

The Hepatitis C Trust

27 Crosby Row
London
SE1 3YD

Helpline: 0870 200 1200

E-mail: info@hepctrust.org

Website: www.hepcuk.info

Health and Safety Executive (clinical waste disposal enquiries)

Tel: 08701 5455000

Mainliners (specialises in blood-borne viruses and drug misuse)

38-40 Kennington Park Road
London
SE11 4RF

Tel: 020 7582 5434 / 3338

Fax: 020 7582 6999

Helpline: 020 7582 5226 (Mon - Fri : 9.30am-5.30pm)

E-mail: linersmain@aol.com

Website: www.mainliners.org.uk/

NHS Direct

Tel: 0845 4647 (24 hours)

Website: www.nhsdirect.nhs.uk

NHS hepatitis C website

Website: www.hepc.nhs.uk

Playingsafely.co.uk (the NHS website on sexually transmitted infections and diseases)

Website: www.playingsafely.co.uk

Sex Education Forum

National Children's Bureau

8 Wakley Street

London

EC1V 7QE

Tel: 020 7843 1901 (Available Monday to Friday, 9.30am-5pm)

E-mail: sexedforum@ncb.org.uk

Website: www.ncb.org.uk/sef/

The Sexual Health Line (provides free and confidential information, advice and support, 24 hours a day, 7 days a week. Can refer callers on to other organisations/sources of advice.)

Tel: 0800 567 123

Talk to Frank (provides confidential information and advice to drug users and anyone concerned about drugs)

Helpline: 0800 776 600

Website: www.talktofrank.com

Terrence Higgins Trust (THT)

52-54 Grays Inn Road

London

WC1X 8JU

Tel: 020 7831 0330

Fax: 020 7242 0121

E-mail: info@tht.org.uk

Website: www.tht.org.uk/

THT Direct Helpline (provides HIV information, advice and support over the phone. 10am-10pm Monday-Friday and 12noon-6pm on Saturday and Sunday).

Tel: 0845 1221 200 (calls charged at local rate)

UK Hepatitis C Resource Centre (a Mainliners project)

195 New Kent Road

London

SE1 4AG

Information Line: 0870 242 2467 (9.30am-5pm Monday-Friday)

E-mail: info@hepccentre.org.uk

Website: www.hepccentre.org.uk

The Who Cares? Trust (*works to improve public care for children and young people living away from their families in residential or foster care*)

Kemp House

152-160 City Road

London

EC1V 2NP

Tel: 020 7251 3117

Fax: 020 7251 3123

E-mail: mailbox@thewhocarestrust.org.uk

Website: www.thewhocarestrust.org.uk

www.rhrn.thewhocarestrust.org.uk



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