

3.3 Training for other Professionals

Paediatric units caring for children and families with HIV should lead local training about HIV for all health, social care, and educational professionals coming into contact with families. This is very important as there continues to be stigma and misinformation surrounding HIV, which may affect families especially when seeing professionals other than the HIV team. Units should maintain a log of training sessions undertaken.

3.4 Managing disclosure of the HIV Diagnosis, to the Child and to others

Disclosure to a child about their HIV diagnosis is a process which needs to take place over a period of time, in partnership with the family. CHIVA Practice Guidance “Talking to Children about their Health and HIV Diagnosis” should be followed (www.chiva.org.uk).

1. There should be a multidisciplinary health team approach to talking to children with HIV about their health, in partnership with their carers. Where centres do not have access to the full multidisciplinary team, specialist advice could be sought through the CHIN network.
2. A lead worker should be identified who will co-ordinate the work around disclosure with the family and child.
3. The lead worker should undertake an assessment of the child and family’s needs around disclosure to the child.
4. From the assessment, an individualised plan should be developed for the care and support needed to enable the child to learn more about their health diagnosis.
5. The disclosure plan should be reviewed and updated regularly.
6. Children and young people should have ongoing explanations about their health condition appropriate to their age and level of understanding. This knowledge should be built upon in stages over time. (see Disclosure Table www.chiva.org.uk)
7. The majority of children should have had an open discussion about having HIV by the time of transfer to secondary school. Exceptions should be documented, along with the plan for ongoing appropriate interventions to advance the child’s knowledge.
8. After telling the young person that they have HIV, discussions need to continue to build upon the young persons understanding of HIV and sexual health.
9. The child’s level of understanding of their illness and the plan of disclosure should always be part of the multidisciplinary team meeting discussion.
10. There should be clear and up to date documentation in the child’s medical notes on the child’s understanding of their illness pre and post naming; the disclosure plan and the name of the lead worker.

11. All parents/carers should be offered support and advice around how to talk with their child about their health condition and HIV.

12. All children and young people should be given information about their health and HIV appropriate to their age and level of understanding (see Disclosure Table (www.chiva.org.uk)).

Adequate information and resources should be available for healthcare professionals around talking to children about their health and HIV (see Disclosure Table (www.chiva.org.uk)). Disclosure to other professionals or individuals about a child's HIV diagnosis should only happen with the parent's, and if age appropriate, the child's consent, in partnership with the family and where it is definitely in the child's best interest. There is no obligation to automatically inform any other institution, e.g. nursery or school, that a child has HIV. Members of the MDT can actively support families during disclosure to other professionals, and offer up-to-date information on HIV for them, e.g. for teachers or social workers.

The child's HIV diagnosis should not be disclosed to other professionals without the family's permission, except in exceedingly rare situations where children may come to harm if the family's confidentiality is not breached. Such action should only be taken after consideration by the MDT.

3.5 Adherence Support

The success of antiretroviral medication is dependant on adherence to therapy. HIV drugs require a high degree of adherence to treatment or drug resistance can develop rapidly. First line therapy is most likely to result in a favorable outcome with undetectable viral load and effective immune reconstitution. Children are likely to require lifelong treatment and as there are a limited number of antiretroviral drugs available, supporting adherence to treatment is essential for a successful outcome. In addition the formulations available for younger children are limited.

Adherence support will be required more intensively at certain stages which are predictable (when starting treatment; for infants, toddlers, and adolescents; when changing antiretrovirals (ARVs); when changing formulation e.g. liquids to tablets). In addition there will be unpredictable crises which may or may not be related to drug treatment (illness in a parent, side effects, and social, housing and immigration issues).

1. CHIVA guidance on adherence should be followed (www.chiva.org.uk)
2. There should be an identified individual (usually the Paediatric HIV Clinical Nurse Specialist) who will lead on work with families to provide information about drug treatment, prepare children and families for drug treatment, and arrange follow up.
3. In centres supported by a Paediatric HIV pharmacist, they will also play an important role in leading treatment and adherence support.

4. Before starting therapy a plan needs to be made for pre-treatment discussion, starting treatment and follow up. This may be in clinic or at home, and with telephone contact. In some areas there are community paediatric / HIV services trained in adherence, and ongoing support can be offered at home.
5. Before starting treatment, there should be discussion with the family and multidisciplinary team to identify family beliefs around drugs and identify any issues regarding parental drug adherence (if appropriate). An assessment should be made about any issues within the child or family's life which might impact on adherence (e.g. other members of the household not aware the child has HIV infection).
6. There should be a contact plan for unexpected problems with adherence/ side effects, so that families are aware of how and when to seek advice in case of a problem with medication occurring in or out of hours.

3.6 Transition and Optimal Adolescent Care for Young People Born with HIV

1. Transition is defined as ' the purposeful, planned movement of adolescents and young adults with chronic physical and mental conditions from child-centred to adult orientated health care systems' Blum RWJ et al (1993).
2. Generic national guidance on transitional care should be followed (see web links below). Many hospital trusts will also have local transition procedures.
3. The majority of HIV infected children are infected by Mother to Child transmission and, considered as children living with a chronic health condition. The success of antiretroviral medication means that children are surviving with HIV into adulthood with increasing numbers transitioning to adult services. This process of preparation begins in middle childhood and progresses through adolescence at a speed appropriate for each child and their family and culminates at the point of transfer to adult services. (This section does not apply to young people who acquire HIV during adolescent, most of whom receive care from adult services).
4. It is essential that there is an individualised plan for transition for each young person following CHIVA and HYPNet guidelines (www.chiva.org.uk).
5. A lead for transition should be identified in both adult and paediatric services.
6. Health education and promotion are an integral part of the transition process including negotiating relationships, safe sex education and vaccination. HYPNet/CHIVA Guidance: "Sexual Health for Young people with perinatally acquired HIV 2009" should be followed. (www.chiva.org.uk)
7. Each young person who transitions should have a comprehensive paediatric discharge summary completed before transfer to adult services. This should include, presenting and treatment history, immunological and virological response, drug resistance mutations, allergies including to antiretrovirals, long-term toxicities,

co-existing medical issues and a psychosocial, educational and family history. The summary should be discussed with the young person prior to transfer and they, the adult and paediatric service should have a copy.

8. The views of adolescents and young adults should be represented in policy and ongoing service developments. Parents and carers should be supported in enabling young people to gradually achieve independence. Local patient groups should be strongly encouraged to improve clinical care.

National Transitional Care Guidance

- Royal College of Paediatrics and Child Health (2003) The Intercollegiate Working Party on Adolescent Health. Bridging the gaps: health care for adolescents. www.rcpch.ac.uk/Education/Adolescent-Health-Project
- National service framework for Children Young People and Maternity services (2004) www.dh.gov.uk
- Adolescent Transition Care. Guidance for nursing staff. Royal College of Nursing (2004) www.rcn.org.uk
- National service framework for long term conditions (2005) www.dh.gov.uk
- You're Welcome quality criteria: Making health services young people friendly (2007) www.dh.gov.uk
- A Transition guide for all services. Key information about the transition process for disabled young people (2007)
- Transition Information Network. www.transitioninfonetwork.org.uk
- Transition moving on well (2008). www.dh.gov.uk

3.7 Working with community and primary care services

Families should be encouraged to consent to their GP, health visitor and dentist being informed about the diagnosis of HIV in a child in order that information about the child's health can be communicated and appropriate advice and care can be given in primary care.

- The degree of awareness of knowledge of paediatric HIV varies even within health care professionals, and therefore appropriate information should be provided and contact details given for the hospital paediatric team caring for the child, in order to aid easy communication and allow advice to be easily sought. (See CHIVA website www.chiva.org.uk).

3.8 Joint working with social care and safeguarding

- When a child is diagnosed with HIV, there should be a holistic assessment of the needs of the child, including the need for referral and assessment by social care, who may be able to provide appropriate support for the child and family as a child in need.
- In Lead / Network centres there may be a member of the multidisciplinary team from social care who will be introduced to the family as part of the team. In other centres the

referral will need to be made to the appropriate local social care team after consent from the family.

Safeguarding

1. All professionals working with children and families with HIV need to be aware of, and work within national and local child protection procedures
www.safeguardingchildren.org.uk
www.everychildmatters.gov.uk
2. Professionals working with children and families with HIV should foster close links with local child protection teams to allow advice and discussion of difficult situations at an early stage.
3. Difficult cases regarding specific issues round parental beliefs about HIV, consent to testing or treatment for children should be discussed within the multidisciplinary team and with the Lead Centre. Appropriate discussion may take some time before progress on accepting a diagnosis of HIV can be made.
4. Excellent multidisciplinary documentation should be maintained in these complex cases.
5. Where there is a significant risk to the health of a child, which cannot be addressed by in-depth multidisciplinary discussion with the family, (including peer support groups where appropriate), then a discussion with social care within safeguarding procedures will need to take place and subsequent referral under child protection procedures may be needed. This may arise where a child is unwell and consent is not given for appropriate diagnostic tests or treatment, or where the child is under 1 year when there is urgency to test because of the risk of rapid disease progression or opportunistic infection.
6. These issues are complex and should be discussed with Lead Centres within the local paediatric HIV network and with local paediatricians with expertise in child protection.
7. Local legal teams may need to be involved and advice sought.
8. Appropriate consideration needs to be given to the need for wider disclosure of HIV diagnosis to other professionals. This should be done only in the best interest of the child and usually with parental consent. It should be explicit that not all professionals dealing with the family need to be aware of the HIV diagnosis.

3.9 Third Sector groups – partnerships with voluntary agencies

1. There are many voluntary organisations both local and national providing excellent support and services for children and families with HIV.

2. Units caring for children and families with HIV should be aware of these services and provide information to families, so that they can access these services if they wish (see CHIVA website: www.chiva.org.uk). Families may initially not wish to engage with outside agencies, but this should be readdressed at intervals.
3. Peer support for families can be highly effective in helping them to gain knowledge and confidence in the management of their HIV. Peer support helps families and young people escape isolation, renew and strengthen their self esteem. Many organisations encourage positive living, with life skill training courses.

3.10 Working with Commissioners for HIV Services

1. Paediatric and maternity HIV services must work closely with HIV commissioners to optimise funding support for clinical care.
2. Appropriate performance indicators and outcome measures should be negotiated with the commissioners to monitor clinical care.

Section 4 – The Children’s HIV National Network (CHINN)

Standard - All children with HIV should be managed within the Children’s HIV National Network (CHINN).

4.1 The Children’s HIV National Network

Networks for the care of children infected with HIV were established in London by the London HIV Consortium Paediatric Sub-Group in 2004 (*Paediatric HIV – Developing Paediatric HIV Clinical Networks 2004*). Following this the Departments of Health and the specialised services commissioners group established paediatric HIV networks for children outside London in the Children’s HIV National Network (CHINN) review in 2005.

- The London Networks are:
 - Northwest London (Lead - Imperial College Health Care NHS Trust)
 - Northeast London (Lead - Great Ormond St Hospital for Children NHS Trust)
 - South London (Lead - St Georges Healthcare NHS Trust)
- Direct London Linked Spoke Centres, link directly with outreach from the existing London Networks.
- The CHINN Regional Networks are:
 - North East England
 - North West England & North Wales
 - Midlands
 - South West England & South Wales

- Scotland
 - Northern Ireland.
- Each CHINN Regional Network links with one of the London Lead Centres. The exception is Northern Ireland which links directly with Dublin.
 - Some regions have joint Regional Hub Centres (e.g. in the South West & South Wales where Bristol and Cardiff are the Regional Network Centres), see appendix. However, each regional Network has one lead paediatrician.

4.2 Clinical Governance

The lead paediatrician for the regional network takes responsibility for clinical governance within the network

- Each regional network should have local referral protocols and have clear pathways of patient care to ensure the highest quality of care.
- Each network should have regular meetings for training, collaborative audit and research.

4.3 Networked Care

- The lead paediatrician for the regional network needs to be actively involved in planning and delivering the care for all children in the network in collaboration with paediatricians in the other Network HIV Care Centres and the London Lead Centre.
- Initiation or changes to combination antiretroviral therapy for any individual should always be discussed in a treatment meeting, either locally or virtually via the London Lead Centre.
- For effective shared care, copies of clinic letters and discharge summaries should be sent to the London Lead Centre paediatrician.