

Talking to children about their health and HIV diagnosis

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Introduction

“Although I kind of knew before I was told, hearing the name HIV out loud was still a shock...” (B told she had HIV infection at 13 years)

In the UK great strides have been made in the care and outcomes of children who have grown up with HIV from birth. There are now about 1200 children living with HIV in the UK and 60% of them are aged 10 years or more and leading reasonably healthy lives (CHIPS 2008). There is increasing urgency to ensure these children have the knowledge and understanding to enable them to participate better in decisions and management of their health and lives. Throughout this document there is an acknowledgement that guidance about communicating with children must be flexible and able to account for differences, both in terms of individual characteristics such as level of maturity but also recognising that the circumstances or context of children's lives also varies greatly. This guidance hopes to be useful in setting out the general principles involved in sharing information with children whilst recognising that each child will need to have an individualised plan about how to proceed.

This guidance is aimed at health care teams involved in the care of children and young people living with HIV in the UK and provides evidence of good practice and practical ideas to enhance children's knowledge about their health and diagnosis. Throughout the emphasis is on working in partnership with the child's parent or carer on conversations which explain and support the child's understanding. Whilst there is recognition of a need for more guidance on wider issues of 'disclosure', including who else needs to know about an HIV diagnosis, this is not the focus of this document.

Other chronic paediatric conditions have helped inform about the benefits of and how to communicate with children about health, diagnosis and other sensitive topics. Many of these principles are relevant in paediatric HIV, especially the importance of support partnerships and the process of listening and building on knowledge over time. However there are some unique circumstances in paediatric HIV which need consideration as these can hinder

the path towards more open talking about HIV with children. Paediatric HIV usually occurs within context of a family condition so there is increased likelihood of parental ill health or family loss and it is also a condition with stigmatising associations especially about transmission. Further in the UK many families looking after a child with HIV will have originated from countries where health beliefs and or attitudes to children's inclusion may differ to those of the surrounding UK population or health providers. This can present extra challenges to open discussions about a child's health and diagnosis and sometimes naming of the diagnosis is avoided or postponed.

Reports available from UK services and from other countries generally confirm that the process of involving and sharing knowledge enhances children's coping and protects emotional wellbeing in the longer term. This has been found to be the case for most children whatever their cultural background as long as attention is paid to providing appropriate support from parents and carers and taking account of other experiences which may affect emotional wellbeing and adjustment e.g. recent immigration. There is general agreement that conversations about health should start early so the naming of the diagnosis can occur before transfer to secondary school (for most children). This gives time for understanding and avoids overwhelming the child before they have to face the more challenging issues around sexual health and transmission and disclosure to others. In the UK it is usually possible to plan ahead the process of disclosing the HIV diagnosis for individual children: in other countries where HIV is more prevalent it may not be possible to plan ahead or individualise the process. However all children, even in these latter situations, need time and opportunities to obtain an understanding of what HIV means for them.

Evidence presented in the guide includes the findings of the 2007 CHIVA audit on disclosure and other feedback from medical, nursing and psychology colleagues working in paediatric and adolescent HIV clinics together with personal experiences voiced by positive young people plus a contribution from a consultation workshop run with parents of positive children. It provides ideas to increase the confidence of health providers and carers in having

health conversations with children at different ages and suggests interventions which might help when conversations get difficult or stuck.

Standards for Talking to Children about their Health and HIV Diagnosis

1. All workers should be aware of the principles outlined in the CHIVA Practice Guidance on Talking to Children about their HIV Diagnosis (www.chiva.org.uk).
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 of the care and support needed to enable the child to learn more about their health diagnosis.
5. The 'disclosure' plan should be documented, reviewed and updated regularly.
6. The process of disclosure of HIV diagnosis can include some stages of giving partial, truthful information before telling the child that they have HIV. 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.
appendix 5 , Section C
7. The majority of children, who well supported and integrated into life in the UK, should have had an open discussion about having HIV by the time of transfer to secondary school. Exceptions should be documented and what interventions are planned.

8. After the diagnosis has been named discussions need to continue to build upon the young person's understanding of HIV and sexual health.
9. There should be a multidisciplinary health team approach to talking to children with HIV about their health which happens in partnership with the carer. If centres not previous experience around disclosure or have access to a multidisciplinary team, specialist advice could be sought through the CHIVA networks.
<http://www.chiva.org.uk/networks>
10. Centres should hold multidisciplinary team meetings where the child's level of understanding of their illness and the plan of disclosure is discussed. These may be separate meetings or take place prior to or during clinic.
11. 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.
12. All parents/carers should be offered support and advice around conversations which help the child's understanding about health and HIV.
13. All children and young people should be given information about their health and HIV appropriate to their maturity and level of understanding
14. Adequate information and resources should be available for healthcare professionals around talking to children about their health and HIV (<http://www.chiva.org.uk>).
15. Separate guidance needs to be developed to support the sharing of parental HIV diagnosis

16. Health care professionals should be aware of legal and ethical issues surrounding wider disclosure of a child's HIV diagnosis to other health, education and community services and, for older children and adolescents around disclosure to sexual partners.

Section A. Knowledge Timeline

The following diagram provides a visual summary of the overall process of explaining an HIV diagnosis to a child using a birth to young adulthood timeline. The emphasis is building on meaningful and developmentally appropriate conversations over time which enhances the child's coping and involvement in their health care.

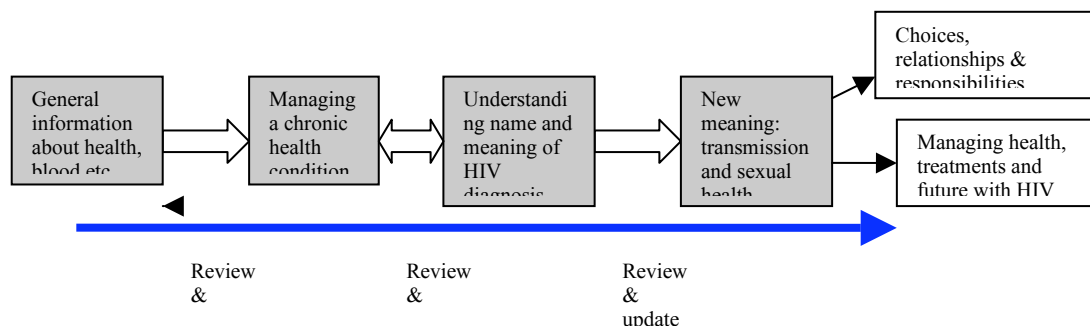
Early years

Primary school years

Older childhood

Adolescence

+ young adulthood



Moderators:

maturity experiences support

It has been found to be most useful to start health conversations at a young age and gradually build up knowledge (in truthful parts) over time. Sometimes it may not be possible to start these conversations early but even in these situations time should be made to review the links with health. Throughout there is a need to consider the individual needs of the child (in terms of maturity and wellbeing) but also aspects of the experiences and beliefs of the parent and family (including their cultural and spiritual beliefs as well as those

to do with health and HIV). The support of parents and carers is as essential to the child as is giving the right information at the right time.

Naming HIV can be the most stressful point on this process for parents, so their involvement throughout early conversations can help build their own confidence and give important messages to the child. Sometimes providing separate opportunities for them to discuss their own views and fears can enhance progress too.

Whilst there is not a 'right' time to name the diagnosis for all children, this guidance uses available evidence and feedback (see Appendices) which indicates that getting past the HIV naming before transfer to secondary school is best for most children in the UK. This allows time for adjustment before the many new demands of adolescence including the new emphasis on transmission as well as on a chronic life threatening health condition.

Section B. General Principles

The following expands on some of the main considerations when supporting children's knowledge and understanding along the knowledge timeline.

Children are individuals.

Each child is different and their personal circumstances and experiences will vary as well as their resilience and coping styles. **Any stated ages or age ranges act only as a general guide.** The primary school years generally have been found to be an important time to establish the foundations of health knowledge. This fits with knowledge about children's cognitive development. (See Appendix 5)

Partnership & Involvement of parents or carers.

A partnership with parents or carers is best way of supporting a child to move confidently along the knowledge timeline. Children's main source of emotional support usually comes from their parent or carer so it is essential

that they are involved and included in conversations about health and diagnosis. Starting a conversation about HIV with their child can be emotionally overwhelming for many parents and their own experiences of HIV can often be quite different from that of the child and compounded by worries about how to talk about their own diagnosis. Working with a trusted and informed health professional can help both initiate conversations and provide wider expertise knowledge about paediatric HIV. The parent/carer will be much more relaxed/confident if they know what is going to happen so plan ahead with parent. This professional may also be able to share experiences about how other children (and other carers) have coped with talking about HIV and also help guide the family towards extra support if that is needed. (See Appendix 3)

Remembering how children cope

- Children often know more than adults think they do.

- Younger children take their lead from adults – so if the adult is confident about something being the right thing to do they will feel confident too.

- Open discussion can protect children so they can make sense of what is happening.

- Communication is key and two-way: children need to be listened to as well as talked to and given chances to share their concerns.

- Not too much new information at a time, better to repeat than overwhelm.

- Children can keep confidences if it is explained how to do this and who they can as well as cannot talk to.

- Children have a wide range of feelings. They may show feelings in different ways to adults and may be better at recovering from upset and not brooding over events as adults do.
- Getting back to doing normal things helps children.

Culture and diversity

Families come from diverse backgrounds and may have different expectations and beliefs about children especially about they can cope with and how much they should be involved in conversations and decisions. However most parents and carers, from whatever background, would also agree that the role of parent is to protect children and support their progress. The process of talking to children about their health and diagnosis fits in with what has been found from a whole range of countries and cultures – that it is generally protective for children and they cope better when they know what is happening to them. Explaining the importance to the child of their parent/carer’s involvement and support in sharing information further enhances the confidence and trust children feel.

Continuity of Input

Where possible the same person(s) should take forward health conversations, especially those that lead up to naming HIV with the child (**Disclosure keyworker**). The regular clinic or specialist nurse in the service, who has an established and trusted relationship with the family, may be in the best position to take the lead on keeping these conversations going (this may happen outside of medical appointments) and provide a link to wider support services. The doctor may be best placed to review knowledge and may have a core role in confirming the diagnosis.

Talking & Understanding: recording and updating conversations

Recording conversations that have been had with a child, especially those leading up to the naming of the diagnosis, can prevent accidental or unplanned disclosure from occurring. Continuing conversations after HIV has

been named is essential, particularly as a child/young person or their carer may not take in all information at one time. **Remember that talking aloud does not always mean understanding has occurred.** Recalling previously presented information is a normal way to check understanding. After naming it helps to continue to use the words 'HIV' rather than 'the virus' in confidential conversations with the child and parent. At the beginning the clinic may be the only place that the child will hear the diagnosis spoken aloud and it will help confidence building and may de-stigmatise the word for the child. Not mentioning 'HIV' can perpetuate ideas that this is a bad or shameful word and should never be spoken about

Naming

There is a general consensus that by the **end of primary school** a child should have been told they have HIV. This gives time for building an understanding about HIV as a chronic health condition before having to deal with new concerns about sexual health and transmission. Starting as early as possible and being mindful of future needs can help avoid the rush to cover all knowledge about HIV in a short period of time. It is important not to underestimate the emotions that maybe generated by talking openly about HIV especially at the beginning and there needs to be time to process the feelings as well as the words. Avoiding giving too much information at one time helps. It is usually possible to provide more times to talk and review. It can take a while for the child to feel confident either to ask questions or to say the words out loud. Offering a chance to review with the nurse, psychologist or other member of the multidisciplinary team soon after learning the name of the diagnosis can be particularly helpful way of clarifying whether any misunderstandings or worries have arisen. The next routine clinic appointment may be too far in the future for this to be left.

Personal or Private Information

Talking about HIV as a 'secret' can reinforce associations about blame and shame that can surround attitudes to HIV. It may also set the scene that telling others involves 'keeping secrets'. **Explaining that health**

conversations are ‘private or personal’ (or even ‘family business’) is a better way of promoting an understanding of confidential and different conversations can happen in different places. So discussing health and HIV at the clinic or hospital is more appropriate than with friends or teachers. It also helps to set the scene for older children that this is *their* information. When being told the HIV name it helps to remind children and their carers who they can talk about the HIV with as well as who doesn’t need to know.

Talking about HIV at home

Practice has shown that many children do not talk much about HIV at home (especially in the initial time after learning the name). This shouldn’t always be considered as denial. It may be that neither the child nor parent feels safe or comfortable in doing so. Often the child and/or parent want to return to their ordinary lives outside hospital visits and this can be a good coping strategy. There are other conversations which the child and carer can have before or after clinic visits e.g. Helping children to ask the doctor or nurse questions at the next appointment.

Sharing a parental diagnosis (See Appendix 6)

One main worry of parents is how the child will respond when they learn that their HIV was passed from their mother and will the child blame or feel differently about them when they are told. It can help to have conversations explaining that when their child was born there were less effective ways of preventing or reducing transmission as are available now. For some children, the impact of knowing the parent’s diagnosis can be reduced by a discussion before naming, which confirms that the mother also has a health condition.

Feelings and Responses

There is no right way to feel or respond after being told important and sensitive information, especially about a diagnosis that is life-long and life-threatening as well as stigmatising. Often children and young people will

have a whole mixture of feelings (sadness, anger, bewilderment etc.). Often when first hearing the name HIV, even with good preparation and support, there can be a sense of shock or disbelief. Sometimes this can lead to open upset sometimes to silence. However clinical experience has shown that it is rare for these initial feelings to become overwhelming and as understanding grows so does confidence and coping. Occasionally there may be more overt negative expressions. Being alert to those children or carers who are struggling with managing difficult feelings or how to express them is part of the review and follow up and sometimes may need referral to psychology etc. Identifying that there are other sources of help in the voluntary sector where the child or parent can meet others and do not feel they are alone in having to manage these.

Positive Information for the Future

Giving positive measures for the future about survival of children born with HIV may help with adjustment.

Informing them that HIV is treatable, although not curable yet.

That it is possible to have babies of their own and that with appropriate management, those children should be negative.

Giving examples of what other young people with HIV are doing or have achieved can be encouraging.

Explaining that there is very little that HIV stops them doing, so planning for the future is important!

Section C. Explanations Grid

The attached grid or table offers ideas for topics for conversations with children and cares at different times along the knowledge timeline through paediatric and into adolescent HIV care.

These conversations aim to gradually increase knowledge about health and treatments so that the HIV diagnosis is associated with messages about health and keeping well. Conversations about managing a chronic health

condition can be added to with more specific ideas about transmission and sexual health.

Using the Grid

1. The grid is organised into the main developmental stages (preschool, primary school age, early and later adolescence) and gives examples for children with HIV infection living in stable and supported situations.
2. The developmental sections in the grid are colour coded, and this coding follows on in section E where more detailed examples and explanations are provided.(See Section E).
3. In each age section the topics are generally organised in developmental ranges and it is expected that new topics are introduced gradually over time and several sessions. It may take several years to cover all the topic items and it is not helpful to overwhelm a child by covering too much in any one session. For example conversations around the name of the diagnosis generally come towards the end of the primary school section; although they occasionally happen earlier. It is important to update and review earlier knowledge as meaning and understanding will change with age.
4. It helps to record which topics have been covered, which need updating and what might be thought about for the next visit. It can also be helpful to record what the parent/carer might discuss outside clinic visits with the child.
5. Discussion with other colleagues before child's visit about who is going to take conversations forward or review knowledge is also a helpful way of reducing chances of accidental sharing of information (See Appendix 1) or that the child is bombarded with too many people covering the same topic.

Age Range	Topics	Range of Conversations with child/young person	Discussion with care giver
4-7 years	Checking Health <i>'Why I go to clinic?'</i>	What happens at a clinic visit How health is checked The blood test as part of health check Medicines as helpers Keeping baddies asleep See Section E : p20-21	<ul style="list-style-type: none"> Set out reasons why health conversations help child
Primary school age 6-11 years	Keeping well : Health & Medicines <i>'I have something wrong with my health which may need support from medicines'</i>	How to measure health Blood test as part of measuring health Role of different blood cells White cells/ health defenders/ CD4's Germs and viruses Immune system How medicines support health & immune system How medicines fit in with life & routines Health as private/personal information See Section E : p22-23 & Appendix 4A	<ul style="list-style-type: none"> Review plan and provide opportunities for discussions Update carer knowledge of paediatric HIV Talk about how children cope. Ideas to keep information 'safe' Separate discussion with carers without child about their own concerns and how to answer children's queries Supporting child's reactions
9-12 years	Open talking about HIV <i>'The virus I have is called HIV'</i> <i>Naming should clarify: HIV stands for Human Immunodeficiency Virus HIV is a lifelong health condition that can be managed Who needs to know and who doesn't Other people often have misunderstandings of HIV – this is not child's fault Source of child's HIV</i> See Section E : p24-25 & Appendix 4B <ul style="list-style-type: none"> Preparation for open naming conversation How to increase understanding Support for talking about parental diagnosis (see Appendix 6)

Age Range	Topics	Range of Conversations with child/young person	Discussion with care giver
<p>Older child and young adolescent</p> <p>10-14 yrs</p>	<p>HIV as a chronic health condition <i>'This virus can't be removed but it can be managed so it can't damage my health.'</i></p>	<p>Growing up with HIV Who else has HIV in family Living with a lifelong virus and managing health CD4 and viral load measurements How medicines work and managing them Life expectancy and addressing fears of death.</p> <p>Routes of transmission Source of child's infection</p> <p>Sexual development Introducing sexual health issues</p> <p>Starting the transition process</p> <p>See Section E: p 26-27</p>	<p>Discussion with care giver</p> <ul style="list-style-type: none"> • Support for conversations about transmission and parental diagnosis • Reviewing wider disclosure – who needs to know, who has a right to know. • Discuss ideas about managing youngsters concerns and queries outside clinic visit. • Discussion with carer and youngster about general changes in adolescence – physical, emotional and social

Age Range	Topics	Range of Conversations with child/young person	Discussion with care giver
<p>Older adolescent 13 -17 years</p>	<p>Managing HIV & Sexual Health <i>'This virus can affect me and could be transmitted to others but I can stop it from taking over my life'</i></p>	<p>General</p> <ul style="list-style-type: none"> • Staying well with HIV • Managing medicines to fit into life • Information on how HIV is spread from person to person, including mother-to-baby transmission • Role of alcohol and recreational drugs & medicines • Peer support options <p>Sexual Health:</p> <ul style="list-style-type: none"> • How to have and negotiate safer sex • Contraception • Post sexual exposure prophylaxis, emergency contraception • Responsibilities • Wider Disclosure to others: • Negotiating relationships, who do they want to tell <p>Adherence and independence</p> <ul style="list-style-type: none"> • Update information on medicines, adherence and resistance • Control & Motivation for medicine taking <p>Transition and transfer of health care</p> <ul style="list-style-type: none"> • Increasing independence around appointments, choices, medications. <p>See Section E: p30-31</p>	<ul style="list-style-type: none"> • Young person starts to take more of lead on what information they want to be shared with parent/carer especially over sexual health • Support ways in which an agreement can be found between young person and their carer about how to keep carer informed of health

Section D.

Interventions to help support explanations to children in circumstances where discussions are difficult.

Most children and their families are resourceful and cope well with learning about their health and diagnosis. However there are some circumstances or concerns that may result in delays or slowing of progress in a child's knowledge.

The following table highlights some of the common situations where personal or contextual influences may interfere with progress along the knowledge timeline, especially around the timing of naming of the diagnosis.

Concern	Possible Interventions
Refusal/Avoidance of parent/carer	<p>Explore concerns further. Here are some common concerns which usually require more discussions with parents or carers.</p> <ul style="list-style-type: none">• Differing beliefs. Challenging personal beliefs is usually unhelpful.(provided that it is not about child protection) Providing a new perspectives on how health care can work alongside existing beliefs is more helpful e.g. For a parent with a strong religious belief it can help to talk about how medicines can support prayer and how they work together etc.▪ Child won't cope. Provide wider information about what has been found (from wider situations as well as in HIV) about children's' resilience and coping. Also emphasise how well child has managed earlier explanations. It is always possible to extend truthful partial explanations even if moving to open talk of HIV is delayed.▪ Review changing outcomes in paediatric HIV with more optimistic futures for children now

	<p>and what has been learnt about how to keep information safe and confidential.</p> <ul style="list-style-type: none"> ▪ Identify who and how parents can have more conversations about their concerns. ▪ Extra difficulties when late diagnosis. Teenagers are more likely to react with anger and distress and can feel betrayed or that their parent has not trusted them or kept them in the dark about their own bodies etc than younger primary school age children (See Appendix 5)
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<p>Concerns about wider disclosure</p>	<ul style="list-style-type: none"> • Identify clearly with child and parent who knows but also who doesn't need to know (reminders about there being no legal obligation to tell schools can be useful etc.) Children can keep rules and keep information safe if they know clearly who they can talk with as well as who they don't need to. • Review and give examples of what is meant by 'private or personal information' • Separate wider disclosure to others from the child's need for an explanation • Remind carer/child about confidentiality procedures in services • Also reassure parents that the majority of children do not disclose their diagnosis to others but keep the information to themselves and their families
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<p>Concerns about child knowing parental diagnosis</p>	<p>Discuss with parent before naming how to respond to the child's questions such as 'where did I get HIV from' or 'who else has HIV?' These are common questions after a child learns their own diagnosis. Reassure parents that the evidence shows how discussion usually brings closeness between child and parent.</p> <p>Consider how parents can feel guilt or blame about their child's HIV diagnosis and where and who might be able to provide further opportunities for them to express this. Explain that there was less knowledge and interventions available which could have prevented the child being infected. Sometimes it can help if the child is already aware that they share the same condition as their mother before naming of HIV occurs. (See Appendix 6.)</p>
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<p>Little support for child in family</p>	<p>Identify who else in family/ personal networks who might be supporter or mentor. Access to a local support group where other children with HIV attend can also be helpful. Some young people are ready for this straight away but for others want to wait so this needs revisiting later.</p>
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<p>Death of Parent/carer</p>	<p>If a recent death of a parent or family member has occurred priority needs to be given to supporting the child's understanding of the death (bereavement and adjustment can be helped by memory work). Continue with explanations when child feels more secure. Any new carer may need their knowledge about HIV updated.</p>
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Learning difficulty	If the child has any difficulties with learning, it helps to break new information into small steps and give more opportunities for repetition, especially of earlier conversations. It should still be possible to support naming even if it happens at slightly older age. The emphasis needs to be on who will help support the knowledge. Also other conversations e.g. independence, keeping safe need to be attended to.
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Recent severe illness of child or carer	Take a pause in new conversations until recovery from an acute illness has happened. Review existing knowledge before proceeding with new information. It can help to reflect back after an illness about how health is vulnerable and needs to be supported by medicines etc.
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Newly diagnosed older child (or new arrival at the service or in the country)	Give time for adjustment to any significant changes especially those which involve loss. It can help to start with explanations aimed at a younger child. Naming should not be prime emphasis in the initial engagement. Most important is to discuss with parent or carer about UK care and outcomes for children with HIV being quite different to what they experienced in previous culture or country. Explain that in the UK it is generally found to be beneficial and protective for the child to be involved and included in discussions about their health and diagnosis. Some may need referring for some extra support to help adjustment.
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<p>Depression or anxiety of child/young person</p>	<p>Help identify ways the individual child expresses feelings and give the OK to having wide range of feelings (as long as they don't hurt themselves or others).</p> <p>Expressing feelings can help adjustment and coping.</p> <p>Recognising there are many causes of emotional upset (trauma, loss, adjustment, bereavement etc).also helps.</p> <p>There is no evidence that supported naming results in excessive or long term emotional trauma. If there are concerns about the emotional/ mental health of a child/young person this may need referral to outside agencies e.g. CAMHS. Explanations and naming HIV are still probably best done within HIV health setting (with consultation with other agency).</p>
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<p>Mental illness of main carer</p>	<p>Identify if there is another 'knowledge 'supporter or adult in family, social care network etc who can be available over time for child as their partner in process of understanding.</p>
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<p>Other circumstances</p>	<p>Situations such as the child being a carer, a history of family conflict or violence or child protection concerns for example, will impact on the vulnerability of the child.</p> <p>There may need to be extra sources of support. The healthcare providers would still have the lead role in helping the young person to learn about their diagnosis.</p> <p>There will need to be good communication within wider multidisciplinary teams.</p>
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Section E: Detailed explanations and resources to help support conversations

4 -7 years old

At this young age the child will need conversations based on the here and now. Knowledge needs to be related to their present experiences. Pictorial material and hospital play equipment helps explain stories about clinic visits, keeping well and managing blood tests.

These are conversations which will usually be initiated in clinic with parent/carer and child together. Ideas can be continued at home about health and keeping well and how health is measured. It can give confidence to carer about 'safe' topics to talk about with the child at home. This is a time too for health professionals to gain an understanding about who else in the home can support the carer and child's knowledge.

What happens in the clinic?

One of the main messages is to begin their understanding of health and about keeping well and growing. How the visit to clinic is a way of checking health and how blood taking is part of health check.

Other conversations

Some children need extra preparation for procedures and how to manage anxiety/upset about blood tests. It helps to explain that the blood test is a way of checking health and not a punishment.

Messages about the role of medicines as 'health supporters'. It can help to make timetables for getting into routine and sticker charts for showing success.

Conversations with parents

At this stage parent or carer will be present with child for most of clinic visit and this enables them to see there are safe conversations to be had with child. It helps them too to see how children do make sense of their experiences and link what happens in clinic to checks on their health.

It helps to discuss with carer who else knows about HIV diagnosis at home as they may need someone to support them in caring for child's needs.

Also it helps to review confidentiality and how this operates both in clinic and in community services. It can help to explain to families the role of GP's as part of the 'health care' partnership.

Available resources:

General books on hospitals especially those with outpatient visits and blood taking e.g. 'Clinic visit'/'Sleeping bug' book helpful

Picture books on bodies and/or health.

e.g. 'How your body works' (Usborne), 'Your body' (Usborne Beginners)

Hospital play kits.

Drawing can be helpful way of child showing their experiences or worries.

6-11 years old

Conversations become more detailed about the body and particularly about blood and cells. What is body's defence system (white cells, CD4's, Immune system). How body and health can come under attack from germs and bugs and viruses. How can health be measured. During this time children may spend some time on their own in clinic looking at resources or chatting to nurse or psychologist. It is important to feedback to parent what has been talked about. This is time when there will be preparation and support for naming the diagnosis.

Keeping Healthy

Other influences on staying healthy – food, fun etc.

Measures of health e.g. growth & while cells etc.

How blood cells work

Blood as a transport system

What is in blood and the job of different cells?

White cells (CD4s) as health defenders- different kinds

CD4s as part of immune system

Germs, bacteria, viruses etc can affect health because they stop/attack the immune system/CD4s

Viruses as difficult baddies that won't go away and need to be managed

Why does health need to keep being checked - chronic health condition?

Medicines

Medicines as helpers and work with the immune system. Protect CD4's so can do their job.

How to keep ordinary daily routines with medicines

How to keep going with medicines

Feelings

Acknowledge its OK to have different feelings about different things. Find out how child shows their feelings.

Private and personal information

What is meant by private or personal?

What are different kinds of conversations you have with different people – homework with teacher etc.

Identifying who you can talk to about health.

Conversation with parent/carer

Up date knowledge about how it is different for children living with HIV to adults.

How to answer children's questions about health, and medicine taking at home

Planning ahead – better to have supported naming than child finding out by chance or accidentally. Share experiences from how other children have responded when told. Discuss what kinds of responses may happen and how to manage these.

Available resources

Blood sheets (CWAC)

Interactive workbook (available from CWAC 2009)

'The team'; Story of the immune system

'I know how we fight germs' Sam Science book

Cell wars' Harper Collins publisher

CD rom – Paediatric Infectious Diseases Team Brussels

DVD: Bristol Children's Hospital (available 2009)

Naming HIV or telling the child they have HIV

'What is HIV?', 'How did I get it?' 'Who gave it to me and how did they get it?'

In an ideal situation, the young person would have had an open conversation about the name of their HIV diagnosis by the time they start secondary school. (See Sections B and D for suggestions to help with progress with explanations).

Beginning the conversation about the name of the diagnosis often starts with reviewing what the young person already understands about their health condition. This can then be expanded upon with a discussion about what it is that is putting their health at risk and now it is important (and their carer agrees) that they understand the name of their health condition. Explaining what the initials HIV stand for can help.

Human Immunodeficiency Virus:

Human, that it is a condition that affects people's health.

Immunodeficiency means that it depletes the immune system which includes the CD4 cells ie makes it not work so well.

Virus is the kind of germ or bug. (See Appendix 4)

Try to give the young person as many positive messages as possible regarding their health at this point and build on what has been their experience. Usually possible to reassure them they are expected to live for a long time.

Discussing how HIV is spread and how it is **not** spread is helpful. Sometimes the conversation will lead to how to prevent transmission and safer sex but often these are issues that will be expanded upon over time. At this first session of naming, be aware that each individual young person will guide how much information is covered. Practice has shown that most young people may

take in little apart from the name. It is still important to give them some basic information but be aware that they may not hear or remember it.

The person talking with the young person should assess the emotional impact naming the HIV has on them and pace the conversations to give them chance to express their feelings. The young person may need time alone with health care worker. Issues around privacy and confidentiality need to be explained clearly to the young person so they know what will happen to any information they give. It helps too to reassure them that they and their health are the same as at the beginning of the conversation; they just have more information. Also it helps too to mention that their parent/carer wanted them to learn more about their condition.

It is good practice to arrange a follow up appointment soon after naming to address their concerns and review knowledge.

'It doesn't matter where you're told and who tells you – it doesn't change the information. You've still got HIV and you've still got to live with that.'

Older child/early adolescent 10-14 years

What it means to live with HIV

'Am I going to die?'

HIV is still associated with dying and this does need to be addressed with the young person. It can help to explain that although many children and adults do die from HIV in developing countries, this is usually because they do not have access to medicines or good health care. Reassure the young person by saying with treatment available now, most children and adults can live good quality lives and that we expect them to have a reasonably normal lifespan. Explaining that HIV is a chronic health condition is important, that it won't go away but can be well controlled by medication. It may be helpful to give examples of other chronic health conditions for which requires on going medications.

'Is it curable?' 'What does it do to me?' 'What's gonna happen from here?'

Conversations are around living with a lifelong virus and staying healthy. The young person needs to be given time and space to express their feelings or fears about having HIV. The worker can promote optimism about the future and encourage the young person to plan for the future. It may be helpful to give examples of what other young people or adults who have grown up with HIV have done, such as exams, college, university, work, sport, drama, have girlfriends or boyfriends. Meeting other young people or having email or telephone contact may be helpful.

Reviewing information remains essential and the same messages may need to be explained many times and what HIV means to them will change as they mature and develop. For example, when the young person comes to clinic, discussing how their blood results are and what they mean eg the CD4 count

measures the strength of your immune system and the viral load measures how much virus is in your blood (See Appendix 4.)

HIV is personal information

'Why can't I tell everyone?'

Explain that other people may not understand enough or are ignorant about HIV and may be worried or have false beliefs about it. This may lead to others misunderstanding or mistreating the young person if they are told about the diagnosis. The young person needs to know that this ignorance and misunderstanding of others is not child's fault but that by helping to keep the information private helps to protect them from the risk of discrimination. In time, as the young person grows up they will gradually make their own decisions about who they would like to tell but and that they can have support and help in talking this through.

As well suggesting caution in telling others it helps if the young person is told who they can talk to openly. It may be hard to contain the information without this. Some people will already know the young person has HIV and maybe the young person can talk to some of these. Contact with other people through peer support groups can be useful especially if there is no one in their personal support networks.

'How did I get it?' 'Who gave it to me and how did they get it?'

Telling the young person who else in family has HIV often happens around this time too. Parents, in particular mothers, are often most anxious about this and how the young person will cope with learning their diagnosis (See Appendix 3). An open conversation between the young person and their carers, with the support of a trusted health professional, can help reduce anxiety. Clinical practice shows that if handled well, the carers feel relieved and there may be a closer connection established between them.

Living with medicines

Talking more in depth about CD4 counts, viral loads and how the medicines work, can help the young person to get a better understanding of the importance of good adherence and how resistance to medications develops. Motivational work with the young person may help them to take more responsibility.

Assist the young person in managing medicines and planning how medicines can fit into their life. Help them to plan how to manage medicines if they are staying away from home or having friends to stay.

Sexual Health

When talking to a young person about sex and sexual health you want to set an environment where you both the worker and the young person feel comfortable and conversations can be confidential. Consideration needs to be given to the age and maturity of the child and which aspects should be covered with the carer present.

It helps to remember that most parents are not comfortable in talking to their child about sexual health. However in HIV this subject cannot be ignored so it is the responsibility of the health care workers to take the initiative but to include and involving parents/carers.

The young person may need information about puberty and the normal physiological changes they will go through before launching in to sexual health and sexually transmission and infections. Bear in mind that many of the young people may have delayed puberty and may be concerned about this. Different discussions will happen at different ages. In early adolescence an 'educational talk' is easier for the young person as they may get embarrassed at this age. Starting the conversation with 'you probably know this, but I'm going to run through it...' Approaching the conversation as this is what all young people need to know about sexual health, use of condoms and negotiating relationships.

Even though it may not feel relevant to them at this stage many young people want to know if they can have children in the future so fertility and conception issues should be addressed but will need to be revisited and expanded upon later. It is important for them to know, that with interventions, the baby should be negative.

Available resources

One to one conversations with the young person

Information leaflets on HIV, CD4 and viral load

Information leaflets on medication, adherence and resistance

DVD: Bristol Children's Hospital (available 2009)

CD -Rom – Brussels

HIV Treatment Sketchpad - Unite

Leaflets on puberty and sexual health

'Adolescents and Sex' Book by Sarah Bekaert – general sexual health for adolescents

Condom demonstrations. Sometimes this can be done by adult colleagues depending on the services available and for others the young person may feel more comfortable to talk to someone they know.

Support groups

Peer support

Websites

Related topics: Transition

The transition process should be introduced and the options for the young person discussed.

Promoting positive self-esteem and emphasising what they can do. (See CHIVA Transition document for more details on transition).

Later adolescence 13-17 years

Discussions about what HIV is and how it can be managed need to continue and be updated as young people get older and demands and awareness change. Often it will be necessary to review information that has been explained before.

Staying well

Empowering the young person to take more responsibility for their own health is a key task of this time. This can help them feel in control and foster independence and self-esteem. Facilitate and support the young person in becoming more independent for example booking their appointments, requesting more medication and in dealing directly with the healthcare practitioners. Becoming more autonomous in decisions and self-care activities is good preparation for future engagement with adult services. Meeting future adult health workers is important too. Some units have dedicated adolescent HIV clinics which are staffed jointly by paediatric and adult workers. In some units the numbers of adolescents are too small and arranging a visit to the adult GUM clinic may be beneficial.

Bear in mind that relationships both within and outside the family are changing at this time and often peers become more important. Being aware of what resources are available locally or via the web. Various organisations are developing their websites and there will be more opportunities for peer contact.

Adherence may deteriorate during adolescence so reviewing how to fit medicine taking into their life, anticipating any obstacles to adherence and suggesting how these can be overcome. Encourage openness about missing any medicines and involve the young person in any new regimen or changes to their medication. Discuss issues around alcohol and recreational drugs and how this may affect their medication, adherence and risk taking behaviours.

As a young person progresses through adolescence and is becoming increasingly independent, there should be more opportunities to talk to them alone about such issues.

Talking to the young person about sex and sexual health

Young people may not want to talk about relationships, sex and contraception every time they come to clinic, but at the same time, the safer sex message is important, and checking they not only understand it, but supporting them in feeling comfortable about it, are essential.

During this time it is also necessary to explore more of the emotional impact having HIV has when considering intimate and sexual relationships. The young people need to feel confident that they know how to have safer sex and to develop skills to be able to negotiate this.

Explain safer sex and condom use including condom demonstrations. A way to lead into conversations about safer sex is to start with talking about risks of different activities: kissing (no risk), oral sex (low risk), and unprotected sex (high risk). Getting the young person to think about scenarios and what they would do (what if.....?). Explain the importance of condom use in protecting them from pregnancy and sexually transmitted infections. What to do if it goes wrong – Post sexual exposure prophylaxis (PEPSE) and emergency contraception and where to go to access these. By alerting their partner that they need PEPSE, they are disclosing their HIV status.

When talking about safer sex, PEPSE and HIV disclosure to sexual partners, young people have reported that it is easier to tell someone their HIV status if they have always used a condom with them. Then the young person can say, 'we've always been safe'. If it has been previously unprotected sex, disclosure becomes more difficult.

The young person may need more information about having children in the future and information on sperm washing or artificial insemination and

prevention of mother to child transmission. There are now some young women who have vertically acquired HIV who are having their own uninfected babies.

Preventing Transmission of HIV to Others

The young person needs information and guidance on how they can have sexual relationships whilst taking responsibility for protecting their partner. It is generally agreed that all young people should be using condoms so they are just doing what all young people should be.

Helping them too understand that this is a serious responsibility and under current law, a person can be prosecuted for knowingly transmitting HIV to a sexual partner (when that partner is unaware of the person's HIV status). This issue does need to be raised with young people, but what is essential is to not make it scary. It is not the remit of the document to go into great detail on this but further information can be found at [HYPNET \(www.hypnet.org.uk\)](http://www.hypnet.org.uk).

In an ideal world, disclosing your HIV status is best and makes for a deeper and more truthful relationship – but it's not necessarily realistic and therefore condom use in the key.

Some young people may feel they can never have sex, as it's just all too difficult. Exploring this in a non-judgemental way may help the young person to feel more comfortable and realise this decision may change.

Talking to others about HIV

"I'm sick of all the secrets, sometimes I just want to tell everyone and get it out in the open."

Young people need to be able to explore telling friends, partners or siblings about their HIV. Helping them to decide what is best for them requires giving them space and time to explore the issues. Reflecting on 'why this person?', 'why now?' 'What might be the consequences?' etc.

“...like the websites for how to make best man speeches, I wish there could be one for how to tell people about HIV”

The young person may benefit from practising telling others in a safe environment either at clinic or in a HIV support group.

Transition process and future plans

Transfer to adult services generally happens between 16-18 years of age. Adult services are very different from paediatric services and the young person should have preparation for this and time to adjust. This process is called transition. (See CHIVA transition guidelines www.chiva.org.uk)

Available resources

CHIVA transition document

PEPSE leaflets

Sexual health leaflets

Adult sexual health workers

Family planning advice and leaflets

Report on residential weekend(See Appendix 2)

Conversations with parents

Some parents can tend to overprotect their children and they may need support in allowing the young person more freedom and autonomy. Giving carers ideas on how they can try to have conversations with their child about growing up with HIV and how they are coping. Also giving the parents ideas of the types of conversations that will be held with the young person, may help them to feel more comfortable. The young person starts to take more of a lead on what information can be shared with carers. Carers may need support through the process of transitioning the young person to adult care.

Section F: Further Reading - Resources

How your body works (Usborne 1995) J. Hindley and C. King

Your body (Usborne Beginners) S Turnbull and A Larkum

I Know How We Fight Germs (Sam's Science Series) 2000, K Rowan. Walker Books

"My visit to clinic" adapted by Y.Heath from original work by T.Clegg and M Sinclair. Sponsored by Octapharma.

"Meet the Team" written by The Paediatric HIV Team at Heartlands adapted from original work by H.Joyce.Sponsored by Roche
Copies of both books can be obtained from
yvonne.heath@heartofengland.nhs.uk

The Immune System (2004) Carol Ballard. Heinemann Library

Cell wars (1993) F Balkwill and M Rolph
Harper Collins publisher, First Avenue Editions

Germ Zappers (2002) F Balkwill and M Rolph
Cold Spring Harbor Laboratory Press

Worksheets – Your Body, Your Blood (Children with AIDS Charity
www.cwac.org)

Miah and Melvin : Interactive workbook for school age children : Supporting understanding of health and diagnosis. Available CWAC 2009

Our Immune System, a story for children. Sara LeBien. Immune Deficiency Foundation
http://www.primaryimmune.org/publications/book_immunesys/OurImmuneSystemFINAL_05_05_2008.pdf

CD Rom – Support the CD4's Paediatric Infectious Diseases Team, Hopital St-Pierre Complex, Rue Haute 322, 1000 Brussels, Belgium

HIV Interactive DVD - Link: Bristol Children's Hospital (available 2009) The Giggle Group

Post Exposure Prophylaxis (PEP) leaflets. Terrence Higgins Trust
www.tht.org.uk

Talking with Children, Young People and Families about Chronic Illness and Living with HIV
<http://www.chiva.org.uk/publications/PDF/2007/Talkingwithchildren.pdf>

Talking to children with HIV about their illness

<http://www.chiva.org.uk/publications/PDF/2006/talking-about-illness.pdf>

Guidance on transition and long term follow up services for adolescents with HIV infection acquired in infancy

<http://www.chiva.org.uk/publications/transition.html>

Growing Up, Gaining Independence Principles for Transition of HIV Care

<http://www.chiva.org.uk/protocols/adolescence.html>

Talking with Children About illness and HIV Children With AIDS Charity

www.cwac.org

Report on residential weekend with Young People with HIV

www.ncb.org.uk/hiv

Voices of Young People Children With AIDS Charity www.cwac.org

Personal stories of young people living with

HIV <http://www.avert.org/ypstory.htm>

Further reading - Articles

American Academy of Pediatrics Committee on Pediatrics AIDS. Disclosure of illness status to children and adolescents with HIV infection. *Pediatrics*. 1999 Jan;103(1):164–166.

Armistead, Tannenbaum, Forehand, Morse & Morse: Disclosing HIV status: Are mothers telling their children? *J. Pediatric Psychology* 26 (1) 11-20. 2001

Clafin & Barbarin. Does telling less protect more? Relationships among age, information disclosure and what children with cancer see and feel. *J. Ped. Psychology* 16 169-191. 1991

Funck- Bretano, Costagliola, Seibel, Straub ,Tardieu & Blanche : Patterns of disclosure and perceptions of the human immunodeficiency virus in infected elementary school-aged children. *Archives Pediatric & Adolescent Medicine* 151 978-85. 1997

Lesch, Swartz, Kagee, Moodley, Kafaar, Myer & Cotton: Paediatric HIV/AIDS disclosure: towards a developmental and process-oriented approach. *AIDS Care* 2007 19(6) 811-816

Lester, P; Chesney, M; Cooke, M, et al. Diagnostic disclosure to HIV-Infected children: How parents decide when and what to tell. *Clinical Child Psychology and Psychiatry*. 2002;7(1):85–99.

Mellins, CA; Brackis-Cott, E; Dolezal, C, et al. Patterns of HIV Status Disclosure to Perinatally HIV-Infected Children and Subsequent Mental Health Outcomes. *Clinical Child Psychology and Psychiatry*. 2002;7(1):101–114.

Melvin, D. Psychological Issues, challenges and achievements. *Journal of HIV Therapy*. 1999;4(3):77–81.

Rushforth: Practitioner Review : Communicating with hospitalised children: Review and application of research pertaining to children's understanding of health and illness. *J. Child Psychol & Psychiat*. Vol 40 5683-691 . 1999

Sherman, BF; Bonanno, GA; Wiener, LS; Battles, HB. When Children Tell Their Friends They Have AIDS: Possible Consequences for Psychological Well-Being and Disease Progression. *Psychosomatic Medicine*. 2000;62:238–247.

Waugh, S. Parental views on disclosure of diagnosis to their HIV-positive children. *AIDS Care*. 2003;15:169–176

Wiener, L; Lyons, M. HIV Disclosure: Who Knows? Who needs to know? Clinical and Ethical Considerations. In: Lyons M, D'Angelo LJ. , editors. Teenagers, HIV and AIDS. Westport, CT: Praeger Press; 2006.

Weiner L, Mellins CA, Marhefka S et al Disclosure of an HIV diagnosis to children: History, Current Research and Future Directions. *J Dev Behav Pediatr*. 2007 April; 28(2):155-166

Wiener, L; Battles, H. Untangling the Web: A Close Look at Diagnosis Disclosure among HIV-infected Adolescents. *Journal of Adolescent Health*. in press.

Wiener, L. Helping a parents with HIV tell his or her children. In: Aronstein DM, Thompson BJ. eds. HIV and Social Work: a Practitioner's Guide. Binghamton, NY: Haworth Press; 1998 327–338.

Young, Dixon-Woods, Windridge & Heney : Managing Communication with young people who have a potentially life threatening chronic illness: qualitative study of patients and parents. *BMJ* 326 305-310 2003

Appendix 1

Summary of the CHIVA Auditⁱ of practice of disclosure of an HIV diagnosis to children

During the summer of 2007, CHIVA undertook a audit on disclosure of diagnosis to children. This involved a semi-structured survey of centres caring for children with HIV in the United Kingdom and Ireland and a notes audit in order to assess current practice around disclosure. 33/52 centres responded (63%) and 133 sets of notes were reviewed. This audit offers an insight into current practice and what can be learnt from that.

91 (68%) of the young people 10 years and over had been told that they had HIV. The median age of open discussion of HIV was 12 years (range 10-15). 69 (76%) were planned disclosures and 15 (16%) unplanned or accidental. Most young people appeared to cope well with learning their diagnosis but need support by their family and multidisciplinary team during this period. Parental concerns were the most common reason for delays in the disclosure process and especially naming of the diagnosis. A multidisciplinary approach to disclosure works well but attention should be paid to preparing parents well in advance of the child

The CHIVA audit found that 26 (78%) respondents felt that problems occurred rarely or never following naming of HIV. However, although children seem to cope well, parental unwillingness to disclose was by far the most common reason for delays in the process of disclosure (60% of respondents). Parents frequently avoided allowing the child to have an open discussion about HIV or were concerned that either the child will disclose to others, or that the child will learn that their parents are also infected with HIV.

Table 2: The main factors cited in the delay of disclosure of an HIV diagnosis to children over 13 years old were :-

- Ill health of parent or child or adverse social circumstances

- Child felt to be socially immature or too young
- Child with learning difficulties
- Parental refusal to disclose
- Parental fear of child disclosing to others
- Fear of child learning parental diagnosis

Case Notes Audit

The audit asked the centres to review the medical notes of 20% of the children who were 10 years and over in their clinic. 133 sets of notes were reviewed from 33 centres. 79 (59%) were 13 or older. 68% were from London, which is representative of the spread of the children throughout the UK and Ireland.

91 (68%) of the children and young people 10 years and over had been told that they had HIV. The median age of naming or confirmation of the HIV diagnosis was 12.0 years (range 10-15, n = 89). 69 (76%) were planned or prepared disclosures and 15 (16%) unplanned. There were three accidental disclosures; two children read their diagnosis in their notes and one child had an accidental disclosure where the health professional thought the child already knew. Three further disclosures were unplanned but had been prompted by a direct question from the child. Half of the discussions took place in the clinic and 30% at home. It was most common for the disclosure to be done jointly with a parent and either the paediatric nurse specialist or paediatrician although some parents had felt comfortable enough to talk to their child themselves. Only 3 (3%) had documented difficulties in initial coping with their diagnosis, but it was not known how 27(29%) coped. New issues were raised in 7 (8%) cases but for the majority it appeared they had coped well with disclosure. It was common for children to receive specific support from a clinical psychologist 20 (22%), social work 20 (22%) or voluntary organisation or counsellor 18 (19%). 4 young people required referral to Child and Adolescent Mental Health services including one who developed an eating disorder following disclosure.

What the audit offers

Clinical teams were working in partnership with families in providing support to children and families around the complex issues of the child learning about their diagnosis.

The majority of children did have full naming of their HIV diagnosis by the age of 12 years, although it is clear that progress along the process is individualised. On the whole young people cope well with learning their diagnosis. This is a testament to the care and support provided by the family and multidisciplinary team.

The audit found that parental views and anxieties were cited as the main reason for delays in disclosure to children. Other psychosocial factors such as beliefs and experiences were also reported. It concluded that whilst children were carefully prepared for disclosure, it might be that attention needs also be paid to preparing the parents, well in advance of the child.

For a full copy of the audit, visit www.chiva.org.uk

Appendix 2.

Talking with young people about HIV: summary of findings from a weekend consultation (M.Conway)

During the summer of 2007, the Children & Young People HIV Network ran a residential for 25 HIV infected 13-18 year olds. The aim of the residential was to consult with this group about their experiences of finding out about their HIV diagnosis and then the information needs they had and have.

The age at which HIV was named varied between 'I've always known' to 16 years. 14 young people had been told between the ages of 11-13, 6 before this and 5 after. The general consensus of this group of young people was that 12 was the optimum age, and definitely no later.

They were generally told by a health professional (Nurse or Doctor) and a parent/carer. Some young people felt they would have like to have been told by a Doctor or Nurse as they saw this as medical information whereas others wanted to be told by a parent or carer as they saw it as something more personal/emotional. A few young people reported a 'support person' who they did not know being present. They were not happy with this and could not understand why a stranger was involved.

Again views varied to where the optimum place was to learn of their diagnosis, as some young people wanted 'safe' and familiar, such as the home, whereas others said somewhere neutral or somewhere they could leave.

These questions produced very powerful discussions where the young people shared their experiences with each other, and were surprised with each other's reactions. Some of the young people had 'an idea' that they had HIV before they were told:

'I'd caught a glance at my notes once, but didn't want to say anything'. This produced feelings of fear and anger.

In one group a young person made an overall comment about the conversation that offered an insightful perspective.

'It doesn't matter where you're told and who tells you – it doesn't change the information. You've still got HIV and you've still got to live with that.'

This underlines the reality for these young people, as this is the starting point of their journey and however well planned and executed this is, this is the beginning for the young people.

The group were asked about the questions they had asked or wanted to ask at different times during and after the naming of HIV.

The questions the YP asked or had wanted to ask were :-

- Mortality: *'Am I going to die?'*
- Who knew: *'How long have you known?', 'Why didn't you tell me sooner?', 'Who else knows?'*
- Transmission and what having HIV actually means: *'What is HIV?', 'How did I get it?' 'Who gave it to me and how did they get it?'*
- *'The first question was why me?'*
- Denial: *'When are we going to eat? Do we still get KFC?' or 'Can I play football now'*
- What this means for life now: *'Is it curable?' 'What does it do to me?' 'What's gonna happen from here?'*
- What does this mean for my future: *'Can I have children?' 'Will I ever find love from others?' 'Why can't I tell anyone?'*

- Medication, whether it is about continuing it, starting it and how long they would need to take it: *'What medicine will I have to take and for how long?'*

What is clear from the responses to these two questions is that a degree of detail is important, even if the young person does not ask. Full recognition needs to be given to the long-term impact this information subsequently has on that young person. Their ongoing need to ask questions and to have information reiterated to them is key.

Equipping and supporting parent/carers to continue offering an open dialogue outside of a medical setting is hugely important. Many young people reported that HIV was never spoken about at home, and they felt unable to raise it.

Finally we asked the young people what questions they had now. Of these questions, the responses mainly fell into 5 main categories:

- Confidentiality and employment, thinking about the future, about adult services as well as employment: *'How much confidentiality is there when you're older?'* *'What do you do when applying for jobs? What do you say?'*
- Disclosing to peers: *'Will I be accepted in my 'group' if I told my friends?'* *'When can I tell my friends? Are they trustworthy?'*
- There were many questions about sex and relationships, these were mainly about disclosure to sexual partners: *'How do I develop a relationship with my girlfriend? How do I tell her? Should I have one-night stands?'* *'At what point in a relationship do I disclose my status?'* Also there were questions about having children and whether they will be HIV positive, *'Will I be able to have a baby that won't have HIV!!'*

- A cure: *'Is there ever going to be a cure?'*
- Many wanted to know about life expectancy: *'What's my life expectancy?'* *'When do we get AIDS? And how old will we be?'* *'Do we all have full lives?'* *'Am I going to die?'*

Conclusion

It is clear from these findings that young people need to have space for questions, and these need to be on their terms, in that the space needs to be made but they will use it when they need it. Following on from this, information needs to be re-iterated as a 12 year olds understanding of a piece of information will differ from a 15 year olds. This group of children need positive re-enforcement about the future and about relationships. Many felt 'stuck' as they felt ill equipped to talk to anyone about their HIV status, and although not all felt a need to tell someone now, in the future they will need to.

Practitioners will not be surprised that many young people reported that they felt they could not speak to their parent/carers and that HIV was never mentioned at home. Engaging and supporting parents to communicate with their children can be extremely difficult, yet their importance in this process has to be acknowledged. Finally, there is the challenge of the child's needs outside of the parent's needs, and the fine line that has to be trodden.

To read a full copy of this report visit: www.ncb.org.uk/hiv

Appendix 3

Mothers views on talking to positive children about HIV

A discussion at Positively Women

The aim of the consultation at positively women was for mothers of positive children to reflect on their experiences of talking to their child about HIV and asking for their ideas about how health services can help.

'Show me how to do it. Help me do it'

Key Themes and suggestions for solutions

1. Theme: Guilt

Guilt was seen a huge influence in aspects of how mothers saw their relationship and parenting of a positive child (who has acquired HIV perinatally). Guilt was both pre and post naming and often added to the parent's anxiety about talking aloud about HIV with the child.

2. Theme: Peer Support

Having the opportunity to share experiences with other mothers with positive children was acknowledged as very helpful. There was agreement that there were different issues between parenting affected children and positive children. Also whilst in groups, mothers were open about their own HIV status but were not comfortable sharing the status of their child in a mixed group where all parents are positive, but not all children.

Suggestion: Talking to others who share this experience. Most agreed that the feeling of guilt would not go away, but being able to share it with others helped manage it. Sharing their experiences and feelings made them feel more confident and realising others felt the same can make it easier to bear.

3. Theme: Being supported by health to be involved in their child's care and knowledge

This group of women felt that they needed support in being an active party in meeting their child's knowledge and wider health care needs. They reported often feeling out of their depth. It is also very emotional for them, and they wanted a 'drip, drip' approach. *They wanted more support in talking to their child about different aspects of HIV, pre and post naming.*

3.1 Pre-naming 'I don't know where to start – I just don't know'

Some had already been through the process of naming, others had not. They all felt it was important that their child knew, but talked about how overwhelming it is to even think about it. One topic they feared was when the child asked 'how did I get it?' This links in with the guilt mentioned earlier.

Suggestion: (Support for continuing conversations)

Health professionals to give gradual pieces of information to help them talk to their children at home. This might help make the home an environment where HIV could be more easily discussed. Also advice and practice from health professional about how to answer questions e.g. on routes of transmission prior to naming, so that they did not worry about their child broaching this subject, and had practiced their reply.

3.2 Post-naming

Those that had been through naming agreed that they often felt very lost post naming, not knowing what or when to say anything. This was expressed too about new ways of supporting their child in adolescence.

3.3 Theme: Wider disclosure: Support the child in talking to others

'Disclosure is a very difficult issue; as adults we've been through a lot and lost family members and people we love because we've told them'

They acknowledged how difficult disclosure is and how many of them had experienced rejection and discrimination from telling others. There was a discussion about the dilemma of telling a child to not tell anyone, knowing that at some point in their lives they will need to tell others. They did not want their children to fear relationships and physical closeness nor get into trouble (i.e. reckless transmission). They wanted support to get the balance right.

Suggestion: *(Working in Partnership)*

Having prompts from health about how to raise topics after learning the name. For example getting feedback from doctor/nurse summarising which topics have been spoken about and how the parent can follow up on it at home. Sex education and HIV was discussed and whilst agreeing it was important, most mothers felt ill equipped to discuss this. A resource or information sheet might help to skill them up e.g. to talk about puberty and sex at different ages.

4. Ongoing worries

This group of parents worry tremendously about their positive children and recognise that they can over compensate and over protect. At the same time they reported that they felt ill-equipped to communicate with their positive child, and more support (peers and professionals) would make them feel less anxious. They worried that their child was feeling different compared to what the child said they were feeling. Mothers wanted to have a level of connection so that they can share their experiences of living with HIV

Suggestions:

- *a national event for positive parents, somewhere they could share their experiences and learn parenting and communication skills as well as acquiring up to date information about children and HIV.*
- *Separate events where their positive child could be present (maybe a national event where children, who know their*

diagnosis, can meet each other too and promote more open conversation and feedback to parents).

Conclusions

This session was brief, but the messages were very clear and are complementary to feedback from youngsters and from health workers. These mothers feel ill equipped and need support in talking to their children about living with HIV. They carry a lot of guilt, and this causes them much worry. They want information; to want to be an active partner but they need to be guided through the process. They also want opportunities to meet others who parent positive children and help in communicating about health with their children.

Appendix 4. Information sheets

A. Before naming: Information to cover

(Illness concepts in developmental steps, Sarah Waugh, Clinical Psychologist 2003)

What understands about their illness

1.	I go to the doctor / hospital / clinic
2.	I'm different from other children, because not everyone goes to the doctor / hospital / clinic
3.	There's something wrong with me
4.	I get lots of infections / chest problems etc.
5.	I have treatment for the illnesses
6.	I get the illnesses because there's something wrong with my blood
7.	The white cells in my blood don't fight off infections well enough
8.	I have to have treatment for what's wrong with my blood
9.	The 'something wrong' is a virus
10.	I'll always have the virus
11.have got the same thing
12.	The treatment for the virus should keep it in control, but it won't go away completely

B . After Naming: Information to cover with children and young people.

HIV – What Does It Mean?

HIV stands for **H**uman **I**mmunodeficiency **V**irus. It is a **virus** (germ) that gets into your body and blood and damages your immune system. Your immune system is your body's defence system and protects your body from attack by germs. The immune system is made up of several types of **white blood cells** – these help your body to fight off infections. HIV attacks a particular type of white blood cell known as a **CD4 cells** (sometimes called T-lymphocyte cells).

The HIV virus wants to grow in your body, but it can only do this by finding a home for itself. Our bodies are made up of millions of tiny cells and the HIV virus finds a home by attacking some of our healthy cells. Here it grows by making more and more copies of itself. The cells that the HIV attacks are the CD4 cells, which are the captain of the immune system.

When the CD4 cells are attacked by HIV, they become **infected**. Cells that are infected eventually die. Everyday lots of old cells die in our bodies and lots of new ones are born too. When a person first gets HIV their bodies make enough new CD4 cells to replace the dead CD4 cells. This becomes harder for your body to keep doing as time goes on. When your body is struggling to keep up the number of CD4 cells, you will be more likely to become unwell with infections and illnesses. HIV mainly affects CD4 cells but it can also get into other parts of the body such as the lymph glands, lungs, brain and other organs in the body.

How Does HIV Get Into Your Body?

Most children with HIV were born with it. HIV is spread through contact with body fluids like blood. Babies can get the virus from their mothers either

- before they are born (while they are still in their mother)
- whilst they are being born
- when they are feeding from their mother (through breast-feeding).

HIV is also spread through unprotected sex (without a condom) or sharing syringes and needles.

You cannot give HIV to anyone through day-to-day things such as touching, sharing cutlery or crockery, swimming etc. The virus cannot live long outside your body and dies very quickly when it dries in the air.

What Is The Difference Between HIV and AIDS?

When you have HIV you might get more infections than someone without HIV. Remember this was due to your bodies struggling to make CD4 cells. If someone with HIV has particular infections or illnesses which are more serious, we call this AIDS. AIDS stands for **A**cquired **I**mmune **D**eficiency **S**ndrome and is **not** the same as HIV. This is often called advanced HIV now. Even with AIDS, once you are on medicine and it is working well, you can still do very well and live a long time.

What is a CD4 Count?

We can count the number of CD4 cells that you have. We call this your **CD4 Count** and it tells us how likely you are to become unwell. It can help us decide whether you need to start or change medicine to fight HIV. We call this **anti-HIV medicine**. CD4 counts over 350 means your body will be good at fighting off infections. If your CD4 count is below 350 we usually recommend that you need anti-HIV medicines as you are more likely to become unwell.

What does viral load mean?

We can also measure how much HIV virus is in your blood. We call this the **viral load test** and it tells us how many copies HIV is making of itself. Usually, the more HIV in your blood the more quickly your CD4 count will go down. So the viral load tells us how quickly you should start your anti-HIV medicines. If you are already on medicines, the viral load also tells us how

well your medicines are working or how well you are managing to take your medicines.

When will I start anti-HIV medicines?

There is no cure for HIV yet, but there are medicines that can control it and keep you well. This means that once you start medicines you usually have to take them for good or until a cure is found.

To decide when to start the medicines, we must think about:

- your CD4 count
- how well you are
- how well you are growing
- how ready you are for the medicines.

Anti-HIV medicines work by:

- getting the viral load down (stopping the HIV virus making so many copies of itself)
- helping your CD4 cell counts to go up
- making your immune system better and stronger

Most people take 3 or 4 HIV medicines as the drugs work best together and this is often called **combination therapy**

Appendix 5

Normal Cognitive Stages for children

Early developmental theories, such as those of Piaget in 1950's, describe the sequences in which cognitive and learning skills change over time. More recent studies have added to this knowledge by illustrating that development is a dynamic process in which a child's progress in cognitive skills and understanding is influenced by their experiences as well as age and maturity. Theories are now based more on information processing and narrative theories

The following gives the reader some ideas about the way in which cognitive understanding changes during the main developmental stages.

Age range	Cognitive Stage	Main concepts emerging during this stage	Examples of thinking about health at this stage
Toddler	Sensori – motor stage Problem solving based on object manipulating and trial and error and	Learning about cause and effect and permanence of things (even if the object is not visible) Beginnings of own communication skills	Feel things done to them even if don't have words or concepts to express. Effects shown in behaviour or core expressions e.g. crying when blood taken . Start of associations in own and adults behaviours e.g. move away when see medicine put on spoon

Preschool	<p>Pre-operational stage</p> <p>Uses what is perceived in real world rather than what is remembered for problem solving.</p>	<ul style="list-style-type: none"> -Increase in language and make believe/symbolic play. - Language related to here and now. -Egocentric perspective i.e. others think or feel same as I do. - Reasoning is intuitive with some magical links between events. -Difficulties in re-telling stories -Inability to take perspective of another person, or focus on more than one dimension at a time. 	<p>Examples of some magical links</p> <p>e.g. <i>I have to take medicines because I was naughty .</i></p> <p>e.g. <i>Hospitals are where you go to get sick.</i></p>
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<p>Primary school age</p>	<p>Concrete Operational /logical</p> <p>Use of logic or reasoning rather than intuition to solve concrete problems.</p>	<ul style="list-style-type: none"> - Ability to classify objects and manipulate ideas e.g. number. - Use of rules important. - Moral judgements emerging. - Capable of adopting a self reflective and reciprocal perspective in social relationships and interactions (<i>I know that you know that I know</i>). 	<p>Examples of comments:</p> <p><i>'I know eating and drinking keep me healthy'</i></p> <p><i>'Medicines are helpers'</i></p> <p><i>'Blood has different cells which do different jobs'</i></p> <p><i>Mummy told me what was private information and I mustn't tell others at school but talk to the nurse at clinic.</i></p>	
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Adolescence	<p>Formal Operational period</p> <p>Use of logic to solve abstract problems and relativistic thought emerging</p>	<ul style="list-style-type: none"> -Manipulates 2 or more logical categories (e.g. speed and distance) - Concepts of past, present and future become related e.g. behaviour influenced by upbringing, personality and social forces - Thinking ahead and understands time related changes e.g. knows relationship with parent will be different in 10 years time - Self centred (new egocentrism) – may mean the person is not able to solve interpersonal problems that entail logical conflicts and which contradicts own philosophy. 	<p>Examples of comments.</p> <p><i>'Stress as well as physical things can affect health'.</i></p> <p><i>'What happened when I was younger can affect me know'.</i></p> <p><i>I know I should take medicines but I can't always do it'.</i></p> <p><i>'I know what for the future but don't know how to get there'.</i></p> <p><i>'My parents could have trusted me earlier'.</i></p>
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Appendix 6.

Ideas to support the discussion of parental diagnosis.

Wider consultation is needed to produce detailed guidance on this subject and needs to include ideas which help sharing a parental diagnosis with other family members, including uninfected children.

The following provide some initial thoughts based on existing practice and comments presented in Appendix 3

Whilst a child's HIV diagnosis usually begins with an understanding of health and what protects or puts health at risk, discussion of parental diagnosis brings up issues about transmission routes (both 'how the child became infected' and 'how the parent became infected'). It is often the latter which causes the greatest concern and anxiety. Further parents own experiences of how they were told about their own diagnosis – or some of the adverse events they have experienced, believe or heard about HIV including some negative responses from others. This can mean that conversations with their child about HIV become very emotionally charged discussion. Parents may get reminders of the initial awfulness (and shame) they felt when they were first diagnosed together with the feelings of blame and guilt about having passed HIV to their child. Acknowledging these concerns goes some way to understanding how to support both the parent and child in more open discussions about HIV and be helpful for both of them.

Practice has suggested the following principles:

- Sharing the parental diagnosis at the same time a child hears the name of their own HIV diagnosis for the first time may not happen as there can be other conversations which take priority. However it is important to respond honestly if the child enquires where they got their HIV. Sometimes the child will already know they share the same condition as their parent.

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- It helps to parents to have had the opportunity to have separate conversations away from the child where they can prepare for or practice how to manage possible questions child may ask e.g. 'where did I get it from'. These conversations may happen outside the health setting (in family, support groups, social care, counsellor etc.) but it can be helpful for someone in the paediatric team to check parents are having an opportunity to discuss this. This also helps with for a discussion about some of the parental fears and concerns away from the child.
 - Being prepared and practising what to say beforehand can help both parent as well as child. Waiting until the child asks if the parent has HIV may mean the time and place is inappropriate and parents anxiety or emotional response might give a worrying message to the child.
 - Encouraging the parent to take the lead in the discussion about their own health and diagnosis with their child. It can give a sense of trust and control. A parent may know who else they would like to support the conversation or be available for the child afterwards

Suggestions of helpful conversations for those supporting parents and carers:

- Sharing with parents what is known about children's coping and understanding can be helpful. (See General Principles Section B)
- Talking aloud about the changes in prevention and treatments for HIV which have occurred since parent and child were infected. Often a mother may not have known she had HIV when the child was conceived or born and less means were available which could have reduced the transmission of HIV to the child at that time. This can help reduce feelings of blame.

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- Giving experiences from other parents who have shared their own diagnosis with their son/daughter that often a closeness builds up between parent and child because they have more understanding of each other's needs. This is particularly true if conversations happen during primary school years.
 - Having conversations about the present as well as the past. How different it is now for parents as well as for children living with HIV – a more optimistic future!