

# **Talking to children about HIV in health settings.**

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## Introduction

**In 2011 the World Health Organisation produced guidance, based on all the published evidence about HIV disclosure to children. All the available evidence confirmed the benefits of talking to children about their HIV diagnosis from a young age. Its primary recommendation was:**

*“Children of school age should be told their HIV positive status: younger children should be told incrementally to accommodate their cognitive skills and emotional maturity, in preparation for full disclosure”*

Now the right time to embrace this recommendation as being best practice for those working in health settings in the UK and Ireland and to be moving towards earlier and confident discussions with all children with HIV.

# **Aims and Standards for talking to children about their health and HIV diagnosis in UK and Ireland health settings**

## **Primary Aims**

- Health services in the UK and Ireland should promote approaches which enable the majority of children with HIV to be told their diagnosis during primary school years, ideally by 9 years.
- For any older positive children, who do not know their diagnosis, there should be documentation about the reasons why disclosure is delayed and proactive approaches or interventions in place aimed at increasing the child's knowledge about HIV and participation in health care.
- Staff should talk openly about HIV to children newly referred for care to a paediatric HIV clinic if they are aged 10 years or over.

## **Standards for health professionals**

- All health professionals working with children and families living with HIV should be aware of the principles outlined in the CHIVA ethos statement and the Practice Guidance on Talking to Children about their HIV Diagnosis ([www.chiva.org.uk](http://www.chiva.org.uk)) 2014
- Health clinics providing care to children with HIV infection should have a clear local policy which outlines their general approach to talking about HIV with all those attending the service, in line with the CHIVA Practice Guidance on Talking to Children about their HIV Diagnosis ([www.chiva.org.uk](http://www.chiva.org.uk)) 2014.
- Individual circumstances influencing the child's 'readiness' to cope with new information should be considered in these policies. .
- Each clinic should identify a lead worker to co-ordinate the work around helping children understand their HIV diagnosis and document the progress being made with individuals and guide practice for those children coming for HIV testing. In larger centres the paediatric Clinical Nurse Specialist is ideally placed to do this.
- Talking to young children with HIV about their health and HIV diagnosis should always be in partnership with the child's parent or carer and strive to answer children's questions truthfully.
- Health professionals should provide parents/carers with knowledge and evidence about the known benefits and consequences of telling children about their HIV diagnosis.
- Clinics should have resources about health and HIV which are appropriate to the developmental and emotional maturity of children and take account of cultural influences.

- There should be clear documentation in the child's medical notes of what the child has been told and any interventions or support needed to increase individual children's understanding, confidence and coping.
- Disclosure should be considered a continuing process of knowledge building and is not just naming the diagnosis. It includes knowledge of HIV and treatments; routes of transmission; understanding sexual and physical health aspects and confident onward sharing of the diagnosis. Healthcare professionals should be aware of legal, ethical and confidentiality issues surrounding wider disclosure of a child's HIV diagnosis to other agencies and for older children and adolescents, around disclosure to sexual partners.
- Specialist advice can be sought through the Children's HIV National Networks (CHINN) for centres or clinics not previously experienced around talking to children or HIV disclosure. These can be accessed on the CHIVA website.

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## **1.0 Background**

In the UK and Ireland, talking to a child about their diagnosis usually happens within healthcare settings as this is where there is expertise about the condition and its effects on health and access to treatments. This is true in paediatric HIV as it is for other childhood health conditions.

The following guidance is written for health professionals caring for children with HIV infection but draws on evidence and good practice from other childhood conditions whilst considering the specific circumstances associated with HIV. The recommendations should be considered together with those outlined in the CHIVA ethos statement on disclosure and links to recommendations in the quality standards around disclosure for social and community care (Hamblin, Ely, Donaghy & Melvin 2013; Ely 2012).

### **1.1 Historical perspective**

Talking to children about their HIV status has evolved over time. When paediatric HIV was first identified it was associated with high levels of morbidity, mortality and secrecy. Talking to children about their HIV was difficult and often lacked knowledge and certainty about treatments and the future. Further many children with HIV were quite young and talking about HIV was postponed until they were older. Parents often felt there was no need for the child to know and healthcare professional lacked confidence and experience in broaching this subject.

The approach in paediatric HIV was considered more complicated to that in other childhood chronic illnesses mainly because of the associated stigma, ignorance and source of the diagnosis, making this a family condition. Not telling the child was considered a way of protecting them from potential discrimination if they told others. Parents often also felt anxious about how the child would react to knowing that they acquired HIV from their mother and this sometimes contributed to delays or reluctance in talking to their child.

Over time in the UK many clinics adopted practice which has included building up health information incrementally over time, including truthful partial knowledge about the diagnosis, with naming of the diagnosis occurring before puberty. An audit on disclosure of diagnosis to children was carried out for CHIVA in 2007. (Donaghy et al 2007) This involved a semi-structured survey of centres caring for children with HIV in the UK and Ireland and a notes audit to assess clinical disclosure practice. The median age of naming HIV was 12 years (age range 10-15 years). Whilst there was general agreement of the importance of responding to any child's questions in an honest and open manner, there also a recognition that children often did not ask or initiate conversations about their health or diagnosis. Parental views and anxieties were cited as the main reason for delays in talking openly with children. Following the CHIVA disclosure audit, guidance on talking with children about their health and HIV (2008) was developed which provided general recommendations about how to manage the process within health settings and recommending children were told their diagnosis before moving to secondary school ( Ref Melvin, Donaghy & Conway 2008) .

## **2.0 Catalysts for change in approaches to talking with children about their HIV diagnosis in UK & Ireland**

### **2.1 Improving outcomes**

There are over 1100 children under the age of 18 years living with HIV in the UK & Ireland (CHIPS 2013). HIV is now managed as a chronic illness with a good prognosis if the virus is controlled. Mortality and morbidity dramatically improved following the development of effective anti-retroviral therapy. The focus of care is now often around adherence to treatments which is compounded if the child or young person is not fully aware of the reasons for taking their medication.

### **2.2 Cohort getting older**

In 1996 the median age of the cohort was 5 years (CHIPS) and it is now over 13 years. 78% of the cohort is aged over 10 years old. With an increasingly aging cohort there was a need to revisit children's rights and needs around having information about their condition and being involved in decisions about their own health and treatments. It was also important to help young people growing up with HIV to be more confident and support their adjustment to their diagnosis. Further as young people become more autonomous and independent more emphasis needs to be given to support them over decisions around when and how they can safely share their diagnosis.

### **2.3 Evidence from other countries**

In 2011 the WHO produced their Guideline on HIV disclosure counselling for children up to 12 years of age [http://www.who.int/hiv/pub/hiv\\_disclosure/en](http://www.who.int/hiv/pub/hiv_disclosure/en). This comprehensive document looked at all the published evidence around talking to children with HIV, across the world. It very clearly provides evidence of the benefits for both physical and psychological wellbeing if HIV is discussed with children during their early years.

Following a presentation from Swedish colleagues at the CHIVA conference 2011, a small team from the UK, visited the Swedish clinic where practice is now to talk openly about HIV with all children attending their clinic irrespective of age. Whilst the system in Sweden differs to that in the UK such as the availability of specific HIV support in schools, there are elements from this approach which are relevant to practice in the UK. In particular the confidence gained by carers that young children can cope with hearing the name of their condition.

### **2.4 UK Practice**

In the UK many clinics have been moving towards talking to children about their HIV earlier. It is realised that there are benefits for children to be more actively involved in their care, health monitoring and adherence to treatments and that this requires more understanding and knowledge of their condition.

Following the 2007 CHIVA disclosure audit, some individual clinics looking after children with HIV reviewed progress in their practice.

Example 1. In 2009 at St Mary's Hospital, London, over 85% knew by 12 years. The children who did not know the name by early adolescence either had a significant learning difficulty or were living in families where parents had difficulties discussing or managing their own HIV diagnosis (Monrose & Melvin 2009).

Example 2. In 2011 at St George's Hospital, London, 82% of the children had been told their diagnosis by 10 years of age (Donaghy audit 2011: Personal communication).

A number of different reasons why some children had not been told their diagnosis have been identified by audits carried out. These include the presence of a significant learning difficulty for the child, or if there is parental anxiety about talking of HIV, or where families were living in isolated circumstances. These audits suggest the importance of documenting the reasons why talking about HIV is delayed as this can help identify appropriate or additional interventions which can to support any difficulties with communication, understanding or coping and increase enhance readiness to be told more and coping for both child and family.

## **2.5 Changing practice in one London clinic**

During 2012-13 practice at St George's Hospital, London changed to earlier and more open discussions of HIV. It was explained to parents of children who did not yet know their diagnosis that the clinic staff felt waiting until 10 or 11 years was late and that children had less time to adjust. Most families have been positive about their children being told they have HIV earlier. All children over 11 years now know their diagnosis apart from 4 children, 3 of whom have severe learning difficulties who do not have the capacity to understand. For the children under 6 years of age, all parents except one have agreed to us talking about HIV openly with the child present. Of the remaining children who have not yet had naming of their HIV (age 6-11 years) 6 are aware they were born with a virus in their blood and the remaining 6 have partial knowledge around having had low white blood cells and needing medication to boost the white blood cells.

We still discuss with the child and family about who already knows the diagnosis and who the child is free to talk to about their HIV status. Since changing practice there have been no adverse reactions and it feels more open when we see the children and their families.

Feedback from young people with HIV has consistently reported that they should be told at a younger age and that they can cope with this information. Those young people who are told later often report higher levels of anger and distress at the information about their health being withheld from them

## **2.6 Other studies which support earlier talking about HIV**

A couple of recent qualitative studies supported the view that delaying talking with children can lead to more distress and poorer adjustment. Young people often had a clear memory of when they were told they have HIV. By delaying naming it may give the young person the impression that HIV is too awful to talk about or were not trusted when younger. This can affect their confidence to share their diagnosis with others later. This can also increase their feelings of isolation and loneliness. (Greenhalgh 2012, Dorrell 2007)

Changes have occurred also within practices within support agencies which also promote earlier and more open discussions about HIV. The CHIVA quality standard for social care promotes practice whereby all those working with children in the social care sector develop open and honest relationships about the nature of their work and the reason for their involvement. (Ely 2012).

## **3.0 Background evidence**

### **3.1 Evidence from child development**

Knowledge from development of cognition and learning show children actively try to make sense of the world from the youngest ages. Between the ages of 4 to 10 years most children are using logic or reasoning rather than intuition to solve concrete problems. They like rules and have developed a moral understanding. This suggests this may be the best time to talk about a diagnosis as it gives time for understanding and adjustment before more dominant emotional and social development occurs around early adolescence. Younger children's ability to understand and cope with what is happening is often underestimated. Effective communications which help support coping as well as understanding need to be developmentally appropriate, and mindful of the cultural context. For example paying attention to the pacing and amount of information given at one time with opportunities for the child to participate and be listened to and take an active role in discussions, as well as talked at. (Eiser 1989, Edwards & Titman 2010).

### **3.2 Evidence from studies of involvement of children in health decisions**

The National Service Framework (NSF) for Hospital Services (DOH 2003) stated that children should be encouraged to be active partners in decisions about their health and care and where possible be able to exercise choice. There is evidence that involvement and participation increases young people's self-esteem and sense of responsibility and well-being as well as improves the quality of the service. Having a truthful explanation of what is happening from a young age enables time for children's participation in care to increase over time and for their views and feelings to be gathered and any misunderstandings or distress to be addressed early.

### **3.3 Evidence from other health conditions**

In other situations where children are dealing with sensitive information including a life threatening diagnosis, chronic conditions and end of life situations or death or trauma, the evidence shows that most children show more benefits of being told and included in what is happening but there needs to be especially if there is collaboration between carers and the system so the child and the information is supported. For example research published from childhood cancer shows that most children's anxiety was reduced over time if they were told their diagnosis (Eiser 1993).

Children generally they take their lead from important adults, especially their parents, so if the adult is confident about what is being said this will make them feel more secure. If they are not told what is happening they will build their own stories or conclusions about what is happening which may be more worrying for them than knowing the truth.

### **4.0 Principles in updating a child's knowledge of HIV: An on-going process**

Whilst there is not a 'right' age for all children to be told their HIV diagnosis, it is generally agreed that most children should have this discussion during primary school years (WHO 2011). The approach in the UK and Ireland should be for the majority of younger children growing up with HIV to be told they have HIV by the age of 9 years. For those older children who do not yet know there should be a clear disclosure plan to enhance knowledge, including approaches which consider difficulties with communication or understanding. All of the available literature on telling children they have HIV, emphasises that as well as general guidance for a population there needs to be recognition that there will be individuals who are not ready or who live in unsupported situations or circumstances which may result in delays or difficulties in the pace at which talking about or understanding the diagnosis occurs. (See appendix 2, for examples of circumstances affecting 'readiness'). Documenting approaches or interventions which focus on specific reasons for delays can help ensure the child's needs remain the focus of disclosure.

Building understanding and confidence about health management and what is happening in clinic is as important as naming or mentioning HIV. Incremental steps to supporting understanding in turn enable better adjustment and coping later. Appendix 1 provides some of the topics for conversations which promote understanding and adjustment.

### **4.1 Partnership & Involvement of parents or carers.**

Carers and health professionals working together provide confidence and help support a child's own coping strategies. Parents or carer are the day to day providers of emotional support, security and trust for the child. Their inclusion in conversations about information that directly affects the child is essential in providing reassurance, trust and confidence. Health professionals provide expert information about the condition and its treatments and will be able to

share with parents the experience of talking to other children about the condition and how other children and families have coped. This partnership can also support parents discussing their own HIV diagnosis with the child. (See Case 1 Appendix 3.)

#### **4.2 Sharing the benefits of disclosure with parents/carers**

Sharing what has been found about the benefits to children of talking about their HIV diagnosis is one way staff can help start a conversation with parents about disclosure. These include: -

- *Reducing fear, anxiety for child and guilt for parents.*
- *Allow the child to be included in what is happening and builds on their own coping.*
- *Avoids accidental or unsupported disclosure to child.*
- *Can help support the child's medicine taking*
- *Gives time for adjustment around health implications before having to deal with concerns about transmission and sexual health*
- *Reduces negative messages or misinformation about HIV which can be related to stigmatising attitudes*
- *Normalises HIV to other chronic conditions e.g. evidence shows anxiety is reduced when child knows their diagnosis*
- *Evidence shows young people cope better if they are fully involved and able to participate in their care*

#### **4.3. Taking the initiative about HIV conversations in health settings.**

The familiar clinic nurse or doctor in the paediatric clinic may be in the best position to initiate conversations with the child about health and HIV, in partnership with the parents. They can provide knowledge about up to date care and treatments about HIV in children and can identify appropriate other support agencies should the child or family need more help. The clinic may be the only place that the child will hear HIV spoken aloud, especially when they are young so it is important that HIV is discussed confidently and normally within the consultation to help de-stigmatise the word for the child provide opportunities for the child to express their views or questions.

Hearing HIV talked about in clinic at younger ages may initially be just background talking but sets the scene for allowing more confident and open discussions to happen at the clinic and home

#### **4.4 Readiness for talking about the diagnosis**

Whilst many children cope well with hearing about HIV at a young age there are some known circumstances which may interfere with the child's ability to cope or where some extra support or interventions may be needed. This will be so when a child is learning about their own diagnosis or when they are deciding who and when to share the diagnosis with others. Factors influencing readiness can be related to specific aspects of the child and their personal situation but can also result from circumstances in the support network including parents or carers fears arising from their own experiences or the perceived consequences for the child.

The following summarises some of the common reasons where talking to the child about HIV may be delayed or where extra interventions are needed.

- Child is acutely unwell or coping with recent trauma, death or separation from main carers
- Child has significant learning difficulty
- Lack of personal support such as carer unavailable or avoidant of discussing HIV.

Appendix 2 summarises some of the situations where progress with naming HIV maybe delayed and provides ideas about different approaches or interventions which may be helpful to support the child and family and work towards readiness. This includes more opportunities for discussions in paediatric clinic or onward referral to a psychology or counselling service experienced with communicating with children and families.

Sometimes partial truthful information needs to continue until circumstances change or the child is in a more stable or supportive situation. There will always be some children or young people with extremely severe learning or neurocognitive difficulties e.g. sever autistic spectrum disorder, who may not have the capacity to understand their condition. Appendix 3 gives some case examples.

Sometimes those in the health system may lack confidence or knowledge about how to share HIV information with children and families and linking with others with more experience of disclosure may be helpful via CHINN networks or CHIVA website.

#### **4.5 Checking feelings and adjustment responses**

There is no right way for a child 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. Sometimes this can lead to disbelief or shock, open upset, sometimes to silence but in general younger children cope well with this information. Checking concerns and behaviours with the child and family after new information has been given is a helpful way of clarifying both misunderstandings and worries. It may take a while for the child to ask questions about HIV or even to say the words out loud, so it is not always easy to check understanding or adjustment. Clinical experience has shown that it is rare for extreme initial distress but as awareness grows responses sometimes change, so checking mood and behaviours over time is necessary.

There are other sources of help in the voluntary sector where the child or parent can meet others and not feel they are alone in having to manage these feelings. On occasion a referral to a psychology service may be needed to help with the adjustment and coping or with expressing or managing feelings.

## **4.6 Words are important**

Talking about HIV as a 'secret' can reinforce associations about blame and shame that can surround attitudes to HIV. Health and HIV are better discussed in the context of 'private or personal' conversations discussed with the experts at clinic or hospital rather than with friends or teachers. It also helps to set the scene that this is *their* health information. Being clear about who knows about their diagnosis can help children understand who they can talk to as well as who doesn't need to know. Talking about all health conversations being private is also helpful. Reminding families that systems in health, education and social care also have clear confidentiality policies.

Gradually encouraging children take a more active role in conversations at clinics such as suggesting questions to ask the doctor, making a personal record of CD4 and viral load measures also enhances understanding and can be the first steps towards more personal involvement in their own health care and decisions.

Appendix 1 covers some examples of specific topics of conversations to be covered with children as they get older and can manage more details.

## **4.7 Giving positive information about the future**

- Explain that there is very little that HIV can prevent the child from doing.
- Give information about survival and health of children born with HIV to help with adjustment and coping.
- Explain 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 space to discuss other aspects of their life and pointing out their strengths and how they have managed
- Some examples of what other young people with HIV are doing or have achieved can help too.

Refer to Appendix 1 for more examples.

## **5.0 Parental and wider disclosure**

### **5.1 Sharing a parental diagnosis**

For some children it can help to talk about the source of their HIV at the time they are first told about their HIV diagnosis. This can help open up communication between the parent and child. Sometimes parents are concerned how the child will feel about them when they learn the source of their HIV and whether the child will blame or feel differently about them after they are told. There is little documented to show that this has been the case when other children have been told and clinical practice gives examples of how parents and children can be brought closer together when they learn they are both taking HIV medicines and looking after their health. It can help too

to explain that when their child was born there were less effective ways of preventing or reducing transmission as are available now. Some parents or carers may benefit from further individual discussions, away from the child, about their own diagnosis.

## **5.2 Sharing the diagnosis with others**

Much less evidence is available about the benefits and outcomes of young people sharing of the HIV diagnosis with others. Adult evidence suggests psychological wellbeing can be enhanced if share with special others. (Adult psychology standards BHIVA 2012)

Young people may need to explore the issues of what it might be like to tell friends, partners or siblings about their HIV. Supporting them to decide what is best for them can be helped by giving them space to reflect on 'why this person?', 'why now?' 'What might be the consequences?' As well as a discussion about the difficulties of 'untelling' etc. Further, young people may benefit from practising talking aloud or telling others in a safe environment either at clinic or in a peer support group. Techniques such as role reversal with young person becoming expert and the health professional the 'newly diagnosed patient' may be one way of checking knowledge as well as helping young person practice safe talking about HIV. Identifying a long standing close friend (or trusted family member) with whom to share the diagnosis may provide confidence and practice before the pressure of sharing the diagnosis in a sexual relationship. It is important to inform young people regarding the legislation around criminalisation and transmission as they get older.

Who and how to share the information with others is the most pressing disclosure issue for young people and for health providers in the next decade of care.

## **5.3 Wider disclosure to other services**

The clinics caring for children with HIV should actively encourage disclosure to GPs and other healthcare professionals involved with the care of the child, explaining the benefits of doing so. Families should be reassured that these professionals have a legal and ethical duty of confidentiality.

### **Schools**

The decision whether to tell schools or not should be discussed with the family. It can sometimes be important for someone at the school to know the child's diagnosis for example if a young child is going on residential school trips so that someone can support the child with medicines and be aware of their diagnosis if they become unwell.

It can be helpful to consider who needs to know rather than who has a right to know. It is not usually helpful for all workers at a school to know a child's diagnosis but it may be very beneficial for key people to be aware, particularly if the child has other difficulties interfering with school progress. Further advice is available for schools on

<http://www.chiva.org.uk/professionals/health/guidelines/youngpeople/hiv-in-schools.html>

## **6.0 Summary**

Most children and their families are resourceful and can cope with learning about HIV and the evidence shows that most children cope better when told at younger ages. However for some children there will be circumstances or concerns that can delay or slow the progress of disclosure or limit their understanding.

Changes in the needs and outcomes for children with HIV living in the UK has made it increasingly important that those in health services caring for children who are HIV infected take more proactive approaches to talking aloud with them about their condition from a younger ages. This will enable children to take more active roles in their own care and treatments as they get older.

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## Appendix 1: Conversations to increase knowledge and understanding of HIV

The following conversations help link the meaning of the diagnosis to health and medicines and enable better understanding. Ideas are organised into 3 sections organised developmentally (and identified in different colours) The first section aimed at the very young child or with limited capacity to understanding about health and HIV, the second consolidating information about HIV as a health condition, and the last covering topics of HIV as a chronic health and potentially transmissible condition.

	<b>Topics for Conversations</b> with child/young person	<b>Discussions with care giver</b>
<p><b>Checking Health</b></p> <p><i>'Why I go to clinic?'</i></p> <p><b>Keeping well: Health &amp; Medicines</b></p> <p><i>'My health needs looking after'</i></p>	<p>What happens at a clinic visit How health is checked The blood test as part of health check Medicines as helpers</p> <p>How to measure health Blood test as part of measuring health Different blood cells White cells / health defenders / CD4's Germs and viruses HIV is a virus What is the Immune system?</p> <p>How medicines support health &amp; immune system How medicines fit in with life &amp; routines Health as private/personal information</p>	<ul style="list-style-type: none"> <li>• Set out reasons why truthful conversations help children</li> <li>• Update carers own knowledge of paediatric HIV</li> <li>• Talk about how children cope and their resilience</li> <li>• How children look to their carers for confidence</li> <li>• Separate discussion with carers without child about their own concerns and how to answer children's queries</li> <li>• Ideas to support child's reaction</li> </ul>
<p><b>HIV as a chronic condition</b></p> <p><i>'This virus can't be removed but I can manage it so it won't damage my health.'</i></p>	<p>CD4 and viral load measure health.</p> <p>How medicines work to support health and keep virus in control</p> <ul style="list-style-type: none"> <li>➤ Getting viral load go down</li> <li>➤ helping CD4 cell counts to go up</li> <li>➤ making the immune system stronger.</li> </ul>	<ul style="list-style-type: none"> <li>• What is different for children with HIV compared to adults with HIV</li> <li>• How children's understanding changes with time</li> <li>• Support for conversations</li> </ul>

*The virus I have is called 'HIV'*

The meaning of the letters:  
**H= Human**  
**I=Immunodeficiency** ( *how this relates to damage to health*)  
**V=Virus**

There is no right way to cope or feel about this information

HIV is a lifelong condition which can't be cured but can now be managed.

Being born with HIV

Who else has HIV in family

Who child can talk to about HIV  
(*Who knows and who doesn't need to know*)

Discussing fears – about death, about future choices, relationships having children etc.

Opportunities to practice talking aloud about HIV

Taking control of health and HIV and not being controlled by it

Where to get up to date information about HIV

Having HIV shouldn't achieving your plans

Some examples of what other young people with HIV are doing or have achieved

What is known about future and living with HIV (longer, healthier lives, having own babies etc.)

Giving space to discuss other aspects of their life

about transmission and parental diagnosis

- Avoid talk of 'secrets' encourage words such as private
- Reviewing wider disclosure – who needs to know, who has a right to know.
- Updating knowledge about confidentiality
- How to support youngsters' concerns and queries outside clinic visit.
- Emotions may changes as understanding grows

<p><b>Managing HIV &amp; Sexual Health</b></p> <p><i>'I need to manage my HIV and prevent passing it on but it shouldn't take over my life'</i></p>	<p><b>General</b></p> <ul style="list-style-type: none"> <li>• Being interested in the young person not just the HIV</li> <li>• How to stay well with HIV</li> <li>• Managing medicines so they fit into life</li> <li>• Review how HIV transmitted,</li> <li>• Who the young person would like to talk about HIV to.</li> <li>• Where/how to practice talking about HIV safely</li> <li>• Role of alcohol and recreational drugs with HIV medicines</li> <li>• Peer support options</li> </ul> <p><b>Sexual Health:</b></p> <ul style="list-style-type: none"> <li>• How to have and negotiate safer sex</li> <li>• Contraception</li> <li>• Post sexual exposure prophylaxis, emergency contraception</li> <li>• Responsibilities &amp; negotiating relationships,</li> <li>• who else they want to tell about HIV</li> </ul> <p><b>Adherence:</b></p> <ul style="list-style-type: none"> <li>• Update information on medicines, adherence and resistance</li> <li>• Control &amp; Motivation for medicine taking</li> </ul> <p><b>Future health care</b></p> <ul style="list-style-type: none"> <li>• increasing involvement &amp; independence around appointments, choices, medications</li> <li>• Transition and transfer of health care</li> </ul>	<ul style="list-style-type: none"> <li>• <i>What changes as children grow into adults</i></li> <li>• <i>How to find new ways of supporting young person</i></li> <li>• <i>Providing gradual opportunities for greater independence in life</i></li> <li>• <i>Respecting privacy and agreeing what can be shared with parent/carer especially over sexual health</i></li> <li>• <i>Understanding young person's need for autonomy</i></li> <li>• <i>Negotiating changing relationships in the family</i></li> <li>• <i>Being included in discussions about transition</i></li> </ul>
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## Appendix 2

Suggestions for help if the disclosure process is delayed or there are concerns about child's readiness to cope.

<b>Concern</b>	<b>Suggestions for help</b>
<b>Parent/carer concerns</b>	<p>There can be a whole range of reasons why some parents or carers are worried or reluctant for their child to be told their HIV diagnosis (e.g. negative thoughts or consequences arising from their own HIV, worries child will talk about HIV diagnosis to others, think child will not cope with the information)</p> <p>If their concerns are related to their own experiences it may be helpful to give time to discuss their anxieties or beliefs away from the child's appointment. It can also help give up to date information about what is known about HIV and children in the UK.</p> <p>Alienating parents and families over disclosure issues may result in them disengaging with the health clinic which will not benefit the child's care. Understanding and listening to parental concerns but confidently discussing what has been found from wider experience can give parents a different view. Suggesting the same person(s) in clinic to take the lead on future disclosure conversations can also be reassuring.</p>
<b>Concerns that the child won't cope</b>	<p>There is no evidence of excessive or long term emotional trauma when children are told about their diagnosis in a supported way. More distress is reported in older children/teenagers who are told late or when disclosure is accidental or unsupported way. Children with an active coping style, and who are able to communicate or talk about their feelings may be more resilient. This can be used to help discuss with parents, and the child, how well they have managed other things in their earlier life. If there are concerns about the emotional/mental health of a child/young person this may need referral to outside agencies e.g. CAMHS. However explanations and naming HIV are still probably best done within HIV health setting (with consultation with other agency).</p>
<b>Concerns about the child telling others about the diagnosis</b>	<p>The evidence shows the majority of children who have been told about the HIV diagnosis in a planned and supported way generally keep the information to themselves and within</p>

	<p>their families. It can help to explain how children can keep rules and understand what is 'private' if this is explained. Identify who they can talk with as well as who they don't need to. Drawing a 'privacy' circle together (&amp; putting inside who knows about health and HIV) can help. Reminding families about confidentiality procedures in services and that there is no legal obligation to inform schools or colleges can also be useful. It is important that children are given opportunities as they get older to review and reconsider who they want to be included in their privacy circle.</p>
<p><b>The child with difficulties in learning or understanding.</b></p>	<p>Children with severe difficulties with learning or interacting with their surroundings may not have the capacity to understand or make sense of what is being discussed. These youngsters will always need an adult with them to manage health decisions and daily life. HIV should be spoken confidently about at clinic with their trusted adult companion, as this may not be meaningful to the child. Resources for helping understanding of health should be appropriate to their developmental age. Youngsters with less severe difficulties may need information broken down into smaller steps with more chances to review ideas and a range of materials egg pictures should be used. The emphasis needs to be on who will help support the knowledge. Also other conversations e.g. independence, keeping safe, need more attention. Accessing specialist professionals or services with experience of communicating with children with learning or communication difficulties may be needed.</p>
<p><b>Concerns about child knowing parental diagnosis</b></p>	<p>Explaining that the child has had HIV all of their life may best be discussed when child is first being told about their diagnosis. This can make it easier to lead on to later conversations about the source of the child's HIV and who else has HIV in the family. It can help to reassure parents that the evidence shows many children and parents are brought closer together when the child knows that they and their parent have the same condition. Providing separate discussions for parents who may feel guilt or blame about their child's HIV diagnosis and where and who might be able to</p>

	provide further opportunities for them to express this.
<b>Time of acute illness of child or carer or recent experience of death, loss or trauma.</b>	<p>Emotional resilience and coping can be significantly reduced at times of illness or when there are other stressful or distressing events occurring. Giving some time for adjustment or waiting until health is improving may be necessary before new information is given. It can help to reflect back after an illness episode about how health is vulnerable and needs to be supported by medicines etc.</p> <p>If there has been a recent death of a parent or family member has occurred priority needs to be given to supporting and bereavement concerns. It can help reduce any misunderstandings if the child's knowledge is reviewed together with their new carer.</p>
<b>Child or family socially isolated</b>	<p>Some children live in isolated or unsupportive families where there is little personal support. Others may reside in areas where there are few services for families with HIV.</p> <p>As children attend clinic only once every 3-4 months' work around understanding may proceed slowly. It can help to identify whether there is someone else in the personal or professional support network who could be a community partner to the child and/or family around HIV discussions outside clinic visits.</p> <p>Accessing the secure CHIVA webpage for young people with HIV may also help them access up to date information and raise confidential concerns.</p> <p><a href="http://www.chiva.org.uk">www.chiva.org.uk</a></p>

## **Appendix 3 Case Illustrations**

### **Case 1: Coping at a young age**

Jane is a single parent with an 8yr old boy Tom with HIV and 6 year old negative girl Freda. Tom was already aware that he was born with an inner problem in his blood; that mum had the same problem and that medication controlled the problem. At the age of 8 Jane agreed to Tom being told that the name of the illness they have is HIV. This was done in the clinic setting with Jane and the nurse specialist. Tom asked if his sister had the same problem and was told she was negative. Jane explained that the HIV was picked up when she was pregnant with Freda. This led to a conversation how if women with HIV have medicine and good care in their pregnancy there is no reason why they should not have a negative child. Tom showed no signs of distress and is comfortable about asking questions about HIV and his care. With the support of a voluntary HIV organisation, Freda was then told about her mother and brother having HIV. Jane was very happy with how all of this went; she said there are no secrets anymore. This allowed for openness both at home and in the clinic setting. Jane is able to continue supporting her children at home and is comfortable in discussing HIV with them. There is on-going work to increase his understanding as he gets older.

### **Case 2: Why didn't you tell me before?**

Beatrice 8 years and Charmaine, 11 year old sisters who both have HIV. They live with their mother, Grace and the adult siblings live in Africa. Both were aware they had been born with a germ in their blood that was kept under control by taking daily medication to keep it asleep and that their mother had the same problem with her health. Naming was delayed for the Charmaine so that the siblings could be told together. The children were told together at home by Grace and nurse specialist. Charmaine had a more emotional response and asked why she wasn't told before. Grace explained that she had wanted to tell them together. Separate one to one work was done with the Charmaine as she needed more information and details than Beatrice was ready for. The family had already been attending a support group and then the sisters attended a group for children who were aware of their diagnosis. The sisters had telephone support from their older siblings in Africa. Grace was very happy and felt relieved it had all gone well.

### **Case 3 Hearing the words is OK.**

Amy is a 5 year old girl living with her father and his partner. Clinic staff discussed the new approach of openly talking about HIV in the clinic and both felt this would be beneficial. HIV is now discussed openly during clinic appointments and Amy remains in the room. Amy was not especially interested in HIV and it is probably background talking to her. The focus is on using pictures and books looking at white blood cells; how they help the body fight infections and stay strong; pictures showing a virus in the blood which can get up to mischief but with medication it goes to sleep and doesn't cause

trouble. For young children HIV does not have much meaning and it is important to use developmentally appropriate explanations and pictures to help them make sense of why they come to hospital; have bloods taken or have to take medication every day. .

#### **Case 4: Too late or not ready?**

Ester learnt the name of her diagnosis when she was nearly 14 years. This discussion had not been possible earlier because Ester's mum (also positive) had been reluctant to engage in discussions about Ester's knowledge, the family lived a long way from the paediatric clinic and HIV support organisations. When Ester was 10 years, mum went to Africa for a family celebration but found herself unable to return to the UK for 18 months because of visa problems. Ester had been living with an older sister during her mother's absence. During this time Ester knew she needed to take medicines to keep her well but her sister did not feel confident to tell Ester more. On mum's eventual return there followed a new period of social change when Ester returned to live with her mother and a great deal of conflict between the older sister, Ester and the mother.

When she was told about her HIV in clinic Ester showed little reaction and did not seem concerned and asked no questions of the doctor or her mum who was present but contributed little to the conversation. However on the way home she texted her school friends telling them she had HIV. This led to a great deal of anxiety at school which eventually resulted in Ester changing schools.

Ester said at a later clinic visit that she told her friends about her condition because she wanted to get back at her mother for not letting her continue to live with her older sister. Family relationships remain tense but Ester is more settled although she remains cagey about talking about HIV and has told no-one else. She and mum do not discuss it at home. Some extra work is underway to help build new understanding and confidence about HIV

What can be learnt from what happened to help others?

Would it have helped Ester had been told at a younger age before it got associated with 'secrets' and adverse consequences?

Could 'important' others (in this case Ester's sister) be usefully included in disclosure discussions?

#### **Case 5 : Talking about the name may be easier than talking about what it means?**

Simon has HIV and a mild learning difficulty which includes some autistic features. He attends a mainstream school but receives extra help. He has been well known to the psychology service at his HIV clinic because of his long term cognitive and school issues and adjusting to change. He lives with his mother who is also positive and older sister who is negative but does know about HIV in the family.

He had some earlier support to understand about health monitoring and what medicines do and before he transferred to secondary school his mother requested help from the psychologist to talk to him about his and her HIV

diagnosis. This was done at home and followed up with a clinic visit so that Simon could ask the doctor some questions he had generated about HIV. Over time he has had several sessions with pictorial resources about health and HIV as he finds it hard to remember verbal ideas. Simon coped well with understanding his HIV and knows about his mother also having HIV. He does not want to talk about it with anyone else outside his family or the clinic and is mortified when there is any discussion about sex or sexual health. He is now 15 years and his transitional care plan is being updated.

How to take his understanding forward especially wider aspects of independence and future living with HIV?