

The individual in the picture has no connection to the text in the brochure.



Information for healthcare professionals

about children with HIV infection

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The healthcare needs

of children with HIV

This informational material was written in spring 2008 and was commissioned by the National Board of Health and Welfare and the Unit for HIV Prevention. The aim was to meet the need for a summarised account of the healthcare needs of HIV-infected children in Sweden. The authors of this informational material are trained social workers with vast experience working with HIV-infected children and adolescents. In this report, we combined our clinical experiences with regulations and guidelines regarding children's needs, such as the Health and Medical Services Act, the Communicable Diseases Act, NOBAB's standard (Nordisk Förening för Sjuka Barns Behov) and the Convention on the Rights of Children.

The text has been revised and updated prior to this printing and is now published by the National Knowledge and Resource Centre for children and adolescents with HIV infection. We hope that this publication can be used for support and inspiration in work with HIV-infected children.

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Introduction

About 130 young people in ages ranging from 0 to 18 years are living with known HIV infection in Sweden. The most common route of transmission for young people is mother-to-child transmission, i.e. the virus is passed on from mother to child during pregnancy, delivery or breastfeeding. All pregnant women in Sweden are offered HIV testing at the start of the pregnancy. If the woman is infected with HIV, preventive medical treatment is initiated to prevent the infection from being passed on to the child. In combination with Caesarean section and a ban on breastfeeding the child in accordance with the Communicable Diseases Act, this has resulted in the birth of only a couple of children with HIV infection from women known to have HIV infection in Sweden since 1999. Each year 40 to 50 children are born to HIV-infected women in Sweden.

Most children living with HIV infection in Sweden were infected at birth in their home country. Other, less common causes of infection are via sexual contact, drug abuse or even blood transfusion in the home country. The children came to Sweden together with one or both parents, as an immigrant based on family ties to a parent or relative who already lives in the country, as an adopted child or as a refugee child who arrives on his/her own. Most of

the children with HIV infection live in the Stockholm region and in Central Sweden.

Unlike most other chronic diseases, HIV is classified in the Communicable Diseases Act as a disease constituting a public danger because HIV is a communicable disease similar to hepatitis and tuberculosis. The Communicable Diseases Act is intended to prevent the spread of diseases and should be considered a law with both obligations and rights. The attending physician is obligated to provide information to parents and children in a manner that ensures that they understand the meaning behind the Communicable Diseases Act regulations. The patient is obligated to comply with the regulations. Through the Communicable Diseases Act, the patient gets access to free healthcare and free medicines.



Children with HIV in the healthcare system

In the Western World, including Sweden, HIV is currently considered a chronic, life-long disease that you live with – not a disease that you die from. Through regular examinations and treatment with anti-retroviral inhibitors as necessary, the HIV-infected child is given the chance to live a normal life with the same medical conditions as other children as regards school, leisure activities and future plans.

Most HIV-infected children in Sweden get outpatient treatment in children's clinics or infection clinics. Like children with other chronic diseases, the children come to regular medical centre visits, normally every three months. The healthcare staff weigh, measure

and take samples from the children and a doctor examines him or her. With the help of test results, the doctor determines whether the child requires medication. If the child is already on medication, the doctor checks that it is working. During these visits, the child and his/her guardian also have the opportunity to discuss their situation with a medical social worker.

If the child is on medication, you can presume that the treatment is life-long and must continue without interruption. It is unusual for HIV-infected children to require hospital care.



The right of HIV-infected children

to good, child-tailored care

Approach adapted to age, maturity and life situation/context

Like other children receiving care, HIV-infected children need to be approached from a child's perspective. The child's maturity level does not always match his/her biological age and the child must always be approached at the maturity and emotional level he/she is actually at. If several family members have HIV, each individual child must be approached and treated as an individual and not part of a collective.

The majority of children and adolescents living with HIV in Sweden are born outside of Sweden, moving here from countries where HIV is more widespread. In order to understand the child and the family and approach them with dignity, it is important to ask the family and child about their knowledge of HIV and their view of the disease. Taking a thorough developmental and family history is important to clarify the child's disease history.

Healthcare professionals should also talk to the family about their current life situation, about the child's and family's view of the future and their thoughts on and practical handling of the HIV infection.

Children's need for information at different ages

Our experience shows that it is important to talk to the HIV-infected child about his/her HIV from an early age. An honest and straightforward approach with the child on the part of healthcare professionals builds the groundwork for understanding the disease and increases the child's self-respect and self-awareness.

Children with HIV will have regular, life-long contact with healthcare staff/services. It is therefore particularly important that our approach and treatment of the children is well thought-out right from the start. Clear, age-appropriate information on HIV gives children better understanding of the illness. Preschool children with HIV generally do not know about their HIV diagnosis. The child may not have been given a name for the illness. The child may not have been fully informed of his/her disease because of the stigma associated with HIV infection. Parents – often in consultation with healthcare professionals – may decide that it is better to wait to give the child information until he/she has reached school age. This decision is often based on the fear that the child will not understand the significance of the diagnosis and will tell outsiders, which could lead to the child and the family being subjected to negative consequences,

such as stigma. However, a child that has not yet reached school age can be informed of the disease in a manner tailored to the child's maturity level. The collaboration with the parents/guardians plays an important role in the approach for HIV-infected preschoolers. Details of the HIV infection, the parents' concerns and the child's future prospects can be discussed in individual conversations.

Our general experience shows that it is appropriate for the child to be informed of his/her HIV infection at a young school age. At about ten years of age, children are usually fully informed of their disease, including the name – HIV. At that point, information work has already been going on for several years and the child has gradually received more and more information. At this age, children often have an uncomplicated view of HIV infection.



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Informing a child in puberty of his/her HIV diagnosis may be more problematic, as at this age the pre-teen or teen often has a lot of other things to think about and handle. When the child learns about the diagnosis, he/she should get information on the test results and be continually educated about the disease. The child must learn what his/her medicines are called and why it is important to follow the doctor's dosage instructions. Giving the young person up-to-date information on the research being conducted is one way to give hope for the future.

In autumn 2009, the members of the team for children and adolescents with HIV infection at the Astrid Lindgren Children's Hospital have changed the way we work. We now speak openly about the HIV infection with all new patients who have come to us since autumn 2009. This means that we – regardless of the child's age – talk about HIV during the medical centre visits in both our dealings with the child and with the parents. At the same time, we provide age-appropriate information to the child and try to explain and provide information about the disease in a way the child understands.

It is important that the healthcare staff have the necessary knowledge and pay attention to the fact that different children need different amounts of time with

their caregiver depending on age and maturity. The possibility of having one's own time with a doctor, nurse or medical social worker is part of the child's development to take increased responsibility for the illness, to gain knowledge and be able to talk about things that his/her parent does not need to know in detail. The child needs encouragement to ask his/her own questions during these visits.

The teen years are a time of rapid change for the growing child. The child enters puberty and the body develops. The child also becomes more independent in relation to his/her family. Most teenagers test boundaries. Children with chronic diseases, including HIV-infected teenagers, may test their body in relation to the disease, for example by not taking their medicine. "Will I really get sick if I don't take the pills?"

Upon reaching the teen years, the HIV-infected child is subject to the Communicable Diseases Act in a more obvious way than before. The teenage years are a time when most start to have a sex life. For HIV-infected teenagers, this is often a challenge. It is therefore important to be able to offer support conversations and education on safer sex and informing one's partner of the HIV infection. According to the Communicable Diseases Act, everyone in Sweden

who is infected with HIV must use a condom during intercourse and inform sex partners of his/her HIV status. It is often a good support for an HIV-infected teenager to be able to talk to other teenagers in the same situation.

Many like it because it helps them realize they are not the only one living with HIV. The caregiver should therefore inform them of national education opportunities for children and youth of different ages.

Care programme – special needs of children with HIV infection

A care programme for HIV-infected children and adolescents has been developed at Karolinska University Hospital Huddinge. The care programme contains recommendations for how children of different ages should be approached and cared for – both medically and psychosocially. This care programme can serve as a support for the clinics caring for children with HIV.

Continuity in treatment

The heart of caring for an HIV-infected child lies in the development of long-term relationships with the doctor, medical social worker and nurse. This can be considered particularly important for children

with HIV for several reasons. These children have often suffered great losses and need time to build a relationship of trust with the care staff. Meeting the same individuals each time increases the chances of establishing this type of trusting relationship. This is particularly important considering a major part of care is educating the child about his/her disease. For most families, only an extremely limited circle knows about the child's HIV infection. Trust is placed in the healthcare staff and they can become an important part of the family's network.

Paediatric competency

The child has the right to his/her own doctor, nurse and medical social worker. These should be linked to a children's clinic and have specialist competency in work with sick children. If the child needs contact with a nutritionist or psychiatrist, naturally they must have competence for working with children.



Children with HIV in Sweden are not always treated at a children's clinic. Some instead receive care at infection clinics for adult patients. These children do not have the benefit of the child-tailored environment found at a children's clinic. According to the Communicable Diseases Act 1:5, the patient must be met with the right competency.

One consequence of children receiving care with adults is that they can have the same doctor, medical social worker and nurse as a parent, if the parent also has HIV. Although the interests of the child and parent are not always conflicting, it is important that the staff caring for the child acts as the child's advocate and always works based on the idea that they are the child's representative and spokesperson. The staff needs to put on their "child glasses" when working with children and think "What is best for the child in this situation?" This is based on the concept "child's best interests" in the UN's Convention on the Rights of the Child.

It is important that staff working with HIV-infected children is interested in learning about HIV and have the opportunity to learn more. Because there are only a few children with HIV infection in certain areas, the staff there must be given the opportunity for education and support from others working with HIV.

The National Knowledge and Resource Centre for children and adolescents with HIV infection has been in place since autumn 2008 as a support function.

HIV competency

Recommendations for medical treatment of HIV infection are updated continually. For further information, refer to the section on children's treatment in the recommendations of the Swedish Reference Group for Antiviral Therapy (RAV) at www.rav.nu. HIV medicines have many potential side effects and children who begin treatment will continue treatment for a long period of time – most likely the rest of their life. All infection clinics for adults and several children's clinics in Sweden that care for children with HIV are now connected to the web-based patient support system InfCare. The system includes a consultation function, where one can easily get in touch with a paediatrician who is an expert in HIV. The consultation function can also be used for matters of a psychosocial nature involving children and adolescents with HIV infection.

Medical centre visits

When the child comes to the medical centre with siblings who also have HIV, the visits are often scheduled right after each other to make things easier for the family. In such cases, it is important

that each child get his/her own time with the nurse, doctor and medical social worker since they may have different needs and desires.

When the children undergo a physical examination, it should be done with consideration given to the child's age.

When an older child is examined, the doctor should do it without the parent or other staff present. Having his/her own time gives the child the opportunity to discuss things and ask questions about his/her body and its development without the parent/guardian listening.

Sample taking

An important part of caring for the child is taking samples to check the child's virus level and see how well the immune system is working. Many children associate sample taking with feelings of worry and stress. They often wonder why blood samples are being taken and what happens with the samples.

All children and their parents/guardians should be informed why and how blood samples are taken.

All children have the right to pain alleviation during sample taking and the samples must be taken by a

nurse trained in how to take samples from children. A gift after the sample is taken can often make the experience more positive for the child.

Medical social worker contact

The child should have access to his/her own medical social worker who bases all work involving the family on the child and his/her best interests. In our team for children and adolescents with HIV infection at Karolinska University Hospital Huddinge, we have developed our own working model where the medical social worker participates in each doctor visit. Always having the medical social worker present at doctor visits gives a clear message to the child and his/her family that when it comes to HIV there are things to talk about that are not directly medical. Many families dealing with HIV do not seek out help for the psychosocial problems that often have their origins in the HIV infection. The medical social worker plays an important role in helping the family talk about difficult issues. When necessary, the medical social worker directs that child and family to sources of additional help.

Teamwork

Work regarding the child should be handled in a team. For example, when the child commences ART medication, it is important for the various care-

givers in the team – the doctor, nurse and medical social worker – sit down together and discuss with the family what being on the medicine could mean for both the child and the parent/guardian. The child and the family often need emotional and practical support. The family should be given clear written and verbal information on who is part of the care team. This information should clearly indicate who the family should contact for different matters and where they should turn if in need of emergency medical care.

The parents must be informed of the social insurance system that exists and what rights the parent of a sick child has and what rights the sick child has.

Parental participation

It is the parent/guardian who is responsible for the daily treatment of the HIV infection. This responsibility includes doctor visits and ensuring the child takes the medicines properly.

It is important that the parent fully understands that the child need encouragement, support, discussion and education on his/her illness. This may seem obvious, but experience has shown us that it is not obvious since many parents/guardians are worried that the child will talk about his/her HIV infection with friends and outsiders. They instead cover it up and,

in many families, do not talk about HIV at all. The healthcare staff must support and encourage the parents to talk to the child so that he/she understands the HIV diagnosis. It is important that the parents themselves understand the need for the child to be educated about his/her diagnosis and acquire skills to discuss these issues with the child in an appropriate way. This work often meets resistance and takes time.

It is important for the healthcare staff to encourage parents/guardians to participate in and become involved in the care of the child. It is our experienced that this is not always obvious to parents/guardians who have an HIV-infected child. There may be different reasons for this. The stigma associated with HIV can be a major factor or the parent/guardian could also be sick or wrestling with his/her own problems.

Premises

Children who visit the healthcare system often should come to premises tailored to children. There must be a waiting room with toys and other amusements for different ages. The environment must be attractive and calming. The children should feel that the environment is tailored to them. If the children come to a children's clinic, they automatically get access to this. In the waiting room, they can meet

other sick children and establish a relationship with them if they want. This can be a support and produce impulses and thoughts: "I'm not the only one in the whole world who is sick." Play therapy is also often offered through children's clinics.

HIV – a disease you don't talk about

It is not uncommon for HIV to be a secret within the family. This can happen regardless of who in the family has the infection. Children with HIV may have healthy brothers and sisters who do not know about the infected child's diagnosis or children may not know about a parent's HIV status. Thus, HIV may also be stigmatized at home. For parents/guardians, HIV can be a loaded issue and difficult to talk about. Because of this, they cannot help their children talk about how they are doing and feeling. Relatives and friends are often unaware of the HIV infection and therefore cannot be a support for the child in the family.

Having secrecy and a stigma in the family means that the healthcare staff has a huge responsibility in really being the ones who talk about, inform and educate both the children and the parents/guardians on the disease. It is our experience that the hospital visits for many families are the only times the children and their parents/guardians talk about the HIV infection.



Support for children with HIV

and their relatives

HIV school

For the past ten years, Karolinska University Hospital Huddinge has been running a national operation known as the HIV school. The HIV school is run in project form and is funded by external means, currently from the Stockholm County Council via the National Board of Health and Welfare.

The purpose and aim of the HIV school is to gather all children over the age of ten and teenagers living with HIV to educate them in group form at least once a year. During these get-togethers, the children are educated on HIV, medicines, protecting against transmitting the disease, puberty, feelings, sexuality and relationships. The education is adapted to age. The goal is to show the children that it is possible to live a good life with HIV without exposing others to a risk of infection.

The HIV school is for all children in Sweden who are diagnosed with HIV and are aware of their disease. As we indicated previously, participation in the HIV school is incorporated into the care programme for children with HIV infection at Karolinska University

Hospital Huddinge. It is our goal for the staffs at small clinics with a small number of children to get information, support and education in how to inform and motivate the HIV-infected child and his/her family on the importance of the child participating in the HIV school. This support can be obtained from the National Knowledge and Resource Centre for children and adolescents with HIV infection.

We would like all children with HIV infection to have the opportunity to participate in this group education with other HIV-infected children. It is a good idea for the children to be given the opportunity to participate in the school several times and to consider it a process where the child learns more and more about his/her disease.

Group activities

Like children with other chronic diseases, children with HIV infection have a lot to gain from meeting other children in the same situation. When the child participates in group activities, he/she establishes a contact network that reduces the feeling of being

alone. This can make it easier for the child to accept the disease.

Courses for parents

Parents and guardians of children with HIV do not always have all the available knowledge about the disease. Healthcare professionals often presume that a parent who also has HIV has good knowledge of HIV, but our experience shows that this is not always the case. It is therefore important for the child's clinic to offer group meetings or lectures where the relatives can get information and be given the opportunity to discuss HIV. If there are too few patients, an alternative is to offer individual instruction or arrange this type of course with nearby clinics.

Support for boy/girlfriends, siblings and friends

We encourage our teenage patients with a boy/girlfriend to bring along their partner to the medical centre so that he/she can talk to the healthcare staff about HIV and protecting against transmitting the disease – either alone or with the patient. HIV-negative brothers and sisters of children with HIV may also need to come and talk and learn more about HIV and what is involved. This also applies to friends of an HIV-infected child who have been told about the diagnosis.

Childcare, school and leisure time

HIV-infected children have the right to go to pre-school or be at a childcare provider. The doctor treating the child shall determine whether there are any health reasons for postponing the child's start of preschool. Our experience shows that at least two staff members in the child's preschool group plus the preschool manager should be informed of the child's diagnosis. The preschool staff knows how the child spends his/her days and can work with healthcare professionals in the event of any problems or questions regarding the child.

Going to school is a major and important part of a child's day. The school nurse and school doctor must be informed about child and his/her HIV diagnosis in conjunction with the start of school. School Health Services is an important collaborative partner. The healthcare staff and School Health Services staff can talk to each other about the child's state of health and vaccinations. They can also work together if any concerns or special questions about the child arise.

It is our firm opinion that an HIV-infected child should be able to go to school without informing anyone other than the School Health Services staff of the school. The school nurse should be told when the

child is informed of his/her HIV diagnosis. The school nurse is the individual the child can go to and speak with about everyday situations. The school nurse can often give the child's attending physician and other healthcare staff members a picture of how the child and family function in day-to-day life. This can be important to know when the staff meets the child and his/her family at hospital visits.

In the Stockholm region, there are conduct guidelines for the approach childcare centres and schools are to use for HIV-infected children. The guidelines were established by the team for children and adolescents with HIV at Karolinska University Hospital Huddinge together with the county medical officer, school senior physician and senior physicians in paediatric healthcare in Stockholm. These guidelines can be found on Smittskydd Stockholm's website, www.smittskyddstockholm.se.

Special conditions and stresses for children with HIV

Children with HIV have the same needs and rights as other children and adolescents. There are, however, circumstances that healthcare professionals must be particularly aware of when dealing with and caring for an HIV-infected child.

Communicable Diseases Act

HIV is a disease regulated in the Communicable Diseases Act. Because of this, individuals infected with HIV must follow special rules of conduct. If they are not followed, the patient's attending physician first assess whether the clinic can provide the support necessary to help the patient behaviour. If this is not possible, the attending physician can submit a complaint to the county medical officer indicating that the patient is not following the rules of conduct. After discussing the patient's problems with his/her attending physician, the county medical officer can summons the patient in for a discussion. If this does not help reduce the patient's risk of spreading the disease, as a last resort the county medical officer can apply to the county administrative court to have the patient taken into custody at the hospital for isolation. Isolation of a child, however, would violate the Communicable Diseases Act's guidelines on the best interests of the child.

The Communicable Diseases Act also places requirements on healthcare professions, including requirements to perform contact tracing and inform the patient on the rules of conduct that have been established. The most common route of transmission for young people is mother-to-child transmission, in other words the virus is passed on from mother to

child during pregnancy, delivery or breastfeeding. The healthcare staff therefore seldom perform any actual contact tracing in the same manner as for adult patients. If the mother is not infected with HIV or if her status is unknown, it becomes more important to try to find out how the child contracted the disease. Discussion can also be used to determine a possible route of transmission, but seldom pinpoints it exactly, especially since transmission often occurs abroad.

Migration

It is not uncommon for migration to cause people to not feel well or to go through a crisis. The majority of children with HIV in Sweden are immigrants and many have moved, been separated from loved ones and lived in uncertain circumstances while waiting to come to Sweden. The children and parents generally have not have time to establish roots in Sweden or figure out how they fit into things when they get the HIV diagnosis. This puts great pressure on those working with HIV.

The families are often worried that information on their HIV status will get out in their own ethnic group. It is not uncommon for them to refuse use of an interpreter for doctor visits and discussions. We would like to provide a reminder that we – the healthcare

staff – are the child's representative and must always work based on what is in the child's best interests.

Abandoned children

It is not uncommon for the children with HIV that we meet to have been abandoned for a shorter or longer time by important adults. For example, the child may have been left with relatives for a period of time while the parent/parents moved to a different country. It could take several years before the parent is reunited with the child. The family the child moves in with may be totally different from his/her original family. The parents could be remarried, new and healthy siblings may have been added to the family and there may even be healthy stepsiblings in the family. In such cases, we often know very little about what the child has been through during the time the parents were not directly in the picture.

Many children have moved repeatedly between different relatives and may have even been sexually, physically or mentally abused. Some children have also been forced to support themselves through methods such as prostitution. This is often extremely hard for the child to talk about.

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New family

Children may be alone because their parents have died. They may have spent a long time living with relatives or neighbours and then finally moved to relatives living here in Sweden. It is our experience that families who take in a child or a group of siblings for relative adoption often do not know about the child's HIV status. The status does not become known until the child arrives in Sweden. The families do not always actively work to incorporate the child into the family. This could make it more difficult to fit in and cause problems for these children and the families. In recent years, we have also seen several adoptions where families take in a child with known HIV infection that they did not previously have any family relationship with.

Family composition

Most children with HIV in Sweden that we meet do not live in a whole family with biological parents and siblings. Many live with one parent, in a step family or in an adoptive family or have been placed in a "family home". Many children have lost one or both parents and siblings. Talking about the grief and loss therefore becomes a natural part of work with HIV-infected children.

Cultural view of disease

Those of us working in healthcare must be sensitive and open to the fact that illness and healthcare is viewed differently in different cultures. We must also know about and understand how the view of HIV differs depending on the HIV situation in the home country. Our experience is that it is important to sit with the family and discuss HIV from different aspects and ask the family about their own thoughts on HIV.

National Knowledge and Resource Centre

for children and adolescents with HIV infection

A knowledge and resource centre for children and adolescents with HIV infection has been in place at Karolinska University Hospital in Huddinge since autumn 2008. There is a medical social worker, nurse and doctor to contact for support, discussion and knowledge. We offer to come to children's and infection clinics that take care of children with HIV and should be considered a consulting and education enterprise. One example of support can be a doctor and medical social worker travelling to a clinic and sitting with the staff who work with the patients to go through test results, medications, doses, etc. and look at the psychological support. Giving lectures, drafting informational material, gaining knowledge on children and HIV and finding good examples from outside sources is part of the work being conducted right now.

Contact the head medical social worker by telephone +46 (0)8-585 847 56 or +46 (0)73- 699 42 94.





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