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Special Note for Foster Parents:

Before discussing any information about HIV with your foster child who has HIV, your other children, or your other foster children, talk with your caseworker about how to handle HIV information.

(See Special Information for Foster Parents, How does the HIV Confidentiality Law affect foster parents? page 9–15, Who can have HIV information about my foster child? page 9–17 and Can I tell others that my foster child has HIV? page 9–18.)
How do I tell my child that he/she has HIV?

All children need information about their health. Telling your child that he/she has HIV is important. But, it is your decision when to tell your child and what to tell your child. This is not easy for anyone. You may feel like you need to protect your child from being upset. You may also worry that your child will tell others and be rejected. These are real concerns. But waiting for the “right time” may not be a good idea. The “right time” may never come. Even if you do not tell your child with words, he/she can probably sense that something is not right. By not talking to your child about his/her health, your child may feel like:

- something is wrong.
- something bad has happened and it is his/her fault.
- he/she is being punished for something.
- you have a secret and it is not OK to talk about it.

Remember, even as adults, we often think the worst when we do not have the facts.

The HIV information your child needs will depend on his/her age and how much he/she can understand. As your child grows, he/she will need more detailed information. Here are some suggestions that may help you plan how and when to tell your child.
Suggestions for talking to your child about HIV

**Talk to others.**

- Talk to your child’s doctor or **social worker**. They can give you ideas about what to say and set up the support of a **mental health professional, child life specialist,** or support group.

- Talk to other parents to get ideas about what to say.

**Think about what you will say.**

- Take time to think about what you will say and how you will say it.

- Keep in mind your child’s age and what he/she can understand.

- Give your child information in a hopeful way.

- Answer your child’s questions in a simple way and be honest.

- Do not give your child more information than he/she needs.

- Never lie. If you do not know an answer, say so and get the facts.

- Never tell your child he/she has a disease that he/she does not have. This will only hurt your child’s feelings once he/she finds out the truth.

- Make sure your child understands that **HIV** is not a punishment for something he/she has done.
Talking with a young child about HIV

You may have already been talking to your child about his/her health. You do not have to start by using the words “HIV” or “AIDS.” Those words will have very little meaning to a young child. As an example, you might want to tell a young child that he/she was born with a virus and it is important to take medicines to stay healthy.

Your child will give you chances to talk about his/her health. Watch your child's body language and be open to his/her questions. If you see your child is not as active as usual or not acting normal, ask how he/she is feeling. This will let you know how your child is doing and give you a chance to talk about his/her health. Your child may also ask you questions like, “Why do I have to go to the doctor?” or “Why do I have to take medicines that my brothers and sisters do not have to take?” Use questions like these to help your child understand his/her illness. Start by asking your child why he/she is asking the question. This will help you find out:

- what he/she is thinking or worried about.
- how much information he/she needs.

One child asked his mother if he had AIDS. The mother was so surprised that she said no. Later, she was upset that she missed the chance to talk with him about his thoughts and fears.

A young child is often afraid of doctors, nurses, clinics, and hospitals. Most of his/her fear comes from not knowing what will happen. A child may fear being left alone or feeling pain from shots and tests. Your child may best be able to show you how he/she feels by drawing pictures or using puppets or action figures to act out his/her fears.
Questions a young child might ask and possible answers

Why do I have to go to the doctor so much?
- “The doctor wants to see how big you are getting.”
- “The doctor wants to see how well your medicines are working.”
- “The doctor wants to keep you healthy.”

Will I get a shot? Will it hurt?
If you know your child will get a shot, be honest and say so. You can also say, “When I get shots, they hurt a little bit, but only for a few seconds.” Or say, “It might sting for a minute.”

Why do I have to take medicines?
“The medicines you take will help you stay healthy.”

Will I have to go to the hospital?
If you are not sure, say so. You could say, “The doctor will tell us what she thinks and we will talk about it. Do not worry. No matter what, you will not be alone.”

Why am I so small for my age?
“Not everyone grows at the same rate, but if you are concerned about your size, we can talk about it with your doctor.”

(See Keeping My Child Healthy, How can I prepare my child for doctor or clinic visits? page 2–15.)
What is HIV?

“HIV is a virus that can make you sick.”

Why do I have HIV?

“You were born with it.”

A mother with HIV might also say, “I had HIV when I was pregnant with you. That is how you got it.” A foster parent might say, “Your mom had HIV while she was pregnant with you. That is how you got HIV.”

As your child gets a little older, he/she will be able to understand the importance of his/her immune system. And how hard it works to protect him/her from getting sick. Your child will also be able to understand:

- If given a chance, HIV can change itself.
- His/her immune system needs the help of medicines to stay strong.

(See HIV: The Basics, What are the goals in treating HIV? page 1–10 and How do medicines slow down or stop HIV? page 1–11.)

You also need to teach your young child

- not to let other people touch his/her blood.
- not to touch other people’s blood.
- not to share toothbrushes.

Give your young child simple information. As his/her understanding increases, give him/her more detailed information.
Talking with an older child about HIV

Your older child may want to know how he/she got HIV and if others in the family have it. He/she will also need more information on how HIV works and how it can be controlled. Your child needs to understand:

- why it is important to go to doctor and clinic visits.
- how HIV attacks the immune system.
- how the medicines he/she takes help control HIV.
- how a strong immune system will keep him/her healthy.
- how the virus and his/her immune system are checked by the doctor.
- unless a cure is found, he/she will always have HIV.

Knowing about HIV will help your child work with the doctors to make decisions about his/her treatments and medicines. Including your child in decision-making may help him/her stick to the medicine schedule and keep a healthy outlook about living with HIV.

(See Keeping My Child Healthy, How do I prepare my child for doctor or clinic visits? page 2–15.)

You also need to teach your older child how to

- prevent passing HIV to others.
- protect himself/herself from other infections, such as STDs.
Make sure your child understands that HIV is passed from person to person when someone with HIV gets his/her blood, semen, vaginal fluid, or breast milk inside another person's body. This means HIV can be passed in the following ways:

- having unprotected sex (sex without a condom).
- sharing needles or works to shoot drugs or sharing needles for piercing or tattooing.
- sharing toothbrushes or razors.
- during pregnancy, child birth, or breast feeding from mother to infant.

When your child protects others from getting HIV, he/she also protects himself/herself from getting other infections. Other infections may include STDs, different strains of HIV, hepatitis, etc.

(See Helping My Adolescent Deal with HIV, How can I teach my teen about health risks and preventing the spread of HIV? page 8–11 and What does my teen need to know about sex and HIV? page 8–23.)

**My child did not react to being told he/she has HIV.**

Most children have a hard time understanding how HIV will affect their lives. This is especially true for a young child. When children are told they have HIV, some will listen, and some will start talking about something else. They may forget what was said and need the information given to them a number of times.

Be patient with your child. Look for chances to give your child information about his/her health. Make sure the information you give is at the level your child can understand.
What if my child accidentally finds out he/she has HIV?

If you decide not to tell your child that he/she has HIV, chances are that sooner or later he/she will find out.

- Your child may hear people talking and feel like something is wrong.
- Your child may see ads for HIV medicines he/she is taking.
- Your child may see HIV information in the clinic or doctor’s office that relates to him/her.

**By not talking about HIV, your child may think it is not OK to talk about his/her feelings.** An example of this is a 7-year-old boy who told his doctor he had AIDS. He asked the doctor not to tell his mother because it would make her sad. In another case, a 14-year-old boy found out that the medicine he was taking treated HIV. The boy became angry and depressed and stopped going to school.

If your child accidentally finds out he/she has HIV, chances are that he/she may be very angry or upset. This may affect your child’s behavior at home and at school. And worst of all, your child may have a hard time trusting you and the rest of the family. Your child will most likely need the support of a mental health professional. Talk with your child’s doctor or social worker to help set up a meeting with a mental health professional and see if there is a support group for your child.
(See About Mental Health, What is mental health and why is it important? page 6–2, What does a mental health professional do? page 6–6, and Where can my child get mental health care and how do I pay for it? page 6–8.)

How do I tell my other children that their brother/sister has HIV?

When a person has HIV, the whole family is affected. Even if you have not told your other children, they may already sense that something is different about your child with HIV. Brothers/sisters see your child with HIV:

- getting a lot of attention.
- taking medicines.
- going to doctor and clinic visits.
- not feeling well.

Never force information on your children, but if they ask you questions, be honest. You may not be ready to say the word “HIV,” but they need to know about the health of their brother/sister with HIV. You might say:

- “Joey has a problem with his blood and needs to take medicines to keep him healthy.”
- “The doctor wants to see Maritsa to make sure the medicines she takes are helping her.”
“Denzel started taking new medicine and is not feeling well, but in a few days, he may feel like playing again.”

“Tanya is not going to school today because she has a very bad cold.”

Your children need to know:

- they did not cause their brother's/sister's illness.
- they will not get it from their brother/sister by everyday activities, such as playing together, sharing toys, or hugging each other.
- their brother/sister is getting good care from the doctors and nurses.

If you decide you want to tell your children about having HIV in the family, talk to your child’s doctor, social worker, or other parents who have children with HIV. This will help you think about what you will say to your children. It may be best if you and the other adults in the household decide:

- who should be told.
- what will be told.
- when the information will be told.

Depending on the ages of your children, this information may be very overwhelming for them. Before you tell your children, set up needed support for them. This may mean:

- finding family members or friends who know and are willing to help your children if they need to talk about HIV, and what it means for them and their family.
- setting up social worker or mental health professional visits for them.

Use the information listed in Living with HIV, How do I tell my other children that their brother/sister has HIV? page 5–11 as a guide to help you talk to your children. HIV: The Basics, pages 1–2 – 1–11, will also give you information to help you explain:

- how HIV is passed from person-to-person, and how it is not.

- what HIV does to the immune system.

- the goals of treating HIV.

You also need to make sure your children know:

- not to touch blood.

- not to share toothbrushes, razors or anything that may have blood on it.

Once you tell your children, watch their behavior. They may feel sad, act out at home or in school, or want to be alone. Talk with your children about their feelings. Let them know their feelings are normal and that you have set up a support system for them.
How do I tell family members outside my household that my child has HIV?

It is your choice to tell family members that your child has HIV. Some family members can be very supportive and helpful. By telling these family members that your child has HIV, it may take some of the pressure off you and your family. Family members can:

- give you a break from time-to-time by taking care of the children.
- help with meals, household chores, and errands.
- help you take your child to doctor or clinic visits.
- be helpful when your children have questions or need to talk to someone.
- keep HIV information private.

Some family members may not be supportive or be able to deal with HIV in the family.

Family members may:

- reject you and your family.
- tell others that your child has HIV.

Special Note for Foster Parents:

Foster parents may disclose HIV information concerning their foster child to others only if it is necessary to provide care, treatment, or supervision of their foster child. For instance, family members who are not caring for the child do not need to know. If you have questions, talk with your caseworker.
How can I teach my children to know when it is OK to share private information?

Some information we do not share with just anyone. It is information that should be kept within the family. This is called private or confidential (konˈ fi den shel) information. Private information might include:

- how much money the family has.
- how much money we owe on our credit cards.
- our health problems.

Privacy is something everyone needs and deserves. Sharing HIV information with family members, friends, neighbors, and others is a personal decision. For some families, HIV is a private matter. Your children need to know that they have a right to their own personal privacy and the privacy of their family. The first step in talking about private or confidential information may be respect. Your children learn from you and the other adults in their lives. Respecting privacy may best be taught to your children by how family members treat each other. You may have already set up rules to teach your children to respect privacy. Examples may include:

- knocking on the bathroom door before going in.
- not listening when someone is talking on the phone.
- not telling friends that a brother or sister has a problem, like bed wetting.
Give your children guidance as to what to say and when to say it. Unless your family is very open about HIV, you may want to tell your children that you will be responsible for letting people know that someone in the family has HIV. This will take some of the pressure off your children.

Your children will also face questions from family, friends, and neighbors. To help them think about what they will say, you may want to help them practice answering some questions.

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
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<tr>
<td>Does your brother/sister have AIDS?</td>
<td>No. He/she has a problem with his/her blood, and needs to take medicine to stay healthy.</td>
</tr>
<tr>
<td>Why does your brother/sister have to take medicine in school?</td>
<td>“He/she takes medicine to stay healthy.”</td>
</tr>
<tr>
<td>Your brother/sister has been out of school a lot. What is wrong with him/her?</td>
<td>He/she has not been feeling well, but he/she will be back to school soon.</td>
</tr>
<tr>
<td>Do you have AIDS?</td>
<td>No.</td>
</tr>
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You also have to prepare your children for people who do not understand what it means to have HIV. Your child with HIV, your other children, or you may be called names or talked about in unkind ways. Talk to your children about what to do when this happens, and how to handle their feelings.

Last, you need to prepare your children for what they might hear on the news or in their classrooms about HIV and AIDS. The information they hear may seem very scary when they think it relates to themselves or to their brother/sister. News of the
death rates for people with AIDS is very high in some countries, especially in Africa. School health classes may also scare your children with the information they are given.

As said earlier, the whole family is affected by HIV. Do your best to encourage your children to talk about issues with you.

- Be open to your children’s questions.
- Make sure they have family members or friends they can talk with.
- Talk with your child’s doctor or social worker about mental health support for your children.

**When is it important to share my child’s HIV information?**

Your child will have a team of health care providers taking care of him/her. For your child to get the best possible care, it is important that they all know your child has HIV. Even when your child may need the help of another health care provider, like an emergency room doctor, it may be best to tell him/her, as well.

(See *Keeping My Child Healthy*, How do I get the best care for my child? page 2–5.)

Doctors, nurses, dentists and other health care providers must give people the best possible care they can whether a person has HIV or not. By New York State law, health care providers, social service providers, and anyone else who gets HIV information from a special written HIV release must keep patient HIV information confidential.
How do I set up and keep routines and family rules for my child with HIV and my other children?

Routines

A routine is something that usually happens the same time everyday. Routines are very important for children. It makes them feel secure by giving them a sense of order and knowing what to expect.

Examples of routines include:

- going to bed.
- waking up.
- eating meals.
- brushing teeth.
- washing hands after using the bathroom, and before and after meals.
- taking a bath or shower.
- getting ready for school.

Try to make routines as regular as possible.
- doing homework.

Taking medicines or vitamins should also be part of your children’s routine.

- For your child with HIV, it will help him/her take medicines on time everyday.

- For your children who do not have HIV, they can get their vitamins everyday and feel as important as the child with HIV.

Since most medicines are taken 2 times a day, medicine-taking may be linked to brushing teeth before going to school and getting ready for bed. Be careful when routines are less likely to happen, like on Saturdays, Sundays, or when your children have school vacations.

**Family rules**

Family rules make daily routines work. All children, including your child with HIV, need to know the rules and what behavior is OK, and what behavior is not. Adults in the household should agree on family rules, and what will be done when rules are not followed.

**Be realistic with the rules you set.**

For example, your children will need more than 15 or 20 minutes to get ready for school in the morning. (This is very true if some children have a hard time getting up, you have 1 bathroom, or there are issues with what your children want to wear.) If you are always after your children for breaking the rules, you may need to rethink the rules you have set.

Make sure the rules you set and the discipline you use when rules are not followed are based on your
children’s age, health, and development.

**Praise your children often, even for the small things.**

Be careful not to focus only on the rules that get broken. We all can get caught up in the events of the day. Stop and notice the things that go right. Even if those things seem small or unimportant, they deserve your praise. For example, thanking your child for going to bed on time without an argument will:

- make your child feel good about himself/herself.
- let your child know you appreciate his/her good behavior.
- likely make him/her go to bed on time without an argument the next time. Do not forget to praise your teen. Believe it or not your teen needs just as much praise as a young child!

**If possible, talk with your children before a rule or routine needs to be changed.**

This may happen when you let the children stay up late for a special party or event, or when your child with HIV is not well enough to do his/her chores. Try to avoid your children feeling hurt or angry that their brother/sister with HIV “gets away with everything.”

**It is not easy being the brother/sister of someone with a life-long health condition like HIV.**

Brothers and sisters may:

- feel less important because so much time is spent...
with the child who has HIV.

- feel guilty that they are not sick.

- feel like they want to be sick to get more of your attention.

- feel like they want to make the child with HIV better.

- feel like they need to protect the child with HIV.

If you think this is happening, talk about these feelings with your children to help them understand this is normal. Your doctor or social worker can help you find a support group or mental health professional for your children. The whole family is affected by HIV and everyone needs to express their feelings from time-to-time.

(See About Mental Health, What is mental health and why is it important? page 6–2 and Where can my child get mental health care and how do I pay for it? page 6–8.)

If you have questions about your children’s behavior, how to set limits and rules, or how to maintain them, your doctor, nurse, or social worker can help. They can also refer you to parenting programs if you need additional information.

**Can my child go to day care or school?**

Children with HIV can go to day care and school.

**Going to school**

_gives your child a normal routine, lets him/her make friends while learning, and keeps your child active._
like all other children. School is the major social activity for all children. It is important for your child with HIV to be part of as many normal childhood activities as possible.

You may have questions about letting your child be around other children. You may be worried that your child could get sick from one of his/her friends. Children in day care and school may get frequent colds and upset stomachs. But this can happen even at home when your child is around other members of the family. No matter where they are, when children get together, colds, upset stomachs and other illnesses can happen. If you are worried about sending your child to day care or school, talk to your child’s doctor or nurse. There are very few children with HIV that cannot be in day care or school because of their health.

Questions you can ask to find out how day care or school staff handle children’s illnesses or accidents

- How are parents told about illnesses that are easily passed from child to child? For example, how would you find out if someone in your child’s class has chicken pox?

- Is there a nurse in the building during school hours or a few hours a day?

- Who gives medicine to children who need it during the day?

- What is done when a child is bleeding?

- What are the rules for keeping a child at home if he/she has diarrhea (diˈərəˈe), a fever, etc.?

- What is the policy for children who bite?

- What is the hand washing policy for staff
and children?

If the answers to these questions are OK, you may feel better about sending your child to day care or school.

If the answers to these questions are not OK, you can:

- pick another day care for your child.
- talk to the school nurse at the public or private school your child attends to discuss your concerns.

You will also have to teach your child about washing his/her hands while in school, and what to do if he/she:

- gets sick.
- comes in contact with a person who is sick.
- gets a nose bleed, cut or scratch.
- needs to take medicine.

Are there times when my child should not go to day care or school?

There are some reasons why your child should not go to day care or school.

- If your child has severe diarrhea, or your toddler has very frequent messy diapers. He/she should stay home until the diarrhea is better.
- If your child has a fever, he/she should stay home.
If your child has a draining sore, he/she should stay at home until it is better.

If your toddler bites, he/she should not be in day care until he/she stops biting.

If you are not home during the day and your child is too sick to go to school or stay in school, you need to find a responsible babysitter. It may also be a good idea to find a back-up babysitter. You may need to teach this person how to give medicines, if needed, and how to give other special care that may be needed. A regular babysitter may need to know your child has HIV. This will help the sitter give your child the best care, make sure the sitter protects herself/himself, and lets the person know not to babysit when he/she is not feeling well.

What if my child needs extra help to learn and develop skills?

Early Intervention Program

There is so much for infants and toddlers to learn. Although not all children develop and learn at the same rate, some infants and toddlers need some
# Skills Most Babies and Children Learn

## At 3 months, most babies:
- move both eyes together in the same direction
- react to sudden sounds or voices
- make cooing sounds
- make fists with both hands
- grasp toys or hair
- wiggle and kick with arms and legs
- lift head and chest when on stomach
- smile

## At 6 months, most babies:
- turn toward a normal sound
- follow moving objects with their eyes
- reach for objects and pick them up
- switch toys from one hand to another
- play with their toes
- help hold the bottle during feeding
- recognize familiar faces
- babble

## At 12 months (1 year), most babies:
- sit without support
- pull up to a standing position
- crawl
- drink from a cup
- play peek-a-boo, and wave bye-bye
- put objects in a container
- know 5 or 6 words

## At 18 months (1 ½ years), most children:
- follow simple directions ("Bring the ball.")
- pull off shoes, socks, and mittens
- feed themselves
- walk without help
- like to look at pictures
- go from a low step to the ground and keep their balance

## At 2 years, most children:
- use 2 or 3 word sentences
- say names of toys
- carry something while walking
- feed themselves with a spoon
- recognize familiar pictures
- like to imitate their parent
extra help. Some children born with HIV may also need extra help. Getting help early can make a difference in the way your child learns and develops. To keep track of how your child is developing, here is a chart listing some things your child will be able to do from 3 months old to 2 years old.

If you think your child is having some trouble learning the things listed on page 5-25, ask your child’s doctor or case manager about the Early Intervention Program. The Early Intervention Program is free. Program staff will evaluate your child (infant–2 years) to see if extra help is needed. If your child needs extra help, you and the Early Intervention Program will plan how best to help your child. For the phone number of the Early Intervention Program in your county, call:

New York State Growing Up Healthy Hotline
1-800-522-5006

New York Parent’s Connection
1-800-345-KIDS (1-800-345-5437)

In New York City
1-800-577-BABY
(1-800-577-2229)

Special Education Services

As your child gets older, he/she may need a special education program. Special education programs help children from 3–21 years old. If your child needs special education services, his/her school district must provide an education program based on
your child’s needs.

- If your child is 3–5 years old and you notice he/she is not developing skills such as walking, talking, or playing like other children, talk with your child’s doctor. If the doctor is concerned about your child’s development, work with your social worker or case manager. He/she can help you get your child evaluated, and if needed, enroll your child in the preschool special education program.

- If your child is already in school and having trouble with school work or getting along with others, talk to your child’s teacher or work with your social worker or case manager to get your child evaluated. If needed, the teacher, social worker, or case manager can help you make sure your child gets an appropriate special education program.

Special Note for Foster Parents:
If you think your foster child needs help from the Early Intervention Program or a special education program, contact your caseworker.
Help your child choose activities and sports that are appropriate for his/her health.

Transportation

Transportation to school may be a problem for your child if he/she cannot walk long distances or ride the school bus. Each school district has policies on transportation for children with special needs. Talk to the school nurse or your child’s doctor to get special transportation services.

Can my child join activities and sports?

Your child may want to join an activity or sport. Your child may be able to join an after school activity or sports program, a community group or club activity, or play with neighborhood friends. Activities with other children will help your child feel good about himself/herself and be like the other children. When choosing an activity your child wants to do, keep in mind how it will affect him/her.

- Can your child handle a longer day?
- Does your child have enough energy for the activity?
- Will your child have to take medicine during the
activity time?

To make sure the activity is OK for your child's health, it may be best for you and your child to talk about the activity with the doctor. If it is OK for your child to be in a contact sport, like football, you will also need to know the organization's policy for dealing with injuries.

**Can my child go to camp or stay overnight with a friend?**

Children with HIV can go to camp, but you may need to choose a camp that has special medical services. If your child needs medicine during the day, you will need to find a camp that has a doctor or nurse to give the medicines. If your child wants to go to an overnight camp, there are camps that have access to a health care provider 24 hours a day.

There are day camps, overnight camps, and special camps for children who have health conditions. Several camps provide services for children infected and affected by HIV. Ask your doctor or social worker for a list of day camps or overnight camps that are best for your child.

If your child wants to sleep at a friend’s house, you need to decide if it is appropriate. If your child has to take medicine while at a friend’s house, you need to make sure he/she packs it. It may be best to pack your child’s pill organizer rather than packing the pill bottles. You may want to make the friend’s parent responsible for giving your child the medicine. Or, if appropriate, your child can be responsible for taking his/her medicine.