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How can I meet the challenge of caring for my foster child who has a life-long health condition?

Being a foster parent can be very rewarding but also very challenging. A child in foster care with a life-long health condition, like HIV, needs what every child needs: love; understanding; stability; nurturing; and support. Every foster child also needs to have regular check-ups by a doctor and dentist. Medical and dental care are very important for a child in foster care with HIV. A health care team, including an HIV Specialist, will work together to keep your foster child healthy. A mental health professional may also be part of the team to give your foster child support.

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

As a foster parent, it is important to remember that children in foster care may have been neglected or abused by their parents or other family members. Children in foster care often have emotional scars that make it hard for them to trust adults or form bonds with their foster caregivers.

It may help you cope with your foster child’s physical and emotional problems if you keep in mind:

- the family situation(s) your foster child had.
- the reasons your foster child was placed in foster care.

Your foster child’s caseworker is a good resource to answer questions, discuss difficulties, find needed services, and provide support.
What kinds of loss might my foster child experience?

Children in foster care experience many losses. Losses may happen from a single event, such as being removed from his/her home. Losses may also happen over time where each loss builds on earlier losses.

Multiple loss

When a child is removed from his/her home and placed into a foster care home, he/she experiences many losses. These may include:

- less or no contact with a parent or parents.
- death of a parent or parents.
- less or no contact with brothers and sisters (if they are placed separately).
- death of friends with HIV in clinic or support groups.
- not being able to do what the other children do because of a life-long health condition.
- less contact with family members, neighbors, and possibly teachers or coaches.
- loss of a familiar way of living.

Even in families that had many problems, children in foster care will grieve the loss of their family home and familiar surroundings.
How do children react to loss?

Grief is an emotional reaction to loss. Everyone usually goes through the same process to resolve their grief. This grieving process takes us through 5 stages. These stages include:

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<th>Description</th>
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<td>1 Shock/denial</td>
<td>“How could this happen to me?”</td>
</tr>
<tr>
<td>2 Anger</td>
<td>“I’m so mad that you left me!”</td>
</tr>
<tr>
<td>3 Bargaining</td>
<td>“If I’m good, Mom will come back for me.”</td>
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<tr>
<td>4 Despair</td>
<td>“I’m never going to go back home.”</td>
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<td>5 Accepting/understanding</td>
<td>“Right now, it is not safe for me to live at home. Mom is getting the help she needs.”</td>
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Although we all go through the same stages of grief, children do not always show their grief in ways that adults do. Children may bounce back and forth between the stages. They can also get stuck in one of the stages. Grief can sometimes even seem like it comes and goes. This may be especially true for young children who have a limited ability to tolerate painful feelings.

Holidays, birthdays, and anniversaries may be difficult since they bring back so many family memories. It is not unusual for children and adolescents to feel sad, behave poorly, or show grief in other ways. Remember that everyone, even children, grieve in their own way. Here are some ways that children may show grief.
Emotional responses

Children and teens may experience a range of emotions as they grieve. These may include being sad, lonely, guilty, angry, anxious, depressed, jealous, or fearful. These reactions may come and go over time. Some grieving children may:

- constantly think about their losses.
- constantly ask questions or talk about losses.
- glamorize parents or other people from their past.
- struggle spiritually with losses, asking “Why would God do this?”
- have difficulty getting close to others or relating to others.
- have trouble concentrating.

Children in foster care may feel like they were taken from their home as a punishment for something they did. They may also feel anxious or depressed. This may lead to nightmares, temper tantrums, aggressive behavior, or not doing well in school. All of these reactions are normal. No matter how bad things were at home, most children in foster care will feel deep sadness, confusion, and grief as a result of being removed from their home.

Physical responses

Children and teens may experience grief physically. They may complain of aches and pains, such as headaches or stomachaches, or feel very tired. It may help to notice if there is any pattern to these physical symptoms. For example, do they happen before or after a visit from a parent?
Behavioral responses

Children may also show their grief in how they behave. Some children may express grief by:

- acting out.
- withdrawing.
- going back to baby or young child-like behaviors (thumb sucking or bed wetting);
- having problems in school (trouble learning, following directions, etc.).
- having sleep disturbances (nightmares, cannot fall asleep or stay asleep).

How can I help my grieving foster child?

Your support in helping your foster child grieve and resolve his/her losses will affect how your foster child handles loss now and in the future.

Your foster child needs the consistent, comforting presence of an adult who can be trusted and relied upon. Listen carefully to your foster child’s words and watch his/her actions. Some children, especially young children, may not be able to talk about their feelings or tell you what is bothering them. Instead, their behavior may show you how they are feeling. Work with your caseworker and,
if possible, the parent(s) to recognize your foster child's need to grieve. A mental health professional may also be needed to help your foster child work through and resolve his/her grief.

**Listen, Listen, Listen.**

The most important gift in helping your grieving foster child or teen is to listen when he/she needs to talk about losses. Your foster child will most likely talk about grief when he/she feels it is safe to express feelings and experiences. Do not get defensive, overprotective, or try to talk your foster child out of his/her grief. Your foster child’s comments about how he/she misses a parent or home does not mean he/she rejects your care.

**Set boundaries.**

While a grieving foster child or teen may show grief in the way he/she behaves, it is important to set limits on behavior. Clear, consistent rules will help your foster child as he/she deals with grief. It may be best to discuss concerns and strategies with your caseworker and your foster child’s doctor or mental health professional.

**Use resources.**

There are many books and videos to help children and teens deal with loss. These resources can help you talk with your foster child. They can also help your foster child understand his/her losses and his/her reactions to those losses. A support group for grieving children or teens may also be helpful.
if available. Talk with your caseworker, foster child’s doctor, nurse, mental health professional, social worker, or school guidance counselor about resources.

Get Help Now!

If your foster child acts in ways that are dangerous to himself/herself or dangerous to others, get immediate help. Call your caseworker, and your foster child’s mental health professional, doctor, or nurse if you have any concerns about how your foster child is coping with loss.

(See Helping My Adolescent Deal with HIV, How can I tell if my teen is depressed? page 8–38.)

Take care of yourself.

As children move in and out of your foster home, you also will experience a sense of loss. You may also share their personal losses. As you care for a grieving foster child or teen, be aware of your own losses and grief. Being aware of your own grief and loss can make you better able to respond to your foster child’s needs. It is always helpful to talk about your own experiences of loss and the ways these losses are affecting you. Ask your caseworker to recommend a counselor or support group that may help you cope with the emotions and stresses of being a foster parent.

(See Taking Care of Myself and My Family, How can I stay healthy and get the support I need? page 7–2 and What if I need a break? page 7–5.)
How can I work best with my caseworker?

It is important to understand your role and the role of your caseworker. Your caseworker is the person you call when you need information, services, or support. The caseworker is there to answer your questions, discuss problems, recommend solutions, and help arrange necessary services for you and your foster child.

Foster parents have a key role in identifying the needs of foster children in their care. You must be watchful and talk with the caseworker about your foster child’s adjustment to foster care, as well as any successes, difficulties, or special needs your foster child may have.

Important questions for your caseworker

You should already have information about how your foster child will be cared for in the future. As a foster parent, you have a right to know, to review and to participate in the foster care agency’s service plan, and the family court’s hearing on the permanency plan for your foster child. It is very important for you, your foster child’s parent(s), and your caseworker to work toward your foster child’s permanency plan for the future.

As a foster parent, you have a right to the background information of all children placed with you. You can get this information from your caseworker. Here are some questions to guide the discussions you have with your caseworker.

Good communication between you and your caseworker may help your foster child adjust better to foster care.

Make a list of your questions and concerns before you meet with your caseworker.
Family

- What is my foster child’s background?
- Why was my foster child placed in foster care?
- Is there a visitation plan for my foster child and if there is, what is it?
- What can you tell me about my foster child’s family and/or previous placements that will help me better care for him/her?
- Can you tell me a little about the family members so I can talk to my foster child about the people he/she is missing?
- Is there a telephone number(s) my foster child can have to contact family members?
- Are there any family pictures, or other personal belongings my foster child can bring?
- Can I meet the parents to learn more about their child and how I can best help?

Health care

- Who are my foster child’s doctor and dentist?
- Does my foster child have more than one doctor? If so, what are the doctors’ names, telephone numbers, beeper numbers, and emergency numbers?
- When and how often does my foster child go to the doctor for routine care? When is his/her next visit?
- How has HIV affected my foster child so far (any hospitalizations, surgery, special problems)?
Does my foster child wear glasses, contacts, hearing aids, or need other special equipment, such as a nebulizer or epi-pen?

Does my foster child have special care requirements, such as allergies or a special diet or developmental needs?

Does my foster child have a mental health professional? If so, who is it? What is the telephone number, beeper number, and emergency number?

Has my foster child been hospitalized for a mental health issue?

**About medicines**

Is my foster child taking medicine? If so:
- How does my foster child take medicine(s)?
- When is it given?
- Is it given with or without food?
- Is it in liquid, powder, capsule, or pill form?
- Are pills crushed and mixed with liquid or food? If so, what seems to work best?
- Does he/she take pills?
- Does he/she like a special drink to help swallow medicine(s)?

What are the common side effects of the medicine? Are there any other medicines that may cause problems if mixed together?

Has my foster child had any side effects from medicine? If so, what are they and how have they been managed or treated?
Is my foster child taking any **antiretroviral** (an tı´ ret rō´ vī ral) **medicines**, or has he/she taken any in the past?

Is there any advice for when my foster child needs to take medicine, get shots, or go to the doctor?

**Disclosure**

- Who knows my foster child has **HIV**? (Such as, family members, neighbors, school nurse, etc.)
- Does my foster child know he/she has HIV?
- What has my foster child been told about his/her illness?

(See **Special Information for Foster Parents**, Who can have HIV information about my foster child? page 9-17, How does the HIV Confidentiality Law affect foster parents? page 9-15, and **Legal Issues**, How does New York State protect the privacy of my child with HIV? page 10–2.)

**School**

- Where does my foster child go to school?
- Does anyone at school know my foster child has **HIV**? If so, who?
- Are there any special transportation needs?
- Does my foster child need to take medicine during the school day?
- Does my foster child have any problems in school, such as not being able to do his/her school work, following directions, paying attention, getting along with others, etc.?
Is my foster child in special education classes?

Does my foster child have a favorite teacher or favorite class?

Is my foster child in any after school activities or sports?

**Likes and dislikes**

- Does my foster child have any fears?
- Are there special foods my foster child likes?
- Does my foster child have a special toy, stuffed animal or blanket?
- What are my foster child’s interests? (Such as, music, sports, clothing, etc.)

**Information and services for me**

- How do I get more information about HIV?
- Are there support groups for me?
- Are *respite* services available?
  
  __________________________________________
  
  __________________________________________

**Other**

  __________________________________________
  
  __________________________________________
Who can consent to health care for my foster child?

The foster parents are not permitted to consent to health care for a foster child at any time, or under any circumstance.

Your foster child’s birth parent or guardian must consent to health care for his/her child. The local commissioner of social services, or the person he/she identifies, may provide consent for your foster child’s medical care and treatment:

- if the birth parent’s rights have been surrendered or terminated and your foster child is freed for adoption.

- if the child had been taken into protective custody because of abuse or neglect or had been adjudicated as an abused or neglected child.

- where the birth parent/guardian has delegated their right to consent to the local commissioner of social services.

Be sure your caseworker gives you a letter stating that your foster child is in the custody of the Local Department of Social Services (LDSS) and you are the foster parent. The letter should also name the person to contact that can give permission for the doctor to provide care (have blood work and tests done, admit to the hospital, etc).

(See Legal Issues, Who can give permission for my child or adolescent to get medical care and treatment? page 10–8.)

Foster parents are never permitted to consent to health care for their foster child.
Minors

Anyone younger than 18 years old, including a child in foster care, is a **minor**. In New York State, there may be times when a minor does not need anyone to say OK for him/her to get health care. If a minor can understand the risks and benefits of treatment, he/she does not need anyone else to **consent** for:

- emergency health care.
- certain mental health services.
- certain alcohol and drug abuse services.
- reproductive health care.

Reproductive health care includes: family planning; abortion; prenatal care; care during labor and delivery; **HIV** testing; and care for **STDs** (sexually transmitted diseases).

Some **minors** can **consent** to all of their own health care. This includes minors who are married or who are parents. Also, minors who are pregnant can consent to health care related to their pregnancy.

How does the HIV Confidentiality Law affect foster parents?

New York State has a law that protects the confidentiality of all people with **HIV** or **AIDS**. The **HIV Confidentiality Law** (Public Health Law Article 27-F) protects HIV information for people who have been **exposed** to HIV, tested for HIV, or have HIV or AIDS. Foster parents, prospective

Minors who can understand the risks and benefits of treatment can sometimes get health care without the OK from their parent, guardian, or the local commissioner of social services.

New York State law protects the confidentiality of all persons with HIV, including children in foster care with HIV.
adoptive parents, health and social service providers, and child welfare agency staff who have information that a foster child has been tested for HIV or has HIV must keep that information confidential. Unauthorized disclosure of HIV information by health care providers, social service providers, or anyone else who gets HIV information from a special written HIV release could result in a fine of up to $5,000 and/or one year in jail.

(See Legal Issues, How does New York State protect the privacy of my child with HIV? page 10–2.)

HIV information includes:

- verbal reports or written records of any medical tests that show a person has been tested for HIV, has HIV, or has a medical condition caused by HIV.

- verbal reports or written records of a person who has received medical treatments for HIV or an illness caused by HIV.

- other information that shows a person has or may have HIV or an illness caused by HIV.

The HIV Confidentiality Law holds no penalty for your family members, friends, neighbors, or your foster child’s teachers who do not keep HIV information private. For this reason, it is very important to be careful about sharing your foster child’s HIV information. Be sure to talk with your caseworker before you disclose your foster child’s HIV status.
Who can have HIV information about my foster child?

Under New York State Law, the following persons or agencies can have access to HIV information about a child in foster care:

- foster parents or approved kinship foster parents who have responsibility for the foster child’s medical care.
- health care providers who are caring for the child in foster care.
- authorized agencies involved in the foster care or adoption of the child or another authorized agency if the child is transferred.
- prospective adoptive parents of a child in foster care who is legally freed for adoption.
- the adoptive parents of a child in foster care.
- the birth parents of a child in foster care when the child is returned to their care (if the child lacks capacity to consent).
- the birth parents of a child in foster care when the child is returned to their care (if the child has the capacity to consent and provides written consent to disclose the information).
- the attorney of the child in foster care for the purposes of representing the child.
Can I tell others that my foster child has HIV?

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.

If necessary, foster parents may disclose HIV information to the following people or agencies:

- health care and social service providers (doctor, nurse, dentist, case manager, etc.).

- relatives, neighbors, or others directly and substantially involved in the care or supervision of your foster child.

Foster parents should be sensitive to their foster child’s desire to keep his/her HIV information confidential. When appropriate, foster parents should have open and honest discussions with their foster child before HIV information is shared.
What if I am ordered to give HIV information in court?

Foster parents and prospective adoptive parents never have the right to disclose in court any HIV information concerning a foster child, his/her birth parents, or guardian except in abuse and/or neglect cases (Article 10). Only the foster child’s birth parent, attorney, or, in certain situations, the Local Department of Social Services, may do so. It is important to know that HIV information cannot be shared even if you are issued a subpoena. Tell your caseworker if you receive any requests for HIV information about your foster child from family members, school authorities, lawyers, courts or others.

Seek advice from your caseworker if you are asked to give HIV information about your foster child.