



Toolkit for Health Care Providers Treating Children with a Life-Threatening Illness

General Information:

- Having a life-threatening illness can be traumatic for children and families at many points along the diagnosis and treatment continuum (including survivorship,) and can be impacted by perception of life-threat.
- Perception of life threat is often unrelated to (objective) prognosis. Parents who believe that their child might die or children who believe that they could die can be at increased risk for persistent posttraumatic stress.
- Parents and siblings can also be affected, even after treatment ends. Some parents become hypervigilant for signs and symptoms that the illness has returned. Siblings may worry in private about their brother or sister.
- Treatment can be painful and emotionally difficult at times. Treatment setbacks sometimes occur, in addition to physical changes and limitations. Parents often feel helpless when they see their child in pain, and a child in pain can feel angry, frustrated or depressed. In addition to pharmacologic and behavioral interventions, emotional support and family resources are vital to helping children and families cope with the painful and emotional aspects of treatment.

Universal Interventions for Providers:

1. Educate yourself about traumatic stress responses in children and families in medical settings (see brochure.)
2. Actively assess and treat pain, using your hospital's protocol.
3. Take steps to minimize additional exposure to traumatic elements within the hospital environment (e.g. scary sights and sounds, painful procedures, etc.)
4. Provide information to parents on coping with traumatic stress responses. See parent handouts:
 - At The Hospital: Helping My Child Cope
 - At The Hospital: Helping My Teen Cope
 - After The Hospital: Helping My Child Cope

Maria is a typical 13 year-old girl — active, social, and friendly. One day, she complains to her mother of “not feeling quite right.” A few days later, Maria looks pale and complains of being tired all the time. She begins missing school and after school activities...

Maria’s mother becomes concerned and takes Maria to her pediatrician, thinking that she might have the flu or be anemic. The doctor examines Maria and does some blood tests. The next day, the doctor recommends that Maria and her mother see a specialist at the hospital for further evaluation for cancer.

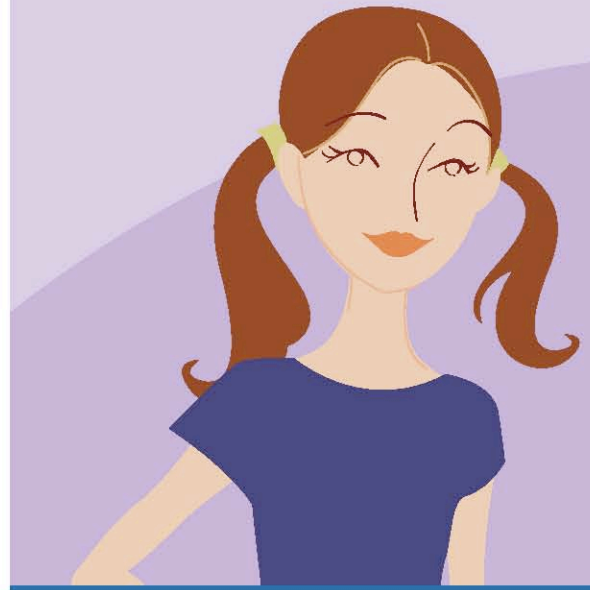
More tests are done. Maria’s father leaves work early to join them at the hospital. The doctor tells mom and dad that they think Maria may have cancer, but he wants to admit her and do more tests to be sure. Mom and Dad become very worried. They arrange for their 15 year-old son, Anthony, to stay overnight with his grandmother.

Maria feels sick, but also feels scared and worried when she realizes that she may have cancer. She tells her mom that she wants to go home. Mom agrees to stay with Maria at the hospital and reassures her that the doctors have a lot of experience in treating patients with all kinds of illnesses.

Two days later, a team of oncologists tells Maria’s mom and dad that Maria has Leukemia — a common form of cancer in children. They give them comprehensive information regarding diagnosis and treatment, which includes chemotherapy. The doctors seem very hopeful. Maria’s parents can’t believe that Maria has cancer, and feel empty and numb at the news. Mom keeps thinking: “but she was fine two weeks ago...”

Maria’s parents and medical team tell Maria that she has cancer, and that it can often be treated with good success. However, she will need to stay in the hospital for awhile for treatment. Maria’s mother promises to stay with her. Maria gets upset and cries — she wonders to herself whether she will die. Maria’s parents try to be reassuring, even though they are unsure of how they feel themselves.

Maria begins meeting a lot of people — doctors, nurses, a social worker, and a teacher who will help her keep up with her schoolwork. The nurse also tells her about other teens on the floor with cancer. Even though she thinks that everyone is nice, Maria doesn’t want to say much to them. She gets upset when her mom leaves the room for just a few minutes.



Intervention Point #1: ADMISSION

D E Providers and staff admitting Maria should understand that:

1. Unexpected hospitalization is associated with increased risk for posttraumatic stress for children and parents.
2. Like other families in their situation, Maria and her parents feel very anxious due to unexpected admission and uncertain diagnosis/prognosis.

Intervention Point #2: DIAGNOSIS & TREATMENT PLANNING

D E F Providers treating Maria should be aware that:

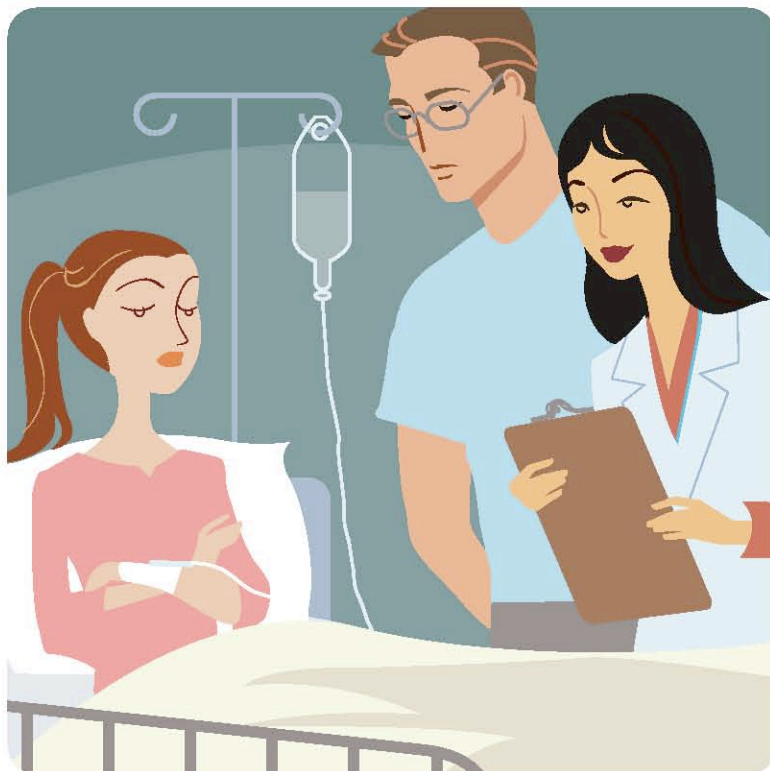
1. Time of diagnosis can be especially traumatic for children and families, and can be impacted by their perception of life-threat.
2. Perception of life threat can be unrelated to (objective) prognosis. Parents who believe that their child might die or children who believe that they will die can be at increased risk for posttraumatic stress.
3. As is the case with Maria and her parents, most initial responses to diagnosis, including shock and disbelief; crying; feeling worried or overwhelmed are common and often temporary.
4. Recent losses within the family or other family stressors can increase risk of posttraumatic stress responses.

See page 7 for recommended assessments and interventions for Maria and her family.

Maria's father brings in a package with cards and letters from Maria's friends and teachers at school. Maria is happy to hear from her friends. Her mother and the social worker help her decorate her room with the cards. Maria's mom suggests that she write a thank you letter to the school. The social worker recommends that Maria keep a journal of her hospital experience, as other teens have found this helpful. The social worker also suggests that she may be able to share parts of her journal with her friends and teachers after she returns to school.

Finally, with some encouragement, Maria begins to leave her room on a regular basis. She likes going to the group room for school lessons and the recreation room with the computers, books, and games. She begins meeting other patients with cancer, including some who have no hair and who look sick. Maria thinks she has little in common with them, and at first, doesn't want to make friends with them.

Maria's treatment is painful at times. Some of the medicines make her sick; she doesn't want to eat, and at times, she throws up. While she writes in her journal periodically, most days she says she "doesn't have anything to say." Her dad comes every night, and her brother frequently visits on weekends, along with her aunt. One night, Maria asks her mom: "Am I going to die?" Mom reassures Maria that both they and her doctors believe her cancer is treatable, and because of the chemo, she is going to feel sick sometimes. But privately, Mom is upset at seeing her daughter so ill, and wonders about whether she will die.



Intervention Point #3: ADJUSTING TO INPATIENT TREATMENT

E Providers treating Maria while inpatient should be aware that:

1. Like Maria, children can initially feel isolated, alone, and self-conscious during a hospital stay. As a result they may withdraw from family and friends or feel depressed. These initial responses are often temporary, and improve with support.
2. During an initial hospital stay, children and parents often don't know what to expect. What may seem "routine" to providers, staff, and experienced families can seem unfamiliar, awkward, and sometimes frightening to newly admitted children and families. It is helpful to spend extra time with children and families initially, and to explain routines and procedures to them in advance.

Intervention Point # 4: **D E F** COPING WITH PAINFUL TREATMENT

Providers treating Maria should be aware that:

1. Children who experience significant pain or painful treatment can experience traumatic stress reactions during treatment and are at increased risk for persistent posttraumatic stress.
2. In dealing with painful treatment, children and families sometimes feel helpless. It is often difficult for parents to see their children in pain. Combining the use of pharmacologic and behavioral interventions (e.g., teaching relaxation or distraction techniques) for pain management is often helpful.

See page 7 for recommended assessments and interventions for Maria and her family.



Maria's doctors decide she can go home for two weeks during a down cycle. At first, Maria feels very excited and happy to be home. Then, as the family tries to readjust to normal routines and expectations, Maria feels irritable because things don't feel the same to her. She and Tony fight a lot. After a week, Maria begins to feel very tired. She doesn't want to eat. She begins to have a fever one evening.

Maria's mother calls the doctor. They tell her to take Maria to the emergency department and she is readmitted. Maria begins to cry — she wants to go back home. The nurses stop by to say “Hi” and to tell her that they've missed her — but she doesn't want to talk to them. Mom suggests that they re-decorate Maria's new room, but she doesn't want to. Maria feels very angry to be back so soon.

Maria's treatment resumes. After a few days, clumps of Maria's hair begin to fall out. The social worker talks with Maria and her mother about how other patients have coped with having their hair fall out. Maria doesn't like the idea of wearing a wig, and she doesn't want a lot of other people to see her. She cries a lot and seems to withdraw from the staff and other patients at the hospital.

Slowly, with support from her family and treatment team, Maria begins to cope with the changes in her appearance. Thanks to her friends, she has a new collection of cool hats to wear. Still, she has good days and bad days. She begins to interact with other teens and staff on the floor again. She develops a pen-pal relationship with an older girl who had the same type of cancer a few years earlier and is now finished with treatment.

A few weeks later, Maria gets excited when the doctors say that she will soon be ready for treatment at the outpatient clinic. But, she worries about going home too; she's not sure how her friends will react, or if they will understand what she's been through. Mom is worried about how she will cope with all of Maria's medical needs at home, without the medical team around. She thinks to herself — “What if something happens to Maria and I'm not able to help her in time?”

Intervention Point #5: TREATMENT SETBACKS & EMOTIONAL REACTIONS

D E Providers treating Maria should be aware that:

1. Like Maria, common emotional responses to treatment and setbacks can include feeling sad, depressed, irritable, angry, scared, or withdrawing from others. These responses are often transient and improve with patience, understanding, and support.
2. Some children and parents experience treatment setbacks as failures, rather than as a “bump” in the treatment road. Setbacks can also trigger earlier distress and emotional reactions.
3. Emotional support and family resources are vital to helping children and families deal with emotional effects and treatment setbacks.

Intervention Point #6: DISCHARGE PLANNING

E F Providers treating Maria should be aware that:

1. Some families experience discharge as a time when they lose medical support and a sense of safety. They can worry about coping with medical and treatment issues at home, without frequent support. Providers can help families anticipate challenges they will face and problem-solve with them in advance, as well as provide reassurance.

See page 7 for recommended assessments and interventions for Maria and her family.

Maria finally goes home. The re-adjustment is difficult at first. Mom is anxious about letting Maria do the things she did before, while dad thinks the family should be getting back to normal. Maria's brother, Tony, is mad that Maria is getting "special treatment" at home, too. Maria has brief visits with friends, but she still feels different from them. Once a week, she gets a knot in her stomach when she has to go back to the outpatient clinic for treatment. There is talk of going back to school, but Maria is not sure if she's ready to go back. She worries that other kids at school might make fun of her or say things about her.

Maria *begins to adjust to outpatient treatment and life at home. Mom is less anxious about letting Maria do things on her own and has been giving her small chores to do around the house. Dad seems more relaxed, too. Tony, is more sympathetic and recently asked Maria a lot of questions about being in the hospital and having cancer. Maria's friends are visiting more often and she was able to attend an art show at her school where one of her drawings was displayed. Her parents and doctor have begun making plans for Maria to go back to school part-time. She is writing in her journal again.*



Intervention Point # 7: OUTPATIENT TREATMENT

E F Outpatient providers treating Maria should be aware that:

1. Having a life-threatening illness can be traumatic for children and families, and can be impacted by perception of life-threat. Parents who believe that their child might die or children who believe that they could die can be at increased risk for persistent posttraumatic stress.
2. As in Maria's case, the transition from hospital to home can be difficult. Families can feel isolated from social and medical supports. Parents, children, and siblings may become irritable and anxious while trying to reestablish normal routines and expectations. Children may look and feel different and worry about how friends will react. These reactions are common, but can improve with understanding, support, and advance planning.
3. Recent losses within family or other family stressors can increase risk of posttraumatic stress during and after treatment.
4. Parents and siblings can also be affected, even after treatment ends. Some parents become hypervigilant for signs and symptoms that the illness has returned. Siblings may worry in private about their brother or sister. They may also feel jealous of the special attention their sibling is getting.

See page 7 for recommended assessments and interventions for Maria and her family.

How can I help Maria (and others like her) within the scope of my job?

ADMISSION:

- Provide simple explanations about what is happening and realistic expectations about what will happen next to reduce fears and worries.

DIAGNOSIS AND TREATMENT PLANNING:

- Acknowledge common emotional reactions to trauma and traumatic stress.
- Ask about fears and worries.
- Connect parents to family support resources in the hospital.
- Provide simple explanations about medical procedures and treatment to the child and family to reduce fears and worries.
- Provide child with as much age-appropriate involvement as possible in treatment planning.

ADJUSTING TO INPATIENT TREATMENT:

- Connect children and parents to supportive resources in the hospital.
- Provide simple explanations for medical routines and procedures to the child and family to reduce fears and worries.
- Help families establish daily routines and behavioral expectations, when possible.
- Identify family strengths and resources. Gauge family distress and other stressors.

COPING WITH PAINFUL TREATMENT, EMOTIONAL EFFECTS, AND TREATMENT SETBACKS:

- Acknowledge common emotional reactions to pain, painful treatment, and setbacks.
- Encourage and promote a stepped approach to confront emotionally painful thoughts, fears, worries and avoidant reactions.
- Combine pharmacologic and behavioral interventions (e.g., relaxation and distraction techniques) for pain management.
- Involve psychosocial staff in a team-based approach to helping the child and family experiencing setbacks or difficulties in treatment.

DISCHARGE PLANNING:

- Anticipate challenges in returning to the home environment and help families plan accordingly.
- Support child's physical and emotional transition to the home environment.

OUTPATIENT TREATMENT:

- Monitor child and family's physical and emotional recovery.
- Connect parents to family support resources in the community.
- Make referrals to mental health resources for children and families with symptoms of traumatic stress and those who are at increased risk. (See QUICK SCREEN.)

D-E-F Protocol for Assessing and Treating Children and Families with Traumatic Stress

D **DISTRESS** - Use brief assessment and indicated interventions for distress (see pocket card,) including:

- Provide child with as much information about what is happening and choices in decisions as possible.
- Listen carefully for child's understanding and clarify any misconceptions.
- Ask about fears and worries.
- Provide reassurance and realistic hope.

E **EMOTIONAL SUPPORT** - Use brief assessment and indicated interventions for emotional support (see pocket card,) including:

- Encourage parents to be with their child as much as possible and to talk with their child about worries and fears.
- Empower parents to comfort and help their child.
- Encourage child involvement in age-appropriate activities when possible.

F **FAMILY** - Use brief assessment and indicated interventions for family needs (see pocket card,) including:

- Gauge family distress, coping resources, and other stressors.
- Encourage parents to use own coping resources or resources available at the hospital or in the community.

D E F Use **QUICK SCREEN** (see pocket card,) to identify

- those who have traumatic stress symptoms or who are at greater risk for traumatic stress.
- Involve psychosocial staff in a team-based approach for those at higher risk.
- Make referrals to mental health resources when appropriate.