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Children with Life threatening illness

Finding out that your child has a life-limiting or life-threatening condition can be an incredibly distressing and confusing time. Posttraumatic stress symptoms have been reported in response to various serious medical illnesses in adults and children. Not surprisingly, posttraumatic stress is probably more common in response to acute, life-threatening, events that are related to the illness. Emerging data suggest that children often experience life-saving medical procedures as traumatic, which puts caretakers and medical personnel in the role of perpetrators for the children. Trauma symptoms are also reported as common and severe in caregivers.



Palliative care for children is an active and total approach to care for newborns, infants, children and young people with a life-threatening condition and their families. Palliative care includes physical, emotional, social and spiritual support. It focuses on improving quality of life for the child and their family. It also provides respite and ongoing support through death and bereavement to help the family continue to function and stay together.

Palliative care for children is different to adult palliative care. A significant majority of children with a life-threatening condition will have a non-malignant disability or illness such as cystic fibrosis, muscular dystrophy or other neurodegenerative conditions, as well as cancer. The child's developmental stage, the type of condition and the uncertainty that can accompany prognosis and treatment, all impact on the child and their family's needs. Palliative care services for children are tailored to those needs.

Diagnosis of a life-threatening condition

When a child is diagnosed with a life-threatening condition, the child and their family's world is turned upside down and a roller-coaster of emotions and challenges begins.



Children and families may feel a wide range of emotions including:

- Confusion
- Fear, shock or disbelief
- A sense of unreality, numbness or emptiness
- Feeling overwhelmed or helpless
- Sadness or anxiety
- Anger
- Guilt
- Hopelessness
- Denial
- Other intense feelings.



Parents may want to protect children from bad news. However, children often know more about their condition than families think or expect.

Key issues with diagnosis of a life-threatening condition

The whole family is affected when a child is diagnosed with a life-threatening condition and specific strategies need to be employed to support children, parents, siblings and other family members. These issues can be physical, emotional, financial, social and/or spiritual in nature, and each issue can affect the other.

Parents may understand their child's prognosis, but still find it difficult to accept. They often need time to absorb information, ask questions and consider the child's best interests. At times, they will feel frustrated, particularly when dealing with multiple services from a range of organisations, including disability, acute health, community, early childhood and palliative care services.

Parents also report that caring for a child with a life-threatening condition is a full-time job that impacts on life, relationships, friendships, community involvement and their sense of identity. If siblings seem to be coping, they may be left to their own devices and often take on additional responsibilities beyond their years. Siblings will need emotional support, to be given age-appropriate information, have a routine (such as school), contact with their sick brother/sister and be included in their care.

Some parents find it helpful to live one day at a time, to maintain some routine and to be flexible when making plans.

Palliative care is provided in a range of settings

Where palliative care is provided depends on what is available, the needs of the child and their family, and the ability of the service to provide care in various settings. Most children are cared for at home. However, some are cared for in hospital, and some children and families use a children's hospice such as Very Special Kids House. Many families will move between these places of care.



Children with Chronic Conditions

What is a chronic condition?

All children will likely have many different health problems during infancy and childhood, but for most children these problems are mild, they come and go, and they do not interfere with their daily life and development. For some children, however, *chronic health conditions* affect everyday life throughout childhood. We'll define a *chronic health condition* as a health problem that lasts over three months, affects your child's normal activities, and requires lots of hospitalizations and/or home health care and/or extensive medical care.

Chronic condition is an "umbrella" term. Children with chronic illnesses may be ill or well at any given time, but they are always living with their condition. Some examples of chronic conditions include (but are not limited to):

- Asthma (the most common)
- Diabetes
- Cerebral palsy
- Sickle cell anemia
- Cystic fibrosis
- Cancer
- AIDS
- Epilepsy
- Spina bifida
- Congenital heart problems



Even though these are very different illnesses, kids and families dealing with any chronic condition have a lot in common. Learning to live with a chronic condition can be very challenging for a child, for parents, and for siblings and friends. Read on for more information, support and resources.

How might a chronic illness affect my child?

Children with chronic illnesses are more likely to experience frequent doctor and hospital visits. Some of their treatments may be scary or painful. Hospital stays can be frightening and lonely. Children with chronic illnesses will feel "different" than other children. Their activities may be limited, and, in many cases, their families must change how they live to accommodate the child.

How do kids adjust to and cope with chronic illnesses?

The way children react to diagnosis with a chronic illness depends on several factors, including the child's personality, the specific illness, and their family. One big factor is the child's developmental stage. Kids' understandings of illness and their coping strategies change as they grow older.

Here's some information about how kids adjust at different stages:

- **Infants and Toddlers** are beginning to develop trust and an overall sense of security. They generally have very little understanding of their illness. They experience pain, restriction of motion, and separation from parents as challenges to developing trust and security. Parents can help by being present for painful procedures, staying with their children (when possible) during hospitalizations, and holding, soothing, and interacting with their baby as much as possible.

- **Preschool Children** are beginning to develop a sense of independence. They may understand what it means to get sick, but they may not understand the cause and effect nature of illness. For example, they may believe that throwing up causes them to get sick, rather than the other way around. Being in the hospital or adjusting to medication schedules can challenge the child's developing independence. The child may try to counter lack of control over their world by challenging limits set by parents. Parents can help by being firm with things the child does not have a choice over (never ask "do you want to take your medicine now?" unless there's really a choice—almost all children will say "NO!"), but by offering choices over flexible aspects of treatment. (For example, "Which to you want to take first, the pink medicine or the purple?" or "Do you want to sit on my lap while you have your blood drawn, or in the chair with me holding your hand?") Parents can help their preschool child be resilient in times of stress.

- **Early School-aged Children** are developing a sense of mastery over their environment. They can describe reasons for illness, but these reasons may not be entirely logical. Children this age often have "magical thinking." They may believe they caused illness by thinking bad thoughts, by hitting their brother, or by not eating their vegetables. Children also begin to sense that they are different from their peers. Parents can help by allowing children to help in management of their illness (with close adult supervision). They should also reassure their children that the illness is not their fault. Parents can help elementary school kids develop resilience in the face of a chronic illness.

- **Older School-aged Children** are more capable of understanding their illness and its treatment, but they should not be expected to react as adults do. They may feel left out when they miss school or activities with their peers. Parents may feel the need to protect their children by restricting them from activities with other children. This is a natural reaction, but it can interfere with the child's independence and sense of mastery. To the extent allowed by the child's doctors, parents should help the child to participate in school or other activities.

- **Adolescents** begin to develop their own identity separate from their family. Self-image becomes extremely important during the teenage years. That can be a problem when the teen's appearance is altered by illness or medication. Teens are also beginning to develop a real independence from their families. Parents who have been very involved in their teen's care for many years may find it difficult to let go of their role as primary caregiver.

- **Teens** - Many teens will go through times of denial of their illness when they may neglect to take medications, follow special diets, or check blood sugars. In addition, the adolescent's body is rapidly changing, which may change the symptoms of the illness or the doses of medications needed. It is important to help the teen to gain control of their disease management. Keep in mind that even with chronic illness, teens are teens! Don't forget to talk about issues facing all teens: independence, college planning, sexuality, substance abuse, etc.



What effects can I expect my child's chronic condition to have on our family?

Chronic illness doesn't just affect the person with the condition. The whole family must come to terms with the illness, make major changes in schedules and priorities, and somehow manage to remain a family.

Parents may struggle with their own feelings about the child's illness while trying to keep up a brave front for

the child. It is normal to feel a sense of disappointment, grief or loss for the way you imagined your child's life would be (without a chronic condition). Divorce is somewhat more common in families with seriously ill children, mainly because of the great stress of parenting an ill child. While your child will need at least one parent with them during times of acute illness or hospitalization, it is important for you to find at least short times now and then to spend alone together with your partner.

Siblings of the ill child may feel left out, and later may feel guilty at any bad feelings they have toward their sick brother or sister. While less time will be available to spend with the other children in the family, parents need to let them know that they are still special and important. You can't just assume that they know this. If you can carve out just 10-15 minutes a day to really focus on each sibling, it will go a long way.

Caregiver burnout and stresses on relationships in the family can become overwhelming. Sometimes counseling can help everyone in the family make the adjustment more smoothly. The most successful families tend to be those that are able to move on from seeing the illness as an intrusion toward working together as a team to face the new responsibilities of managing a long-term illness. They build on their family's strengths to cope with the new stress.



What can our family do to cope better, and to help our child cope better with the chronic illness?

- ***Stay involved and give information***

Discuss with your child (at their age level) what their illness is all about, and what will happen to them in the hospital. When you don't do this, kids may imagine the worst.

- ***Plan for procedures***

Unexpected stress is more difficult to cope with than anticipated stress. Some procedures can cause physical and psychological distress. Some children do better with several days to prepare, while others worry themselves sick. Good communication and flexibility are essential.

- ***Give them choices***

Some tasks for children with chronic illness must be done no matter what. Others are more flexible. Know what tasks are mandatory (scheduled medications, specific diets) and which are open for discussion ("as-needed" medicines, choice of foods within a given diet). Conflict may arise when a child tries to assert independence. As preschoolers, and even older kids test adults' limits, there is natural conflict with adults' demands. Children with chronic illness, more than other kids, need chances to make choices—to have control over any part of their lives they *can* control.

- ***Support their friendships and activities with peers***

Illness often interferes with routines and activities. For children and teens, a particularly devastating consequence can be the weakening or loss of friendships. Friends can grow apart as a result of these changes. Keeping kids involved with their peers and making extra efforts to maintain those connections can go a long way in helping a kid cope with an illness. Helping your child to find new ways to make and maintain new relationships is critical during this time.

- ***Be hopeful***

Coping with a chronic illness can be discouraging and scary. It is incredibly important to stay hopeful. Don't ignore your worries or your negative feelings—they need to be recognized and addressed. But it's not helpful to dwell on them. If you try to find the positive side of things and keep your eye on the potential positive outcomes, you will be teaching your child a valuable lesson, and maintaining your ability to cope as well.

- ***Listen***

Be available so your child can talk about the problems they are facing. Ask them how it's going, and listen to the answer. Listen to their troubles and help them find solutions to their problems. Be able to recognize the warning signs of depression. If your child talks about suicide, take it seriously. Allow your child to express their fears; validate your child's feelings. There's nothing worse than feeling scared and confused and not being able to talk about it.

- ***Be flexible***

To help your child adapt to their illness, you will need to both recognize their limitations and help them to continue with life as usual, whenever possible.

- ***Have fun together as a family***

You can expect the whole family to be under increased stress. Maintaining your commitment to your family and getting support from each other may be harder during times of stress, but it is also even more important! Spend time together that is not focused on the illness. To carve out time for family activities you may need to *schedule* family time, including one-on-one time for parents and parent-child "dates," as well as whole family activities.

- ***Involve the whole family and even an extended support network***

Allow each family member to help in any way that they are willing and able. Seek support and help from people outside your immediate family, such as through your extended family, school, religious community, neighborhood, or children's hospital. People you know will generally be very pleased if they can help, such as bringing over a meal, having your other children over to play, or even just lending a listening ear. Often folks don't know exactly what you need—so don't wait for them to offer it. If someone gives you a generic offer of help, tell them what you need specifically, and ask if they can do it for you. You'll be surprised at how glad people are to be able to do what's needed for your family.

- ***Teach coping skills***

Parents need to help children learn new ways to cope with the special challenges of an illness. Discussing with a teen how their illness is affecting him or her and finding ways to help solve problems or cope with the feelings is very helpful. They can learn to build on their strengths and can even develop pride in their abilities to meet the challenges.

- ***Don't let your kids hear more than you intend***

If your conversations are private have them away from your children. Kids hear more than you may think; don't assume they are sleeping when their eyes are closed.

- ***Coordinate with your child's school***

When your child with special health needs goes to school, good communication between your family and school is very important.

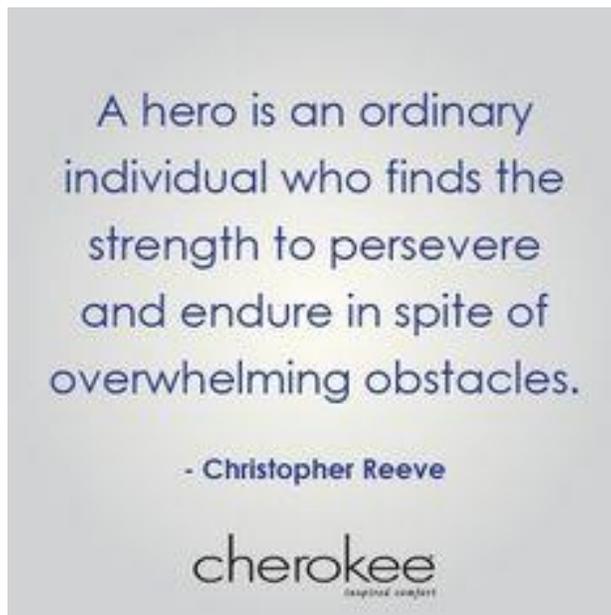
- ***Take care of yourself and your relationships***

Caregivers/parents need to take good care of themselves—otherwise, they won't be able to *give* good care! Talk with other parents who have children with special health care needs, carve out time to do something you enjoy, get support, find someone to listen to you vent, take breaks, spend time with your partner, and learn to deal positively with your stress. If you can keep your family routine as normal as possible, that will help, too. Your relationship with your partner will be stressed and undergo changes, but it can emerge stronger than before you faced the challenges of your child's illness together.

If a child dies

The death of a child is often the most profound loss a family can experience. From the moment of their child's diagnosis, families experience a range of losses and some will begin to grieve in anticipation of their child's death. Grief is a normal experience. Everyone grieves in their own way and in their own time. Parents can feel overwhelmed by their feelings, and have fear for their remaining children. Siblings' experience of grief will be influenced by their level of maturity, understanding and life experiences.

Death in childhood is not regarded as normal, but despite all our efforts at 'saving children', death in childhood still happens. There is also a subset of children for whom death in childhood is anticipated and can be regarded as a normal outcome of the child's condition (e.g. trisomies, inoperable heart conditions). The death of a child is regarded by the Diagnostic and Statistical Manual of Mental Disorders (DSM) as a 'catastrophic stressor' for a parent – on par with experiencing a 'natural disaster'.¹ Yet, why do we learn so little as health professionals about how to deal with it?



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