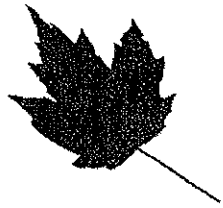


*Helping your child when death is near...*



## *Introduction...*

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Natural and expected bodily changes will occur as illness progresses and body systems become less efficient. This booklet explains some of the most common changes seen in children and offers some simple suggestions of things you can do that can be helpful to your child. You may see some or all of these changes in your child. The important thing at this time is to help your child be comfortable.

You can reach a member of your care team anytime you have questions, need reassurance, or when the suggestions outlined are not working. In the hospital, talk to your nurse or doctor.

If you are caring for your child at home, call your nurse.

RN Contact: \_\_\_\_\_

Phone: \_\_\_\_\_

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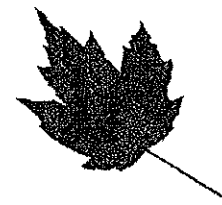
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## *Comfort care and symptom management*

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For most children, medications for pain and other symptoms will be necessary to keep them comfortable as their disease progresses and their bodies become weaker. Pain medications may need to be increased or decreased to keep your child comfortable. Relaxant medications can help the pain medications work more effectively and are very helpful for children who are anxious or restless. Don't be alarmed if it seems that adjustments in medications are being required frequently. Increasing the dosage of pain and relaxant medications will not shorten the life of your child, nor will your child become addicted to these medications. The comfort of your child is the goal of care.





*What can you do:*

*Holding, touching, and rocking your child, reading stories, watching a favorite video or playing soft music may help improve your child's comfort by taking the focus off of pain. Do not hesitate to call your nurse anytime you think your child is becoming more uncomfortable, anxious or restless.*

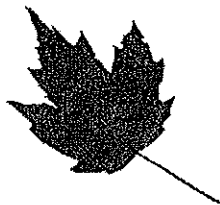
*Appetite and thirst*



As digestion slows and physical activity decreases, the body does not have the same need for calories and does not process food and fluids as well. Your child's sense of taste will become less sensitive and the appetite will decrease. Sometimes the disease process itself causes problems with digestion or swallowing. If your child receives nourishment by tube feeding, you may notice changes in the amount of formula that is tolerated.

*What you can do:*

*If your child is hungry or thirsty, offer favorite foods and drinks. It is okay that your child may only want a few specific foods or drinks. Let your child be the guide about eating. When your child doesn't want to eat or drink, try small sips or even drops of water, ice chips or a favorite liquid. Some children like to suck on sponge toothbrushes or wash cloths soaked in water or a favorite drink when their mouths are dry. Carbonated drinks such as soda pop or seltzer water can help relieve a sticky mouth. If feedings are given by tube, decreasing the amount given and/or diluting the formula with water, may be helpful. If your child experiences nausea or vomiting, talk to your nurse for recommendations.*



*Bowel and bladder*

As your child drinks less, their kidney function slow down, and less urine is produced. You can expect that the urine may look very dark yellow or even tea-colored as your child drinks less. If your child is not eating much, there may be very little stool produced. Slowing of the digestive tract and some medications may cause constipation. Symptoms of constipation may include hard stools, inability to pass stools or a swollen tummy. In some children, the bowels become more active and diarrhea may occur.

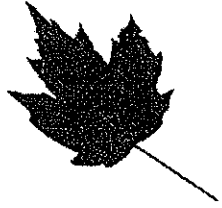




*What you can do:*

*You or your nurse should check to make sure your child is not constipated. Your nurse can recommend ways to relieve constipation. If loose stools are causing the skin to be irritated, apply a skin protectant cream after cleansing.*

*Changes in sleep patterns*



Your child will begin to sleep more and may seem less interested in things he or she enjoys. Some children want to sleep during the day and are more awake at night. Dreams may become more vivid in older children.

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### *Changes in awareness*

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#### ***What you can do:***

*Let your child rest and sleep when tired. Spend waking times doing activities your child enjoys. Many children will want to simply watch while other family members play a game, watch TV or talk. At home, move your child to the family area of the house so that he or she will feel involved and included.*

At times your child may seem confused or "out of touch." Some children have strange dreams. Your child may be more restless. Some children seem to reach for things that can't be seen, mumble or pick at their blankets and clothing. These symptoms most commonly occur because of chemical changes within the brain. Adjusting your child's comfort medications may be helpful.



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*What you can do:*

*Comfort, hold, and talk to your child. Speak to your child often as familiar voices are comforting. Unless your child relaxes with the television leave it off as this may increase confusion. If your child appears very restless or agitated, talk to your nurse.*

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*Visions and unseen visitors*

Your child may tell you about visions or the presence of unseen visitors. You may also note that your child seems to be talking and listening to someone that cannot be seen. For most children, these are not scary occurrences and, in fact, may be quite comforting.

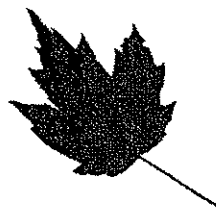
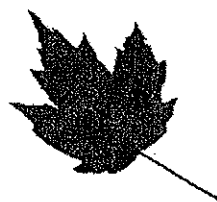


***What you can do:***

*Listen to your child and acknowledge your child's awareness of things you cannot see or hear. If you can, talk with your child about what he or she believes is happening. You may want to ask for help from your faith community or the chaplain in understanding these events.*

***Body temperature***

Frequently a child has periods when he or she feels very hot to the touch, as if there were fever, while the arms and legs feel cold. This occurs because the brain is no longer able to regulate the body temperature.





***What you can do:***

*If your child is not uncomfortable, you don't need to do anything.*

*If your child is uncomfortable, try dressing your child in cool, loose clothing or removing blankets. Some children appreciate lukewarm or cool baths, having a fan or humidifier in the room, or being taken outside into the cool air. Acetaminophen (Tylenol, Tempera) may improve your child's comfort.*

***Skin color changes***



You may notice that the color of your child's arms and legs change, first becoming very pale and later becoming a dusky or bluish color and feeling cool to the touch. This occurs because the heart is less able to circulate and oxygenate blood at this time. *This is a signal that death is quite near. It is not usually painful or uncomfortable.*

***What you can do:***

*Some parents find it helpful to massage the feet and hands to help improve circulation. This may or may not be helpful or comfortable to your child. Cuddling and bundling your child may provide some warmth. Some parents find it helpful to keep the arms and legs covered at this time.*

- *If you are home, call now to let the nurse know that these changes are occurring.*
- *You may also want to call someone you would like to have with you at this time.*



***Seizures***

If your child has a seizure disorder, the frequency of the seizures may change. Increases, decreases, or changes in your child's regular seizure medications may be needed. Most commonly, this is related to changes in the body's ability to metabolize the seizure medications.

It is rare for children who do not have a seizure disorder to develop seizures at the end of life. Children who have brain tumors, brain injuries, or some metabolic changes may be more likely to have seizures.





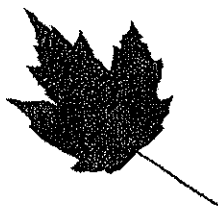
***What you can do:***

*If your child has a seizure, try to remain calm. Turn your child on his or her side. Do not put anything in your child's mouth or try to hold your child still. Talk quietly to your child. Seizures can last for a few seconds up to a few minutes. Although they are difficult to see happen, your child will not suffer and will not remember what happened during the event. If you are at home, have someone call your nurse immediately for further guidance. Your doctor can prescribe medication to help prevent seizures from recurring.*

***Increase in secretions***

Secretions may collect and cause a "gurgling" or "rattling sound" as your child breathes. Usually this occurs when your child is no longer alert and awake. Excessive suctioning may increase the amount of secretions, as it can be irritating to the tissues. There are some excellent medications that can help decrease the secretions.





*What you can do:*

*This is often the most distressing symptom for those sitting with your child. Usually your child will not be awake or alert at this time and the secretions will not cause pain or discomfort. It is important to spend time holding, comforting, and touching your child at this point. If the gurgling sounds become distressing to those with the child, it may be helpful to put a small rolled towel under your child's neck to help extend the breathing passage, or let your child lay over your shoulder or over your arm. It may also help to lay the child on his or her side to allow the secretions to drain out.*

*Bleeding*



Most children will not have any problems with severe bleeding. Dryness of the lining of the nose may cause a bloody nose. Dryness of the gums and lips may result in cracking and oozing. Children who have diseases that have affected their liver, intestines or bone marrow have more risk of severe bleeding. If your child is at risk for severe bleeding, your doctor will talk to you about ways to help manage or prevent bleeding episodes.

*What you can do:*

*A humidifier in the room may help keep your child's nose moist inside. Nosebleeds will usually stop after 10-15 minutes of applying firm pressure to both sides of the nose. There are also some ointments that can be helpful in preventing nosebleeds from dryness. Keeping your child's lips moistened with lip balm can be very soothing. Do not use petroleum jelly (Vaseline) if your child is on oxygen.*

*If your child is having a severe bleeding episode, continual oozing from the nose or mouth, bloody stools or a nosebleed that will not stop with pressure, call your nurse.*

*Breathing changes*

The breathing pattern becomes more irregular and uneven as the time of death comes closer. Your child may have long periods of time between breaths and will probably not be alert or awake at this time. This is often the signal that death is very near. Usually, breathing becomes more and more uneven with longer and longer periods of time between breaths until, at last, there is not another breath and the heart stops beating. This process may go on for a few hours, or it may happen over a period of days.

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*What you can do:*

*Even though your child may not respond to you, he or she can most likely hear you and sense your touch. Keep talking to your child.*

*You can cuddle your child in your lap or in the bed, if you wish.*

*Adding oxygen at this time may not help. Your child no longer can effectively process the oxygen to help breathing. If your child is receiving oxygen you may be more comfortable leaving the oxygen on. However, some parents appreciate being able to hold their child without tubes or masks as the end is near. Either way is OK and will not change your child's comfort.*

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*At the time of death*

When breathing and heart action stop, all of the muscles in the body will relax. There may be one last, long sighing breath as air passes out of the lungs. Your child's eyes may be partially open or closed. It is common for urine and stool to be passed. Your child's body will remain warm to the touch for a short period and then will begin to gradually become cool and pale.

Many families like to continue to hold their child and talk to their child at this time. Take the time you need to say goodbye. If you wish, you can bathe and dress your child.

If you are at home, do not call 911. Call your nurse. The nurse will come to your home to support you and your family. The nurse will call your doctor and others who may need to be called. The mortuary will come to your house or to the hospital to pick up your child's body when the nurse calls them.

### *After...*

Everyone experiences grief in his or her own unique way. There will be good days and not-so-good days. There is no timeline for grief, but how you experience and express it does change as life goes on. Be gentle with yourself and understand that what you are feeling is normal. You may be contacted by a bereavement counselor or other health care professional as part of the service of your care provider and receive information about grieving, grief counseling services, bereavement support groups and other supportive activities. You can choose the services you feel will be most beneficial for you and your family.







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You may also find that questions arise after your child's death about the illness and the events surrounding the death, or you may want to talk with someone who knew what your child went through. Your physician, nurse, social worker or chaplain or faith community can be very helpful to you at this time.

**This booklet has been prepared by The Supportive Care Network Partners**

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The Youth Advisory Council  
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Denver, Colorado

# The Butterfly Program

*provides support and comfort*

*for families with children,*

*ranging from infants to*

*young adults, who have a*

*potentially life-limiting illness.*

*A special team of health care professionals*

*who join a child's pediatrician and/or*

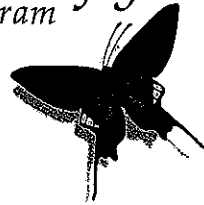
*specialists to provide support and*

*comfort care for all members*

*of the family.*



## The Butterfly Program



### **How to Contact Us**

To inquire about enrolling in The Butterfly Program, or to request a consultation, please call **303-561-5100** or contact any one of the following individuals:

#### **Inpatient Program Coordinator:**

*Nancy King, RN, CRNP*  
**303.764.8569**

#### **Outpatient Program Coordinator:**

*Ashley Mead, LSW, MPH*  
**303.561.5310**

#### **Medical Director:**

*Brian Greffe, MD*  
**303.861.6787**

# The Butterfly Program



*Supportive  
Services and Comfort Care  
for Children, Ranging From  
Infants to Young Adults*

## Philosophy

The Butterfly Program is available to any child, from infancy to early adulthood, who is facing a potentially life-limiting illness – regardless of the current goals of their care, the setting in which their care is provided, or their family's ability to pay for services. It is our hope that The Butterfly Program can provide comfort and enable families to treasure their time spent together.

## The goals of The Butterfly Program are:

- To enhance the quality of life while strengthening the family;
- To provide family-centered care, focused on individual needs and wishes for care and support;
- To provide services across the continuum of care settings, including the hospital and family home;
- To meet the physical, emotional, social and spiritual needs of all members of the family through an integrated team approach that takes advantage of team members' expertise in pediatrics and palliative care; and
- To offer support and counseling throughout the illness and, in the event of death, comprehensive bereavement services for a minimum of one year.

## Services Available

The focus of The Butterfly Program is meeting individual needs and desires for support and comfort care, in conjunction with the patient's current physicians and caregivers. Specific offerings both in an inpatient and outpatient basis include:

- Volunteer assistance for family support
- Skilled intermittent pediatric nursing and therapy services
- Pain and symptom management
- Infusion therapies
- Nutritional consultation and education
- Pastoral/spiritual support
- Counseling for patient and family
- Bereavement services
- On-call clinical consultation

## The Care Team

Under the supervision of the patient's physician, intermittent services are provided by an interdisciplinary team that includes:

- Physicians
- Butterfly Program Medical Director
- Pediatric Registered Nurses
- Social Workers
- Spiritual Care Providers
- Trained Volunteers
- Bereavement Counselors
- Pharmacists
- Physical and Occupational Therapists
- Dietitians
- Home Health Aides

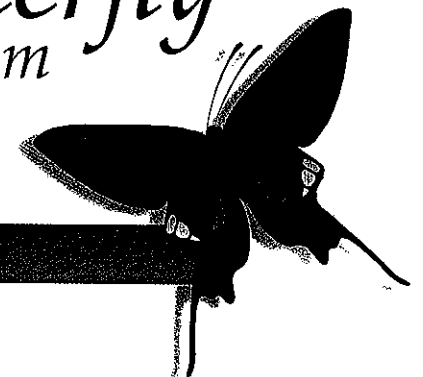
## Care Settings

Care may be provided in the comfort of the home, while at The Children's Hospital, as a part of out-patient treatment at a Children's Hospital Clinic, or in a home-like setting.

## What You Can Do

The Butterfly Program depends on community support to provide the full range of services for every child, from young infants to adults, who has a potentially life-limiting illness. In addition to financial contributions, volunteers can help in many ways. If you are interested in volunteer opportunities, please call 303-561-5100.

The  
*Butterfly*  
Program



For additional information please call 303-561-5100.