

### What is Palliative Care?

Palliative care is a special kind of health care. It gives comfort and support to children and their families who are diagnosed with complex illnesses. It can be provided at any stage of a serious illness and alongside curative treatment plans. Palliative care recognizes that everyone in the family is affected when one member is ill. This care aims to improve the quality of life in physical, psychological (mental), social, emotional, and spiritual ways. It also focuses on information sharing and care planning.

### When is palliative care needed?

- At the time of diagnosis.
- Anytime throughout the medical journey.
- When pain or other symptoms cause stress to your child or family.
- When your child or your family are having problems understanding the illness or what to expect.
- When there is trouble accepting, preparing, or making decisions involving your child's condition.
- When your child, family, or friends need help coping with stress.

### What do palliative care services include?

- **Physical:**  
Special care is given to help improve your child's symptoms, such as pain. This may be done with medicine or other supportive therapies.
- **Psychological (mental) and Emotional:**  
Your child, family, or friends may feel sad, scared, or helpless. You can talk about your feelings to the palliative care team. Counseling and emotional support are offered. Children and families may choose to join support groups or meet other families in similar situations.
  - Child life specialists are available to help talk to your child and their siblings about fear, illness, and stress.
- **Social:**  
Your child is encouraged to join in on activities and decision making as his/her strength, ability, and interest will allow.
  - Social workers and Care managers are available to help arrange services that can help you with practical problems, home health care, or financial concerns.
- **Spiritual and Cultural:**  
This care respects your child and family's religious beliefs and cultural practices. These may include doing a special ceremony, ritual, or following certain traditions.
  - A chaplain is available to help you find support within your own belief system.

(continued on back)



Blank Children's Hospital  
UnityPoint Health



UnityPoint at Home

## What is Palliative Care? (continued)

### Who gives palliative care?

A team of trained professionals work with your primary care and specialty providers to enhance your child's care. This trained palliative team includes doctors, nurse practitioners, nurses, chaplains, child life specialists, social workers, care managers, therapists, and pharmacists.

### How can family and friends be involved with palliative care?

Palliative care services are offered to your child, family, and friends. Your family and those close to you will be taught about the disease, its symptoms, and effects. You will also be taught about treatment choices, side effects, and ways to manage your child's symptoms. Your family helps plan your child's care and helps to make decisions about treatment. Palliative care offers support to your child, family, and friends. Your family will be checked on regularly to see how you are coping with your child's illness.

### What is an IPOST?

The IPOST (Iowa Physician Orders for Scope of Treatment) is a form that documents your family's medical preferences for your child. The IPOST honors your family's wishes for cardiopulmonary resuscitation (CPR) and medical interventions. For more information about the IPOST:

[ipdh.state.ia.us/ipost/](http://ipdh.state.ia.us/ipost/)

### Where can I find more information about palliative care?

- American Academy of Pediatrics (AAP)  
141 Northwest Point Boulevard  
Elk Grove Village, IL 60007-1098  
Phone: 1-847-434-4000  
[www2.aap.org/sections/palliative/](http://www2.aap.org/sections/palliative/)
- American Academy of Hospice and Palliative Medicine (AAHPM)  
4700 W. Lake Avenue  
Glenview, IL 60025-1485  
Phone: 1-847-375-4712  
[palliativedoctors.org/](http://palliativedoctors.org/)
- Center to Advance Palliative Care (CAPC)  
55 West 125<sup>th</sup> Street, 13<sup>th</sup> Floor  
New York, NY 10027  
Phone: 1-212-201-2670  
[capc.org](http://capc.org)
- National Hospice and Palliative Care Organization (NHPCO)  
1731 King Street, Suite 100  
Alexandria, VA 22314  
Phone: 1-800-658-8898  
[caringinfo.org/i4a/pages/index.cfm?pageid=1](http://caringinfo.org/i4a/pages/index.cfm?pageid=1)
- World Health Organization (WHO)  
Avenue Appia 20  
1211 Geneva 27  
Switzerland  
[who.int/cancer/palliative/definition/en/](http://who.int/cancer/palliative/definition/en/)