

Frequently Asked Questions about Palliative and Hospice Care

Our hospital does not have a palliative care team. What are our options?

You can ask your physician for a referral to a palliative care program. There is also a listing of palliative care programs throughout the state of Michigan [on this website](#).

Why should my child be a hospice patient?

Hospice care is focused on pain and symptom control and quality of life for the child, and support for the family. If this is your treatment goal, then hospice may be appropriate for you and your child.

My child's physician has recommended hospice. Does this mean the doctors don't care anymore?

When the healthcare team can no longer offer treatment that will make your child well, recommending hospice shows they care deeply about the kind of life he or she will have in the time remaining. They believe it is the best choice for comfort, caring and the highest possible quality of life for your child and your family.

I don't want to give up hope for my child, but isn't that what hospice means?

Sometimes the things we hope for, like a cure for a child's serious illness, cannot be found. But that does not have to mean we are without hope at all. Hospice can help you reach the hoped for goals of finding comfort for your child and making sure that he or she is lovingly supported in the final stage of life and in a peaceful death.

What if we change our minds?

Enrollment in a hospice program does not need to be a final option. If you decide you want to resume treatments aimed at curing your child, all you have to do is let the hospice provider and healthcare team know. You will be able to transfer out of hospice care if you no longer want the service.

Can we stay home or do we have to stay in the hospital?

You may stay at home as long as you wish and do not need to stay in the hospital. You and your family will be expected to take an active role in caregiving for your child, as hospice workers do not stay in the home twenty-four hours a day. Hospice will help with some of the care and can assist you in finding extra caregiving help if needed.

Do we have to be at home?

No, you may choose to be in a hospice residence. Hospice care can be provided in any setting: home, residential facility or hospital.

May we remain in the hospital?

Yes, if your child's symptoms call for a hospital level of treatment or if you're more comfortable in the hospital, you may stay in the hospital.

I don't know how to tell my child that we're going to have him in hospice care. Can someone help me figure out what to say to my child?

When you talk to your child about hospice, you might want to emphasize the aspects of hospice care that are likely to be especially appealing: your child will be able to stay at home and not have any more treatments that hurt and make him or her feel bad; and there will be special people who care about your child's comfort who will be coming to help you provide care. You can also let your child talk to a hospice nurse or social worker before any hospice care begins. Experienced hospice personnel can help you plan your conversation with your child. They understand that each person and child is different and can give advice based on your specific situation.

My other children are frightened. What can be done for them?

Your children might be worried that they too could become ill, or be worried about you, or feel guilty. It is common for children to have these reactions. Your social worker, physician, and other professionals are experts in dealing with these concerns and can help you address them. One thing for you to keep in mind too is that children usually benefit from being involved and present. It can help them if you try to make sure they do not feel excluded, and then let them take the lead on how much they want to be involved.

I am worried about my other children, spouse, parents.

Hospice personnel are skilled in working with your entire family. Hospice can provide support to your family in a variety of ways. These include art therapy for children, counseling for family members, and bereavement support after the death for children, parents and grandparents.

What does it cost?

Hospice and palliative care are covered by most insurance plans. Some private insurance plans require you to make co-pays. A member of the healthcare team, your social worker, or a hospice representative will be able to tell you ahead of time what the care will cost and how much of that cost, if any, you will have to pay for directly. Medicare and Medicaid may cover some of the expenses for those who are eligible. (See [Who Pays for Hospice and Palliative Care Services?](#))

I need to know for certain that I am doing the right thing.

It is hard to be sure that you are making the right choices sometimes, especially in an area as important as your child's health. Hospice team members can help you in your role as decision maker for your child. Decisions about your child's treatment are usually shared between you and the hospice nurses and social workers. Hospice personnel will provide an attentive and patient ear for your questions and concerns, and guidance as you try to make the best decisions for your child, your family and yourself.

Remember that you can get a fuller answer to any of these questions, or an explanation for something you don't completely understand, by asking a hospice team representative for more information and advice.