

# Supporting Children: When a Parent or Adult Starts Hospice Care

While each child and situation are different, most children benefit from being included when a person is dying. They want to have the choice to be included (especially if the sick person is a parent).

Hospice care is an ongoing process, usually with no specific time frame. People can receive hospice care in their home or in a healthcare facility. Some children will feel best supported with more information, while others will want less.

Please remember that throughout this situation, you know your child best. If you are questioning how much information to share, ask them. Remind them that they can tell you if they are getting more information than they want or can manage. No matter how much they want to know, the information should be open, honest and clear.

## Explaining hospice care

Follow the guidance below during your conversations.

### Hospice

- › “Hospice is for people who will not be alive much longer. The hospice team makes sure their body does not hurt and they are where they will be most comfortable.”
- › “Sometimes hospice is at home, while other times this is in another building.”
- › “The hospice team will give a person medicines that keep a person’s body from hurting. They will get these medicines until their body eventually stops working. When someone’s body stops working, this means the person dies. The hospice team makes sure their body is comfortable and does not hurt when they die.”

## **Sleepiness**

- › “When someone’s body is dying, they will be very tired. The person will be very tired and they may not open their eyes very much. They eventually may not open their eyes at all. Even when this is happening, we can still talk to them to connect with them.”

## **Food and drink**

- › “When a body is dying, it does not use as much energy as it used to. This means they do not need as much food and drink.”
- › “They may not eat or drink at all. The body is not dying because it is not getting food and drink; it just does not need as much anymore.”

## **Pain**

- › “Some medicines help a body get better, and pain medicine is meant to help someone have less pain and be more comfortable.”
- › “Pain medicine can make a body feel tired. When someone is in hospice care, they get a lot of pain medications. This is part of why they may look very tired most of the time.”

## **Confusion or agitation**

- › “The body is going through a lot of change. Sometimes, this can make someone confused or grumpy.”
- › “If this happens, it is not because of anything you did. It is because of how their body is feeling.”

## **Skin color or temperature**


- › “When someone is in hospice care, their body starts to work slower. This also means their body may become colder or start to turn blue. This is normal for someone in hospice care.”

## **Breathing**

- › “When someone’s body is changing and dying, their breathing changes too. Breathing can be faster, slower or even noisier.”

## **Giving ongoing support**

Children may change their coping methods while their loved one is in hospice. You should respect and honor these changes. It can help them feel support and consistency during a hard time.



Below are some suggestions for providing emotional support.

### **Regular communication**

- › Continue talking about the child's loved one. Let the child know how things are going. This can help them feel included, and it allows time for them to process the changes in real time.

### **Questions**

- › Children use questions to let us know they would like more information. Many questions about hospice may not have a concrete answer. It is OK to say, "I do not know the answer to that, but if I find the answer, I will let you know."
- › You can help children feel heard, seen, and understood by letting them know that is OK to have questions and confirming that it can be difficult or frustrating not to have all the answers right away. Encourage the child to write down their questions or have someone help them do so. This helps them communicate all their thoughts.

### **Coping**

- › Many children use play to cope and make sense of what is happening. Encourage play, connection with their peers, participation in their regular activities (such as hobbies or sports practice) and other self-expression. Remind them that, though things are hard right now, you are allowed to feel sad and still enjoy the things you love at the same time.

### **Decisions**

- › Find out how a child wants to be involved in the death itself. This will help them feel empowered. If it is appropriate, find out if they want to be present for the death.
- › In the event they are not present for the death, ask them if they want to know right away or wait to hear once they are home.
- › These decisions may change. Regular communication is key.

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If you need support in talking about hospice care to children, you can email a child life specialist at [NMHChildLife@nm.org](mailto:NMHChildLife@nm.org).