

# Let's talk about...

## When a Parent Begins Hospice Care

### Children and Teens:

Each child and situation is different, though in most cases, children benefit from being included when a parent is dying. The settings where they are receiving care may vary – a parent may be in a hospital, an outside care facility, at a family member's home, or at their home. Although this information is geared for a parent dying at home, much can be applied for helping to include children if care is being provided in another setting.

### Preparation:

To help children cope throughout the dying process, providing developmentally appropriate preparation and ongoing support is important. When a parent is dying at home, children will be able to see changes more gradually; this can be helpful. Some children will cope best with more information and other children will want less. Keeping this in mind will be helpful. Any information provided to the children should be honest, clear, and simple.

Here are some topics to consider addressing at various points:

- **Hospice:** At this point, children must already understand that there are no other treatments that can cure their parent's disease. You can explain that: "Hospice is for people who are not expected to live much longer. The hospice team makes sure patients are kept as comfortable as possible with different medicines while their body stops working and they eventually die."

**For more information or to connect with a Child Life Specialist, please visit: <http://ucdavis.health/childlife>**



- **Visiting:** Review what the expectations are for visits. Should children pay attention to what time of day they visit, their noise/energy level, and would it be best if they were accompanied for the visit. It can be helpful to have a few appropriate activities available as well.
- **Sleepiness:** You can share that dying is a very tiring process. A person may be weak, sleepy, or not waking up much at all. Even when this is happening, they may still be able to hear and know who is around. Right before death, a person's eyes may stay open without blinking. They may also talk briefly before dying.
- **Eating and drinking:** You can explain that when a body is dying, it does not need anything to eat or drink. Clarify that the body is not dying because the body is not getting food or drink.
- **Pain:** Explain that unlike other medicines that help the body get better, pain medicine is to help the body feel more comfortable and can make the body feel more tired. Avoid having children visit if a parent's pain is not well managed.

\*Or other adult in a child or teen's life

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- **Confusion and agitation:** With the many changes the body is going through, explain that a person can become confused or restless.
- **Skin color and temperature:** If the parent's skin color is different than usual, explain why this is happening. When death is near, the arms and legs may become cold, and due to this, some parts of the body may turn blue.
- **Breathing changes:** Breathing patterns change when a person is close to dying. Breathing can become slower, faster, or noisier. If breathing becomes noisy, it can help to explain this as similar to snoring.
- **Ways to interact:** There may be special ways a child wants to interact with their parent; honor the child's ideas when possible. Some ideas for children are decorating their parent's room, choosing music to play, holding hands, telling stories, reading, or doing any quiet activity at the bedside (e.g., homework, watching a movie, etc.).

## Support for Children:

- **Regular meetings:** Set up a time to have regular conversations about the parent and how things are going. These meetings help children know they will continue to be included and allows time for processing.
- **Questions:** When children ask questions, they are letting you know they are ready for more information. Encourage questions throughout the dying process. If you don't have an answer to a question, see if you can find out more information. And if a question doesn't have an answer (much related to death and dying does not have clear answers), it's okay to say that and recognize how hard it can be not to have all the answers.
- **Coping:** Children play to process information. Encourage playing and connecting with peers. As well, promote having children continue participating in their regular activities and provide self-expressive options to promote various outlets for coping.

## Continual Assessment and Planning:

- Continue to check in with children regarding visiting their parent. Honor choices as these could change throughout the process.
- Find out how children would like to learn about the death, especially if away from home. For example, would they like to be contacted while at school or wait until they get home? If possible, would they like to be with their parent when they die? If a child does not want to be present, create a support plan. Writing out the plans with the children and continuing to check back often is helpful.

Grief is a universal life experience and different for each person. Children learn from adults who model through words and actions that grief is a healthy response to change and loss. When children are prepared for and included in an end-of-life situation, they are given a sense of control with opportunities to say goodbye. Grief can be very difficult and made a bit easier with support and while connected to others who are grieving.

## Other Resources (scan the QR code for direct link):



UC Davis Bereavement Book  
(View under "B")



Dougy Center



National Alliance for  
Children's Grief