

How to Support Your Children When Visiting Someone at End of Life

When someone important in a child's life is receiving hospice care, it can be challenging to know how to best support that child. One area that many parents wonder about is if their child should be allowed to visit a patient who is dying. Some worry that visiting will be too scary or tarnish the child's happy memories with that person, while others worry that not having a chance to say goodbye may result in resentment or guilt. The following tips will help parents and caregivers know how to make the best choice.

Should children visit a patient who is nearing the end of life?

Yes, if the child would like to visit the patient, it is important to give them the opportunity to do so, regardless of their age. Often, when children struggle with their experience it is because they feel they did not have a choice, or that their feelings were not considered. If your child wants to visit, be sure to prepare them by telling them about what they might see, how the patient might look or act different from when they last saw them, and what the child might be able to do during their visit.



Think about the timing:

If possible, try to plan the timing of the visit thoughtfully.

- Avoid a visit right before the children's bedtime, allow for time to decompress and process after.
- Is there a time of day when the patient is most comfortable or alert?
- If the patient is in noticeable pain or discomfort, it might be best to limit the visit or reschedule.
- If it is possible that this is the last time the child may see the patient, it's important that the child knows this.

Preparing children for a visit:

Preparation is key to providing a safe and comforting visit for children.

- Make children aware of any changes in the patient's condition.
 - "Grammy may be sleepier than usual, her breathing may sound different, and she might have her mouth open. Grammy might not be able to talk to you, but if you talk to her, she can still hear you."
- Prepare children for changes in the patient's environment.
 - Is there new durable medical equipment in the house (hospital bed, oxygen, commode, etc.)?
 - If the patient is at a hospice house, you can explain:
 - A hospice house is "home away from home" for people who are very, very sick. A hospice house is usually much smaller than a hospital; it is very quiet and peaceful.
 - There are lots of people there to help make the patient feel comfortable (doctors, nurses, social workers, etc.).
 - The rooms are designed to look like a room in someone's home so family members and loved ones can bring pictures or other items from home to decorate.

Care Dimensions has a team of child life specialists who can help you decide how much information to share with your child and how to support them while a loved one is receiving hospice care. Contact ChildLife@CareDimensions.org or ask a member of your hospice team to have a Child Life Specialist contact you directly.

During the visit:

- Provide ideas for how to interact during the visit.
 - “While you are visiting you can choose to draw a picture to put by Grammy’s bedside, you can sing her a quiet song, read her a book, talk to her, or simply hold her hand. If you would like to visit, but do not want to stay in the room with her, you can choose to play in a different room.”
- Ask the child if they have any questions.
- If old enough to be unsupervised, ask the child if he or she would like a few minutes alone with the patient.

Leaving a visit:

- Saying goodbye can bring up difficult feelings. Validate this.
- Make sure your child can identify a supportive adult in their life who can be available to talk about feelings or answer questions. This may be a parent, caregiver, or professional.
- Name the positives of the visit.
 - “That was a special picture you made for her.” Or “It means a lot that you visited.”
- If the patient is very close to end of life, avoid making promises like “we will see him again next week.”

If your child does not visit:

- You can ask your child about why they prefer not to visit to ensure there is not an underlying reason that could be addressed.
- Validate your child’s wishes to not visit. It’s okay to not want to go. Avoid making comments that could cause guilt or shame about this choice.
- Offer alternatives.
 - Draw a picture or write a note to be mailed or delivered by another visitor.
 - Exchange a picture or video message on a cell phone.

Either Way...

- Remind your children that it is okay to have many different feelings about having a loved one who is so sick. Children sometimes feel sad, scared, angry, happy, relieved, and/or confused. Ask your child about what is most helpful for them when they experience these feelings.