# **WONDERS & WORRIES**

# Visiting a Parent at End of Life





Visiting a parent in the hospital can be challenging on its own, but when children are navigating a **final visit** due to an end-of-life situation, it will be unlike any other visit. Parents often struggle with deciding if a child should be allowed to see their parent in such a state. What we know about children is that when they are provided with a choice, included in honest and age-appropriate ways, they value the experience and are able to cope better (in the short and long term). The following information reviews considerations for including children in these situations, especially in regard to preparation and supportive strategies.



# Considerations when preparing for a last visit:

# WHAT DO THEY UNDERSTAND ABOUT THE SITUATION?

After a parent is given a poor prognosis by the medical team, the decline can be slow or extremely fast. In each of these situations, it is important to first understand what the child knows about the situation. This will help you know where to begin your conversation. And then, you can share more about the illness <u>Talking with Children About Parent's Illness</u> and <u>Preparing for the Death of a Loved One</u>. Below are some sample conversation starters:

"I know I told you last week that dad was in the hospital and would be there for a little while as he gets help from the medical team. At that time, I don't think I explained a lot about why he is in the hospital. I'd like to share more about that..."

Depending on how quickly the death is expected, you may not have a lot of time to explain information about an illness or injury and instead need to focus your attention on the limits of treatment and pending death. If this is the case, we recommend re-visiting this conversation after the death. Questions may arise as children want to better understand the details that led to the death.

## TALK ABOUT THE LIMITS OF TREATMENT AND ANTICIPATED DEATH:

Help children understand that the medical team has tried everything to help their parent's body get better. Share that sometimes there aren't any other options to help the body and the body dies. When sharing this information, using simple and concrete terms can be helpful so that they understand the finality of the situation.

"Sometimes doctors can make an illness go away, but other times, the illness is too big or too strong to go away. When that happens, the body stops working and dies. Have you heard that word before?"

"Sometimes treatments help make an illness go away; but for dad, his illness doesn't have a treatment that can do that. He will have some time where his body is still alive, but the doctors expect that his body will become so sick that he will die soon."

# **NORMALIZE EMOTIONS**

Ensuring children know that all of their feelings are normal is essential. Whether a child expresses certain emotions in the moment or not, knowing that emotions will come and go as they process their parent's illness will be helpful. You can normalize this with language and preparation, by modeling with your own emotions and observing what you see in them.

"It may be overwhelming to hear all this information. That is normal. I would expect over the next few days and weeks you are going to have a lot of thoughts and feelings. They are all normal and okay. And we will be there to support you."

"I can see you are worried because you see me crying. I'm sad about dad. I'm sorry if it's worrying you to see me cry, but I also hope it helps you see that it's okay to be sad."

"Susan, I can tell you are nervous. You tend to twist your hair when you're nervous before a soccer game or test. It's normal to be nervous to say goodbye to mom. I'm right here and if you decide you don't want to at any point, that's okay."

Offer options for saying goodbye: Saying goodbye can be thought of in words, in actions and in rituals. A visit allows a tangible memory where a child can say specific words he or she wants to, and to be able to hug, kiss, and touch their parent. These tangible opportunities can often help a child understand why their parent won't come home and provides a sense of closure.

#### **WORDS**

Children can share an "I love you" or "Bye, mom" at a visit. They may also choose to write a letter, a song, a poem or draw a picture. Whether spoken or written/drawn, the act of being able to express how much their parent means to them is valuable. Having choices also allows children to say goodbye even after a parent has died.

#### **ACTIONS**

Some children will need a physical way to express their love for their parent. This can be a hug, a kiss or lying with their parent before or even after their death. It is important that a child chooses this and that this is not forced.

#### **LEGACY ACTIVITIES**

You may have a variety of activities to offer families when facilitating a visit. Activities may include creating a piece of art together (family handprint painting), taking pictures during the last visit, or this can be something the dying parent does for their child (letters for specific milestones, voice-recording of their favorite book, etc.). If the ill parent is not able to participate in a legacy activity, family members and friends can help create keepsakes. Putting together lists of the parent's favorite foods, music, books, movies (etc.) can provide some ways for the child to feel a sense of connection with their parent.

## **MEMORIALIZING**

Grief is ongoing and can manifest differently for each person. For children who have a parent that dies, rituals provide a safe, rhythmic way to remember and integrate the loss of their parent into their present life. Having a specific meal on their parent's birthday or having an activity they do on the anniversary of the death are both examples of creating a ritual to make time and space to remember and carry their parent into their future in a healthy way.

These situations can feel incredibly isolating – please connect with a Wonders & Worries team member via the helpline, 1-844-WE-WONDER or helpline@wondersandworries.org, at any point if you would like to talk through a situation and discuss supportive strategies.



Professional support for children through a parent's illness or injury.

We will, together.