

Patient & Family Information Series



Supporting Children & Teens: When Someone You Love has an Advanced Terminal Illness

Adults often want to shield children from difficult information and situations. In the case of an advanced illness, it may be challenging to hide the physical changes or emotional stressors that are a part of the process. Numerous studies have shown that, in the year following a parent's death, most children will develop some behavioral and emotional disturbances but will reach a normal adjustment in time (Muriel, 2022). When children are informed about what to expect, they are allowed the opportunity to make the necessary emotional preparations which leads to a healthier grief response.

Your **Ancora Medical Social Services** team has been specifically trained in how to help patients and their families through these challenging times. This support includes help for children and teenagers. The team is prepared to:

- ❖ Support honest communication with children and teenagers at an age and developmentally appropriate level
- ❖ Assess the needs of the family in relation to the illness
- ❖ Encourage and advocate for maintaining a sense of normalcy and routine, as much as possible
- ❖ Address specific concerns that arise throughout the illness
- ❖ Discuss ways to honor and preserve family time
- ❖ Facilitate legacy work and memory making as a way to create continuing bonds

Illness in the Home Environment

If your loved one desires to remain in the home, you may be concerned about what effect this can have on the children. One of the biggest advantages is that children and teenagers can continue their routine. Additionally, the parent who is well is accessible to the child on a more regular basis. There are some considerations to review:

- ❖ Use open, honest communication regarding changes in medical condition and expectations
- ❖ When possible, the dying patient should be in a room with a door. Using this approach allows the child to decide how much they will see or hear of the illness or medical equipment
- ❖ Utilize the hospice team to discuss concerns or fears about the death - what will be seen, heard, experienced
- ❖ Contemplate whether the children should be present once the death occurs and the funeral home is present to remove the body

“Addressing these types of logistics allows children and adolescents to think about how much they want to be around during the final days and hours. They can also consider whether or not they want to see the body after death, and they should be supported in making an informed decision about how, when, and with whom they would want to do so” (Muriel, 2022).

Signs of Distress for Children & Teenagers

It is important to monitor and support children during this challenging time. As cited by researchers, “For children living with a parent with cancer, greater anxiety was associated with an inability to discuss the illness, decreased time spent in age-appropriate activities, and ongoing worries about the cancer” (Muriel, 2022).

Some specific signs of distress to watch for:

- ♦ mood changes, ie. increase in anxiety or depression
- ♦ disturbing dreams or nightmares
- ♦ behavior changes at home or school
- ♦ isolation
- ♦ changes in eating or sleeping habits

The support during this time is essential and may not be able to be provided by the well parent. It is good to reach out to caring adults who can assist with this support. Additionally, utilizing your Ancora Medical Social Services team can be beneficial.



Tips for Supporting Children & Teenagers

In addition to the considerations listed in this document, we offer these helpful tips that can enhance relationships through end of life, and set children up for a healthier emotional future.

- ❖ Communicate
 - ❖ About the illness
 - ❖ About the changes
 - ❖ About what this means for the child
- ❖ Listen and watch verbal and non-verbal communication.
- ❖ Check-In frequently and allow space for questions.
- ❖ Use helpful language about what is happening: Using the words “cancer”, “dying”, etc. are helpful in communicating. It is important to assess what they are hearing as well. If there are gaps in their understanding, children will often fill this with misinformation from their own thoughts, something they overhear, or from well meaning friends.
- ❖ Use open ended questions: Ask the child, “What changes have you noticed in (loved one)?”, or “Do you wonder what might happen next/as (loved one) gets sicker?”
- ❖ Utilize support of grief professionals for yourself, as well as your child.

Your ANCORA Medical Social Services/Bereavement Team is available to support you in this process. Please reach out to them with any questions or concerns at 208-452-2672.