Talking to Children When a Cure is no Longer Expected

When someone is very ill and a cure is no longer expected, those who care for children may wonder what and how to tell them. Perhaps the family has lived with an illness for a while. There may have been a lot of energy put into preserving some normalcy and the rhythm of family life. These efforts can be helpful to young people, allowing them to continue their routine of school, friends, and other activities of daily life. When a cure is no longer expected, there can still be a routine, but it may need to change. The routine needs to include some quiet time to spend with the person who is ill, down time for feelings to surface and an opportunity for children to ask questions. Communicating what is happening honestly on their developmental level will help young people understand, process and eventually adjust to the changes in their lives.

Communication is more than words. When giving information about what to expect, use a calm voice. Communicate caring and support. Find a quiet place where your attention can be focused on the child or teen with whom you are talking. Some families communicate support with hugs, an arm around a shoulder, a hand on a knee. If the news is very sad, it is appropriate for everyone in the room to have tears.

Begin the conversation by acknowledging the changes in the person who is ill. Acknowledge if others in the family have been acting differently. Ask the child what changes they have noticed in the person who is ill or in others in the family. Ask what questions they may have about what has been going on. Let them know changes in the family are not their fault. Explain that changes in the person who is ill are because that person’s body is not healthy. For younger children using the words “the body is broken” might be helpful. Sometimes when bodies are not healthy or broken, they can be fixed, but sometimes they cannot. Let them know of people who have tried to help. Perhaps there were aides, nurses, doctors, EMS workers, even friends and family that have tried to help the person’s body to heal, recover, be fixed. Sometimes there were medicines and treatments that are a part of the story. Even though efforts were made, the person’s body could not be fixed, and a cure is no longer expected. This means, at some point, the person will die.

If the child is very young, words will be needed to explain what it means when someone dies. Even if words are perfectly chosen, young children will need time, sometimes months, to understand the permanency of death. The concept of permanency, that a person or an object might go away forever, is something children generally learn between the ages of 3 and 6. Even older children may need time to accept the idea that a person they care about will never be a part of their lives in the way they have been. Some people find it helpful to talk about the parts of the body that are needed for life, our heart, our lungs. Tell them that parts of the person’s body are not working. Remind them that their heart and their lungs are working. If you can say it honestly, let them know their body and the bodies of those who take care of them are healthy and it is expected for you all to live a long time.

Young people of all ages will wonder how the illness and the death will change their lives. Let them know some things will be the same and some things will not. Acknowledge that the person who is ill will be missed. That will be different. Let them know the people who provide care for them will still be in their lives. If you can say it honestly, let them know they will still live in the same house, go to the same school, have the same friends. Remind them they will still have a family even though the family will look different.

For some families, it is important to include their religious or faith beliefs. This can be comforting to young people, but there are also concepts that children will understand on their developmental level. Try to use words that help them distinguish between what they understand as our earthly bodies and what a soul or spirit might be like after death. Be aware of the child’s perception of the words that are used. Children are concrete and can be confused by words that bring an adult comfort. For example, the idea that God needs another angel can bring an adult comfort but scare a child. I knew a 5-year-old who had been told this about a family member who had died. With fearful eyes he said to me, “I hope God doesn’t need me because I need to go to college.”

No matter what age you are, it usually takes time to adjust to the death of a loved one. Most people find it helpful to voice their questions, express their feelings and tell their story. Part of the story of grief and loss is the people who are there to help, listen and show they care. Efforts to be supportive for children and teens will make a difference in how they remember and learn from the grief and loss they experience.