



## Talking with children and teens about frontotemporal degeneration: First steps

Coping with a family member's frontotemporal degeneration (FTD) can be confusing and overwhelming for the entire family. However, it is important to keep children informed about FTD and their family member. FTD symptoms and the abilities of the person diagnosed change over time. Simultaneously, children grow and mature. Good communication requires a flexible, on-going dialogue between children, teens and caregivers.

Below are some suggestions for discussing FTD with children. There will be many opportunities to develop the approach and comfort level you want. Not everything works equally for every family. Try different things and see what works best for you and your family or child.

**Prepare.** Arm yourself with accurate information about FTD. Tell children the name of the disease. Give clear and concrete explanations geared to their age and level of understanding. Make sure children understand that the illness is a medical condition that they did not bring on with their thoughts or actions. Give explanations gently and over time if needed. Let children know they can ask questions as they think of them.

Set the stage for discussions. Plan to join your child in a comfortable activity as a vehicle for opening up conversation. Many children are more open to talking in the midst of activities than in direct sit down sessions.

Consider how you want to address progression of the disease and the issue of death. Familiarize yourself with how children handle loss and grief at different developmental levels.

Even very young children may be aware that some illnesses are passed from parent to child. Questions and concern about the risk of inheriting a parent's FTD are common. Understanding the issues and your family history are important so you can answer simply and honestly.

**Listen.** Children are often aware of problems long before a diagnosis is made. Tune in to what your child thinks and feels about the situation. Patience and time spent listening often facilitates a child's sharing of thoughts and feelings.

The Internet makes it easy for children to research terms on their own. Ask what they know about the diagnosis before you begin. Deal with preconceptions up front so they will be better able to hear new information.

Children need to be reassured that it is okay to ask questions as they arise. It is important for them to know that it is safe for them to express their thoughts and feelings.

Depending on their age and maturity level, children and teens will have differing questions and concerns. Younger children may be concerned about who will take care of them or carry on a

holiday tradition. Pre-teens may be curious about the biology of the disease. A teen may worry about the future. Listen to and try to address each child's specific concerns.

**Be honest.** Naming and sharing information honestly about frontotemporal degeneration from the beginning can help to increase awareness and understanding among others, and decrease the family's feelings of isolation.

Provide truthful answers to questions at the level of understanding the child is able to hear. ie: Is daddy going to die? Am I going to get this?

It is OK to discuss death with your children. This is not one conversation, but another on-going dialogue between caregivers and child. Make sure your child knows that it is OK to think about and process what this means to them, the family, and the person who is ill.

**Empower.** Help children decide what to tell their friends and when about the parent's illness. Help children to find positive ways to express a full range of emotions. Let them know they may feel confusing and difficult emotions and that even unpleasant emotions can be expressed in positive ways. Encourage involvement in sports, music, art or other creative, expressive activities.

**Offer resources.** Children need to be educated on where they can go for more information. Do they know where to go if they read something on Internet and it frightens them?

At times, a parent is unable to address their children's questions, thoughts or feelings due to their own experience of the family member's illness. Help children identify someone within their circle of trusted adults with whom they can talk honestly and comfortably. These adults may be family members, clergy persons, bereavement counselors, school personnel or anyone with whom the family and child have a trusting relationship.

**Model good coping.** Structuring time to take care of yourself, maintaining important relationships and expressing feelings in positive ways will be very helpful coping models for your children.

A loved one with FTD may have trouble communicating effectively. Help children understand this is part of the disease. Help them to see there are many different ways they can still communicate their love for the person.

Acknowledge and appreciate the good things children are doing; children often don't feel acknowledged for what they are doing and achieving in their lives, especially when the care of someone in the family requires significant time and attention.

**Remember.** Experts say over 90% of communication is non-verbal. Facial expression, body language, gestures, signs, and use of space are also important ways to send information and influence how we understand others' messages. Pay attention to non-verbal signs in talking with children and teens.