

FAMILIES WITH CHILDREN AND TEENS

WHAT TO TELL THE CHILDREN?

When a family member is diagnosed with Frontotemporal Degeneration (FTD) or Primary Progressive Aphasia (PPA), parents often worry about what to tell the children. Children are affected by everything that happens in the family. Given the number of changes brought on by FTD or PPA (moods, behavior, communication changes, etc.), children soon realize that family life is different. If someone does not communicate with them about what is happening, they imagine their own reasons for changes. They may attempt to make sense of the situation by listening into adult conversations, looking at written materials brought into the home or by questioning other children. Children can feel isolated from adults, confused and overwhelmed. Parents can help by telling the children the truth and addressing their children's concerns regarding cause, contagion, care, connection and communication.

Cause: Tell children the name of the disease or condition. Explain how and/or where in the brain it began. 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.

Contagion: Children may be concerned that they or other family members will get FTD or PPA, too. Older children may have questions regarding the illness as a hereditary condition. If heredity is a truth for the illness, remember that each one of us needs information in order to cope. Answer questions to the best of your ability and in a manner that is developmentally appropriate. If the form of FTD/PPA is not hereditary, reassure the children that they or other family members cannot get the illness.

Care: Reassure children that they will continue to be cared for and loved even though more attention will be given to the person with the illness. Children deal better with changes in the family when they know they are still important. Also, encourage children to ask specific questions about the impact of the illness on their daily routine.

Connection: Children need to maintain a connection with the person with FTD and PPA. This can be difficult as the individual begins to have more personality changes (with bvFTD) and language decline (with PPA). Be aware of what safety issues need to be addressed. Although the person with FTD or PPA cannot be in charge of the child's care; with proper supervision, he or she may be able to assist or engage in playful activities with the child; for example board or video games, going out for a walk, or preparing lunch.

Communication: 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. If parents are unable to address their children's questions, thoughts or feelings due to their own experience of the family member's illness, be sure to designate one or two trusted adults to whom the child can turn. These adults may be family members, clergy persons, bereavement counselors, school personnel or anyone with whom the family and child have a trusting relationship.

Informational resource: *How to Help Children Through a Parent's Serious Illness* by Kathleen McCue

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FAMILIES WITH CHILDREN AND TEENS COPING WITH FTD AND PPA:

HOW ADULT FAMILY MEMBERS CAN HELP CHILDREN, CONTINUED

The following are some suggestions for helping children when an important person in their lives has FTD or PPA. All families are different and all children are unique—so some suggestions may not apply to all cases. Speaking to a children's mental health professional can help you clarify how to best take care of the children in your family.

- ❖ Learn as much as you can about the illness
- ❖ Use correct medical terms. Don't over explain, but be honest. Fear and fantasies are often worse than reality.
- ❖ If the person with FTD or PPA lives in another setting, offer children choices of phone calls, letters, drawings, and/or visits with the person with FTD or PPA. Prior to a visit, describe what the child can expect to experience at a hospital, hospice, or nursing home-- including how the person who is ill will look and act.
- ❖ Reassure children that noting they did or didn't do caused the illness. Find time to give them love and attention.
- ❖ Take care of yourself and find support to overcome personal fears and anxieties. Children model behavior and coping skills from the adults they live with.
- ❖ Encourage communication. Don't assume lack of questions mean lack of interest. Children are more likely to express themselves in art, play or actions than in words. Find time to observe them during these activities. Ask teachers & others for their observations. Share your own true feelings to help them understand their own.
- ❖ Headaches, stomach aches and behavioral problems may be caused by repressed feelings. Provide healthy outlets for energy release and expression with creative and physical activities.
- ❖ Feelings of abandonment, helplessness, despair, anxiety, apathy, anger, guilt and fear are common in a family with serious illness. Children often act them out aggressively when there are no healthy outlets. Anxiety may lead to hyperactivity and behavioral problems. Try to maintain as normal a routine as possible. Children need structure to feel secure during stressful times.
- ❖ Children need to be involved in appropriate ways. If they try to assume caretaker roles, remember they need to grow up normally without being burdened with adult responsibilities.
- ❖ Coping with illness, financial and personal needs may overwhelm the parent who is not ill. Children need increased support from grandparents, neighbors and friends. They need to grow up knowing there is someone to count on or they may become too independent and distrustful.
- ❖ There is a significant correlation between duration of illness and a child's behavioral difficulties. Illness lasting more than a year requires more intervention because the family focus is on something other than the child. Learn what services are available for your situation and needs through hospitals, churches, schools, community agencies and professional counseling. Inform pediatrician about family problems.

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