

## FTD When There Are Kids in the Home

**P**eople facing FTD disorders have a heavier burden of care than with other types of dementia. When there are young children or teens in the home, the level of support needed is particularly high. A village of support should be constructed to ensure the health of the family and the adjustment and well-being of individual members.

### Access Accurate Information

- Arm yourself with accurate information about FTD to share with the primary caregiver and children as appropriate. Education specific to FTD symptoms and progression is important.
- Help children understand that unusual behaviors and trouble communicating effectively are common symptoms of FTD. Educate them to see that there are many different ways they can still show their love for the person.
- Familiarize yourself with how children handle loss and grief at different developmental stages so that you fully understand their needs and can guide interventions more effectively. Engage children through activities rather than big discussions.
- Expect questions about the risk of inheriting FTD. Help the well-parent to better understand the issues and family history so he or she can answer simply and honestly.

<http://www.theaftd.org/understandingftd/genetics/talking-about-genetics-with-children>

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### Facilitate Use of Support

- Hold regular meetings with staff and family to coordinate care and keep everyone informed.
- Listen. Tune in to what the caregiver and children think and feel about the situation. Patience and time spent listening often facilitate a child's sharing of thoughts and feelings.
- Help the caregiver to tell family and friends about the diagnosis and seek needed assistance. Being open with family, friends, neighbors and schools about the disease eases the stress.
- Assist the well-parent to structure time for themselves, maintain important relationships and express feelings in positive ways. Modeling good self-care is important for the children.
- Make sure each child has a "special," trusted person they can talk to in addition to the well-parent. This may be a family member, clergy person, bereavement counselor, school personnel member or anyone with whom the family and child have a trusting relationship.
- Encourage children to stay involved with school and social activities. Suggest that the family ask for help with transportation and other logistics, or consider an online calendar for scheduling.
- Identify and access a full range of formal and informal support resources that the resident and family may need.

## FTD When There Are Kids in the Home *continued*

### Respond to the Children's Needs

- Facilitate open, age-appropriate dialogue to enable children to understand the symptoms and progression of FTD. Give explanations gently and over time if needed. Encourage questions as they arise.
- Be honest. Provide clear, concrete and truthful answers to questions at the child's level of understanding.
- Make sure young children understand that the illness is a medical condition that they did not bring on with their thoughts or actions, and that they cannot "catch" it like a cold.
- Set the stage for discussions. Many children are more open to talking in the midst of comfortable activities than in direct sit-down sessions.
- Try to maintain as normal a routine for children as possible. They need structure to feel secure during stressful times.
- 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.
- Watch the child's reaction during discussion or while visiting at the facility. Experts tell us that more than 90% of communication is non-verbal.
- 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. Headaches, stomachaches and behavioral problems may be caused by anxiety and repressed feelings.
- Help children decide what to tell their friends and when about the parent's illness. Let them decide if and how often they want to visit in the residential care facility. This can provide children with some control over their situation.
- Encourage kids to pick favorite photos or memories and help with a memory book that they can go through at the facility or at home, to remember the fun things. There are websites that can help to easily create digital books.
- If a family activity is "not the same as it used to be," suggest new activities or a change in location. For example, if the preferred activity had been going to a sports event or the movies, get the event or movie on TV or video at home in a controlled situation and call it "movie night." Avoid buffet-style dining if eating is a problem.
- Respect each child's "limits" for visiting and helping with the parent's care. Some enjoy helping with activities – such as meals or exercise – and others are not as comfortable.
- Coordinate with family and residential staff to be aware of interactions between children and other residents. Take steps to reduce unwanted contact, and coach children in how to respond when and if they are confronted.
- Acknowledge and appreciate the good things children are doing in their lives. They can feel overlooked when a parent requires significant time and attention. Focus on their strengths and accomplishments to build healthy coping.

**Provide clear, concrete and truthful answers to questions at the child's level of understanding.**