



The Association for
Frontotemporal Degeneration
Opening the gateway to help and a cure

**THE AFTD TASK FORCE ON FAMILIES
WITH CHILDREN**

REPORT OF FINDINGS

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Table of Contents

Executive Summary	2
Introduction	3
<i>To Learn and To Lead</i>	<i>4</i>
Guiding Principles and Methods	6
<i>Methods</i>	<i>8</i>
Review of literature	9
<i>Children’s bereavement: Supporting children through illness and grief</i>	<i>9</i>
<i>Anticipatory grief and ambiguous loss</i>	<i>11</i>
<i>Young carers movement</i>	<i>13</i>
<i>Young-onset dementia and children</i>	<i>15</i>
<i>Grief and the school setting</i>	<i>17</i>
<i>Complexity and unknowns of FTD genetics</i>	<i>18</i>
Needs of parents and children	20
<i>Input from task force members</i>	<i>21</i>
<i>Parents phone group information</i>	<i>24</i>
<i>Input from children in the parents phone group</i>	<i>25</i>
<i>Reflecting back on experiences with an affected parent</i>	<i>26</i>
Existing Resources and Program Models	34
<i>Programs in the United Kingdom</i>	<i>34</i>
<i>Programs in Canada</i>	<i>35</i>
<i>Programs in the United States</i>	<i>36</i>
Needs and Opportunities	37
Next Steps and Future Direction	41
Conclusion	44
Acknowledgements	44
References	45

Executive Summary

Information and resources that address frontotemporal degeneration (FTD) are gradually improving, but these diseases are still largely hidden and unrecognized. The challenges for caregivers of a spouse or partner with FTD who also have children or teens at home are particularly urgent. The stress of the emergence of disturbing symptoms, difficulty getting a diagnosis and managing a poorly understood, progressive, and ultimately fatal disease is tremendous. Without adequate support, the demands can thrust both adults and children into significant role changes and increasingly precarious physical, emotional and financial situations.

The Association for Frontotemporal Degeneration (AFTD) Task Force on Families with Children was formed in March 2010 to begin to address the challenges that families face. Its goals included: 1) articulating the specific issues of parents and their children and teens, 2) identifying existing resources to help them, 3) prioritizing projects for AFTD to implement for these families, and 4) stimulating the attention of a wider range of health care and social service providers to these needs. The committee utilized a broad descriptive approach to gathering data from currently affected parents and their children; young adults reflecting on their earlier years at home with an affected parent; and professionals who work with hundreds of families affected by FTD.

Together they provide extensive anecdotal evidence of the need for more and better services for this portion of the FTD community. Families with young children and teens at home are confronted with three fundamental challenges when one parent is diagnosed with FTD: 1) learning about FTD and how to plan and provide care for the affected spouse or partner, 2) deciding how to address the diagnosis and disease with their children, and 3) helping children cope in midst of their own grief, and often overwhelming stress. Some families must also consider the genetic aspects of the disease and that one or more children might have a genetic susceptibility to the condition and that children may be concerned about their risk of heritability.

A literature review of research about dementia caregiving, young-onset dementia, anticipatory grief, children's bereavement, and the young carers movement document the

increased burden of care faced by these families and suggest considerations for intervention and further study. A family with a parent with FTD and children or teens at home needs time to adapt to the progression of disease, grief, a changing family structure, and the growth of the children. Recommendations include developing strategies that promote comprehensive family support, including those that build resiliency in the well parent and the children, and strengthen the changing family unit as they cope with this challenging and uncommon disorder. Avenues for additional research in this area of need in the FTD community are suggested.

Introduction

“Why does Daddy fight us over the remote? Why does he take my things without asking? Why it is OK for him to do things you tell us are not polite? What do I tell people? He doesn’t look sick so do people think he’s just weird? The kids have so many questions and only me to answer them” - Parent in AFTD phone group.

Frontotemporal degeneration (FTD) is a disease process that affects the frontal and temporal lobes of the brain. It causes a group of disorders characterized by changes in behavior, personality, language, and/or movement and an inevitable deterioration in a person’s ability to function. Clinical diagnoses include behavioral variant FTD (bvFTD), primary progressive aphasia (PPA), and the movement disorders progressive supranuclear palsy (PSP) and corticobasal syndrome (CBS). At this time, there are no medical treatments and no cures for this devastating group of diseases.

Obtaining a diagnosis is often a difficult process because symptoms start slowly and can resemble other neurological and psychiatric disorders including bipolar disorder, depression or Parkinson’s disease. Often the young age of the person steers the physician towards a psychiatric diagnosis. An experienced clinician can often make a diagnosis with confidence, but some patients see several doctors before FTD is recognized. Because the average age of onset for FTD is 56 years, many people affected are at the height of their professional careers and have children at home. Research has shown that difficulty obtaining a diagnosis, an early age of onset, and the presence of behavioral features of the disease contribute to a greater burden on

caregivers than Alzheimer's disease (Kaiser & Panegyres, 2006; Freyne, et al, 1999; Luscombe, et al, 1998).

Difficulty with accurate diagnosis and the lack of epidemiological studies make it difficult to know with certainty the number of people affected by FTD. Most reliable estimates indicate approximately 50,000-60,000 people in the United States have an FTD disorder (Knopman, D.S., Petersen, R.C., Edland, S.D., et al, 2004). Life expectancy averages 8 years from the start of symptoms, but ranges from 2-18 years, depending on the specific disorder.

Information and resources that address the frontotemporal disorders are gradually improving, but these diseases are still largely hidden and unrecognized. The resources that do exist are targeted to primary caregivers, the people most involved in assisting with care. This is a critical starting point for education and support, but FTD impacts family members and friends differently depending on their relationship to the person diagnosed and how directly they are involved in care. Adult children of people diagnosed with FTD, parents of those diagnosed, extended family and friends, and especially patients themselves all have unique concerns. Each of these perspectives deserves additional attention, but the challenges of people providing care for a spouse or partner with FTD who also have dependent children or teens are particularly urgent.

The stress of FTD on younger families – the affected parent, the well parent, and school age children – can seem insurmountable. The emergence of disturbing symptoms, difficulty getting a diagnosis and managing a poorly understood, progressive, and ultimately fatal disease is tremendous. Without adequate support, the demands can thrust both adults and children into significant role changes and increasingly precarious physical, emotional and financial situations.

To Learn and To Lead

The Association for Frontotemporal Degeneration (AFTD) is a not-for-profit organization founded in 2002 to advocate for the needs of people with frontotemporal degeneration and their families, and to promote and fund research into FTD. AFTD's constituent base has grown

338% in the past 3 years, with a mailing list at the end of 2010 that exceeded 4200 patients, families, health professionals and friends. Over 2250 people have registered with AFTD as caregivers and 227 (10.1%) of them indicated they had a spouse or partner diagnosed with FTD and children under 18 at the time they registered. The growth trajectory is expected to continue as awareness of FTD and the Association increase.

Information about frontotemporal degeneration and its subtypes is becoming more available. Materials and support that address parenting issues or present information for children in families affected by FTD, however, are almost totally lacking, leaving the well-parent to rely on his or her ingenuity. In April 2009, AFTD initiated a telephone support group for parents who care for a spouse or partner diagnosed with FTD and who have children at home. This group is a unique resource for emotional support, education, and problem-solving assistance for participants and provides AFTD with insight into the needs of this underserved portion of the FTD community. The strong positive response to the phone group, its growing waiting list, and mounting contacts from parents seeking resources through AFTD's Helpline, highlighted the urgency of the need for better information and support.

Contact with caregivers indicates that families with young children and teens are confronted with three fundamental challenges when one parent is diagnosed with FTD: 1) learning about FTD and how to plan and provide care for the affected spouse or partner, 2) deciding how to address the diagnosis and disease with their children, and 3) helping children cope in midst of their own grief, and often overwhelming stress. Some families must also consider the genetic aspects of the disease and that one or more of children might have a genetic susceptibility to the condition and that children may be concerned about their risk of heritability. In a small percentage of cases, approximately 10%, there is an autosomal dominant pattern of inheritance where each child has a 50% chance of inheriting the disease. In 20-40% of cases, there is a less well defined, but increased risk to family members of developing some form of FTD or a neurodegenerative disorder within the FTD spectrum.

The AFTD Task Force on Families with Children was formed in March 2010 to begin to address the challenges that families face. The group's mandate was to *learn and to lead* in the

development of resources for families facing FTD who have children at home. Goals included: 1) articulating the specific issues of parents and their children and teens, 2) identifying existing resources, 3) prioritizing projects for AFTD to implement, and 4) sharing results to stimulate attention to the needs and creativity in the development of resources by health care and social service providers. Seven people comprise the Task Force: AFTD's Program Director, two caregivers from the AFTD telephone support group for parents, and professionals from the fields of children's bereavement, clinical social work/FTD research, familial research in dementia, and secondary education.

Guiding Principles and Methods

"I needed my well-parent to be seeking better emotional support. I also needed emotional support, and would have benefited from knowing other kids who were experiencing similar family stresses, and having others whom I could relate to. Even having an adult who knew about the disease to talk with would have been helpful."— Young adult describing her teen years

The Task Force adopted several guiding principles to direct its work.

Bias for action

The goal from the outset was to develop and provide new resources to help affected families. Research was done to inform the identification of priority projects deemed most fundamental and consistent with the Association's mission, which AFTD would immediately implement. Secondly, the Task Force sought to share its findings to stimulate interest in this area by academic research, treatment, and community providers and encourage the creation of additional resources.

Broad anecdotal input

As the national patient advocacy organization that serves people affected by all forms of frontotemporal degeneration, AFTD has contact with an extensive number of patients, caregivers and professionals. AFTD staff field on average 100 questions per month via phone or

email to the Association's HelpLine. Four telephone support groups for caregivers, contact with the leaders of more than 50 face-to-face FTD caregiver support groups, and participation in a growing number of FTD education conferences contribute to a broad perspective on the needs of the community.

AFTD's telephone support group for parents provides an on-going opportunity to understand the issues families with young children and teens face. The group is limited to 10-12 people at a time to facilitate a supportive environment. Initially it met monthly, then quickly increased to twice per month at the request of participants. Sixteen caregivers from the United States and Canada have participated in the group and generously offered input to this project. Two founding phone group members are integral members of the Task Force.

The Task Force approach reflected AFTD's extensive contact with families and their willingness to share experiences in order to benefit others. The committee utilized a descriptive approach to gathering and assessing information, rather than strict academic research. It engaged others via multiple channels through AFTD as well as through the affiliations of other members.

Focus on frontotemporal degeneration

Frontotemporal degeneration is estimated to be the second leading cause of young-onset dementia, but affects a smaller portion of the total population than Alzheimer's disease. A lack of awareness, the smaller numbers of people affected, and the economics of tailoring local community services specifically for people with frontotemporal degeneration means families must make do with the next best fit. Families often turn to resources developed for people with other neurological disorders such as Alzheimer's, Parkinson's or Amyotrophic Lateral Sclerosis (ALS). While some symptoms and caregiving challenges may overlap, the language impairment and behavior and personality changes characteristic of frontotemporal degeneration often leave people feeling that the available support does not match their needs. This can increase feelings of isolation until they find services and support that reflect their immediate reality.

The Task Force brings attention to the experience and impact of specifically frontotemporal degeneration on families. Children react to the symptoms that intrude into their lives. The impact of a parent losing his or her language ability or displaying disinhibited behavior present unique stresses on each part of the family unit. Resources that are developed primarily around memory symptoms, even in a younger population, are not as directly relevant for FTD families.

The input received, while broad and varied, does not reflect an ethnically or racially diverse population sample. It is challenging to establish economic, racial and demographic diversity in a sampling of FTD families. The people who access services at major medical centers and become involved with AFTD are predominantly Caucasian and middle class. Studies show that people with more education and income are more likely to reach out to community resources of any kind, and this is reflected in the FTD community. There is a need for services that are responsive to people with diverse ethnic and cultural backgrounds, despite their under-representation.

Methods

The Task Force assessed needs, prior research, and existing resources through the following:

- A literature review of studies in burden of care in young-onset dementia, children as caregivers across disability groups, anticipatory grief, parental illness and bereavement.
- An Internet search of support program models for children relating to parental illness, dementia, disability, and bereavement.
- Anecdotal data on concerns and needs of parents and their children compiled from parents in AFTD's phone group, FTD caregiver support groups, and the AFTD HelpLine.
- A survey of young adults who were under age 18 and lived at home when a parent was diagnosed with FTD.

Review of literature

A computerized literature search for quantitative and qualitative studies was conducted. The search examined articles from 1997 to 2011 and utilized the following databases, TRIP, CINAHL, psychINFO, Cochrane Collaboration, PubMed and Google Scholar. The search terms, which aimed to encapsulate broad definitions, were the young carers movement, young onset-dementia, dementia caregiving, anticipatory grief, child bereavement when a parent dies, and parental illness and children.

Children's bereavement: Supporting children through illness and grief

There has been limited research on children's bereavement and the efficacy of specific interventions. As a result, there is no widely accepted or understood approach to helping children—and no standardized clinically based method. There remain strong beliefs and myths about bereavement, especially children's bereavement. At the forefront are the stages of grief first articulated by Elizabeth Kubler Ross in the 1960s. Professionals in the field now recognize that grief is experienced at different times, in different ways, with no particular order or sequence to the stages and rarely in an orderly fashion. However, Kubler-Ross's theory is still widely taught and continues to drive lay-person beliefs about how people should grieve.

Prior to the 1980's, there was little research on children and grief. It was not until the 80's when interest in attachment theory grew as a result of rising divorce rates, prompting new avenues of research. These studies explored how children deal with loss, however, they focused on clinical populations, i.e. children with existing mental health issues. A study by William Worden known as the Harvard Bereavement Study (1996) was one of the first to study children from the general population who experienced the death of one of their parents, rather than children receiving medical or social services, and follow them over a two-year period. Among other things, the study found that that some children who lost parents experience long-lasting debilitating effects such as lower self-esteem, anxiety disorders, and poor school performance.

The current practice in child bereavement follows a support group model popularized in the last two decades. The original model for the program is the Dougy Center in Washington State. These groups provide some activities and support for children in age-specific groups while the parent or caregivers meet simultaneously in another group. These groups seek to help children process their grief and anger through activities. The Dougy model and similar programs also encourage individuals to stay connected with the person who has died. Rituals around saying goodbye, remembering, and celebrating the person are common. Above all, programs such as these seek to normalize grief for children and help them connect with others who have similar experiences. Anecdotal evidence supports the effectiveness of this approach in helping children feel less isolated and less anxious about their grieving experience.

Most interventions consider developmental stage in child grief. For example, children under five years old generally do not understand the permanency of death and may imagine the person returning or needing company. Children under five do experience loss, however, and may experience anxiety and sadness if a caregiver becomes ill or is absent. Younger children tend to have more physical or somaticized symptoms of grief while older children may have these plus cognitive and emotional issues or disturbances. Parents benefit from age-appropriate information about their children and what types of responses are “normal” and developmentally appropriate and which ones might be signs of mental health issues.

It is important to note that none of the popular models including the Dougy model were derived from research. They reflect grassroots efforts to address a need in the community. They are largely volunteer-run and include a parent or guardian support group.

A more recent development in the field is the Family Bereavement Program (FBP), an evidenced-based model developed by Arizona State’s Prevention Research Center. The program is currently evaluating the efficacy of a group intervention for youths who lost a parent and their parents/caregivers during a 6-year period. The program provides support coupled with psycho-education for both child and caregivers. The caregivers also receive skill building in communication and discipline to improve their ability to parent their grieving child. The program has shown promising results including reduced levels of problematic grief, improved

self-esteem, and a higher quality of caregiver-youth relationships (Sandler, I., Ayers, T.S., et al, 2008).

A key element of the research that informs the FBP is the focus on resilience. The model uses a framework of contextual resilience whereby bereaved persons change over time. Resilience here is nearly synonymous with adaptability whereby the goal is a process rather than an expectation of “recovery.” People adapt and interact with each other and their environment to foster developmental competencies, problem-solving abilities, and positive well-being in the face of challenge (Sandler, Wolchik, & Ayers).

The gradual loss of relationship and inevitable death of a person who has FTD links a diagnosis inexorably to experiencing grief. Information about loss and grief can be adapted for those concerned with children where a parent has FTD. The development of a training protocol or informational charts on bereavement could provide important guidance for families seeking to understand and guide their children in coping with FTD. Younger children may respond to using a coloring book to talk about grief; teens may respond to themes woven into a graphic novel, now an increasingly popular genre. Finding the most valuable ways to blend and share information is one of the goals of the Task Force.

Anticipatory grief and ambiguous loss

Recent attention in caregiving research has looked at the role of grief and bereavement in dementia caregiving. A study by Schultz, et al (2006) found that reducing caregiver burden (the physical, emotional, social, and financial problems faced by family members caring for impaired relatives), treating depression before the patient’s death, and providing psychosocial skills training may help the caregiver cope better upon the loved one’s death.

In dementia however, several other aspects of grief are beginning to be studied. Anticipatory grief is the loss experienced by caregivers while the loved one is still alive. This is more prominent in neurodegenerative diseases like Alzheimer’s disease and frontotemporal degeneration, because cognitive and personality changes lead others to feel the person is

emotionally lost to them long before the patient's physical death. Ambiguous loss refers to incomplete or uncertain loss, the lack of clarity experienced when a person is psychologically present despite being physically absent (ie: soldiers missing in action), or physically present, but emotionally and psychologically absent (ie: dementia, addictions or chronic mental illnesses). Pauline Boss explores this phenomenon in *Ambiguous Loss: Learning to Live with Unresolved Grief* (1999) and notes that without knowing who is routinely and fully *there* for them, people find it difficult to function normally.

In recent years, research has begun to explore anticipatory grief and ambiguous loss in dementia caregivers to better understand the important role grief plays in the caregiving experience and to inform development of effective interventions (Frank, 2008; Holley and Mast, 2009; Noyes, et al, 2010; Frank, 2010). As Frank notes (2010, p. 517) "the incongruence between physical and psychological presence creates high boundary ambiguity in the family system and keeps the caregiver and family in a highly stressful state." To date, the focus of research has been on spouse and adult-child caregivers of people with Alzheimer's disease.

A search of anticipatory grief and children largely yields research on the death of a child or on adult children of an elderly parent. Similar results occur in searches on parental illness. Again, the literature is largely concerned with adult children. Research that addresses anticipatory grief in children tends to discuss factors that later affect child bereavement after the parent's death rather than investigating children's response to the terminal phase on its own. There is little available on the effects of a parent's illness on a child or teen during the actual period of the illness and what it is like to "live with" the many stressors associated with an ill-parent. The exception to this are earlier studies by Siegel, Mesagno, Karus, et al. (1992) finding that children of terminally ill parents had higher levels of stress and anxiety and were less well-adjusted than a community sample. It should be noted that these were studies of children of a parent with advanced cancer immediately prior to the parent's death and not over a long period of time.

An additional exception on the topic of anticipatory grief and children is work by Saldinger, Cain and Porterfield (2003) at the University of Minnesota. The group studied 58

parentally bereaved school-aged children and their surviving parents to explore the challenges they had faced dealing with anticipatory death. The study focused on the child's exposure to graphic physical, emotional and mental deterioration of the dying parent. The length of parental illness averaged 2.8 years with the lengthier illnesses including long periods where the parent was asymptomatic. The authors found 10 potential stressors for children with dying parents including graphic physical deterioration of their parent, frightening mental and emotional images, forced exposure to the dying parent, secondary traumatic stress from not being able to help, and separation anxiety relating to both the patient and the well-parent. The authors conclude that parents should err on the side of assuming children will be overwhelmed by exposure to impending death no matter how well informed they are about expected changes. Further, it is not enough to inform and offer choices to children as many will not understand the implication of choosing exposure to an ill parent. Children still need protection, limits, and reassurance to minimize traumatic stress.

Deeper understanding of these concepts in relation to the spouses and children of someone with frontotemporal degeneration could be valuable to the development of information and support for families.

Young carers movement

The concept of "young carers" – children providing care for a parent or grandparent with chronic illness or disability -was first formed in the United Kingdom. The effort sought to raise awareness of children providing substantive care, and address the need for appropriate support and services for the family. Legislation passed in 1995 (Carers Recognition and Services Act) officially recognizes young carers in the United Kingdom and states they are entitled to an assessment of their needs in conjunction with the assessment for services needed by the main care recipient (Dearden & Becker, 1998). *Young Carers in the UK: the 2004 Report* was the third national survey undertaken to look at young carers projects across the United Kingdom and the progress they have made. The largest survey of its kind, the report is based on data from 87 projects that serve more than 6000 young carers.

The Young Carers Research Group based at Loughborough University, United Kingdom, was established in 1992 and applies research and policy evaluation concerned with community care, children, and young carers' issues. A current study tests the usefulness of photographic participation and elicitation research methods (techniques for eliciting perceptions and views from young people, rather than obtaining factual information) among a group of young carers. The study explores 'visual diaries', photographs taken by young carers of what it is like to live with and help care for a chronically ill parent, as one specific research tool for use with these vulnerable groups of children/young people. The aim is to provide deeper insight into the young caring experience and the nature of caring.

<http://www.lboro.ac.uk/departments/ss/centres/YCRG/>

The United Kingdom and Australia have integrated the whole family into the process when a person with a disability or chronic illness is assessed for care. As a result, an effort is made to develop an understanding of the needs of all members, including children and teens who will be impacted by a parent's illness. Heightened awareness of needs facilitates a coordinated approach to the families' needs and connecting all parties with services that address their particular concerns. Australia is following the United Kingdom by embedding the family-centered approach in national policy.

In 2009, the Australian government issued a report entitled: *Young carers in Australia: understanding the advantages and disadvantages of their care giving*. It presents the findings from a multi-stage study on young carers done by the Department of Families, Housing, Community Services, and Indigenous Affairs. Among the policy development issues identified by the research were the importance of:

- Raising awareness of young carers in a range of institutional settings, including schools, the health care system, and mainstream family and young people's services
- Recognizing the centrality of education as a site for identifying and supporting young carers
- Taking a whole family approach to service development and provision that recognizes the close connections between support for young carers and support for the family members for whom they provide care
- Providing appropriate and timely information about available services and supports to young carers and their families (Social Policy Research Paper No. 38 pg. xii)

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The National Alliance for Caregiving and the United Hospital Fund did a survey of children as caregivers in 2005. Until this study no national or large-scale studies of the impact of caregiving on children had been conducted in the United States. The initiative and approach to the issue was informed by efforts established with the United Kingdom and Australia. The project sought to investigate 1) the prevalence of caregiving among U.S. children, 2) learn what role children play in giving care; and 3) learn how the caregiving role impacts the life of a child.

Among their findings were:

- Of the 28.4 million households that have a child 8 to 18 years of age living there, 3.2%, or 906,000 households, include a child caregiver.
- Seven in ten child caregivers are caring for a parent or grandparent (72%).
- The most common care recipient conditions are Alzheimer's disease or dementia (18%); disease of the heart, lung, or kidneys (16%); arthritis (14%); and diabetes (14%).

The authors acknowledge that this survey offers a broad outline of the situation without specific details. For example, it acknowledges that there are likely significant differences in the experiences of children caring for parents versus those caring for grandparents that were not explored. The report is an important step toward bringing awareness to the need for attention and coordination among policy and service providers on behalf families with young children.

Young-onset dementia and children

There has been extensive research on family caregiving for persons with dementia. Caring for a person with young-onset dementia can have negative and/or positive outcomes, and is a complex process layered upon the contextual issues such as life-cycle stage and symptom profile (Weintraub & Morhardt, 2005). While the literature on younger onset dementia acknowledges the effects on the family as a whole, very few studies considered the specific impact of a diagnosis on children. Svanberg, Spector, and Stott (2011) systematically reviewed 26 studies on the impact of young onset dementia on the family. The majority were from the United Kingdom. (16), with the rest coming from Australia (3), the Netherlands (3),

Japan (1), France (1), Ireland (1) and the United States (1). Only two studies reported specifically on the experience of children. They report that one study by Gilliard (1999) discussed the challenges for children and suggested gathering a network of people, such as teachers, to help support the child. The other (Garbutt, 2006) found through interviews that developmental tasks, “such as changes in independence, identity, roles and relationships, are affected.” Svanberg et al., cite additional studies (Luscombe et al, 1998; Seddon, 1999; Nurock, 2000; Liebson et al., 2005; Alzheimer’s Australia, 2007) which recognized the caregiving impact on children in the supportive role they play, the psychological and emotional effects, and the recognition of their exclusion from services.

In a separate study, Svanberg, Stott & Spector (2010), conducted semi-structured interviews of 12 children of younger persons with dementia. The age of the children ranged from 4-16 and the parent’s age was 39-59 years. Five parents had a diagnosis of Alzheimer’s disease, one of vascular dementia and three had FTD. The study aimed to explore the impact of the diagnosis on these children and understand their experiences. In addition to the administration of measures of mood, burden and resilience, qualitative analyses of interview responses identified four higher order categories: 1) Discovering dementia; i.e., noticing symptoms and understanding the impact; 2) Developing a new relationship – needing to accept the loss of the prior relationship; 3) Learning to live with it – adjusting to increased responsibility, caring for parent; and 4) Going through it together – experiencing the impact on their relationships within and outside family.

Three stages of adapting to dementia were outlined. 1) First, the child grieves for the loss of the previous parent-child relationship and the relationship they expected to have in the future; 2) Secondly, the child learns to emotionally detach from the parent and develop a new relationship; i.e., the parent is seen as a different person and the child can blame the disease rather than the parent. This allows for a process of “learning to live with it”; and lastly 3) the child begins to act as an equal to the well parent in order to “go through it together”, becoming more autonomous and “responsible” (Svanberg, Stott & Spector, 2010).

While it is important to recognize the capacity for resilience – the ability to adapt to adversity - among children and teens, it is vital that we do not assume that they are coping. The study cautioned that although children may appear to be “mature and competent carers,” younger people with dementia and their families are in need of support. This is a non-normative time of life for a young child or teen to suffer the loss of a parent.

Grief and the school setting

School plays a significant role in the lives of children and teens, from promoting academic and social development to providing the foundation of their daily structure. Primary and secondary schools are important aspects of the support system for children and teens experiencing difficulties at home. Lawhon (2004) cites estimates that at any given time at least two students in a given classroom are grieving the death of a loved one, most frequently the death of a grandparent or great-grandparent, but that 1 in 20 American children under age 15 has experienced the death of one or both parents.

Access to professional school counselors and coordination with teachers can be essential support for a student who is confronting a parent’s illness, disability or death. To begin, counselors and families should: 1) share information so school faculty can understand the situation and be aware of the grieving child’s concerns or behaviors, (i.e.: inability to concentrate, changes in academic performances, loss of interest in activities); and 2) establish a procedure for communication and working together (Lawhon, 2004).

Recent research shows that there is no consistent pattern of grief for children. Changes in attention to academic work, relationships with peers, and/or interactions in the school environment may reflect the concerns of an emotionally stressed or grieving child. Grief is not isolated; rather it affects transactions and circumstances in every environment (Eppler, 2008). Traditional models within education have looked to individual support and small support groups to address issues of grief and loss. Some schools may offer small support groups on campus, or more frequently connect students with appropriate community resources. The

emphasis in grief groups was on the dominant voice of Elizabeth Kübler-Ross, stages of grief, and a deficit-based approach to bereavement, where students were encouraged to identify and express emotions related to the loss and saying goodbye. Small groups may involve art, journaling or dream work, but they did not foster and reinforce resilience.

The American School Counselors Association (ASCA) advocates working with students from a strength-based approach. Research has begun to address ways that professional school counselors can foster a resiliency approach to managing grief through interventions and supports in the education setting. This can be promoted through identification of certain protective factors that safeguard those at risk and promote successful development. Attention to a strength-based approach can be integrated into a range of possible interventions within the education setting. Examples of this may include developing small groups where counselors are attentive to focus on resiliency factors that bereaved student's report in telling their life story (Eppler, 2008) or the "re-membering" approach of Granados, Winslade, deWitt and Hedtke, (2009) which encourages students to reconfigure conversations that keep the person's stories, memories and feelings of love close in an ongoing, vital relationship. Their work shows this may provide a source of comfort and strength to face the challenges of parental loss.

Complexity and unknowns of FTD genetics

One particularly distressing aspects of a diagnosis of a frontotemporal disorder is the fear that it may be inherited and that the patient's children might be at increased risk for the same condition. The genetics of frontotemporal degeneration (FTD) are very complex, and while research is advancing rapidly, there remains more that scientists do not understand, than that they do. It is difficult for a caregiver to stay current with the information available or know how to approach concerns about heritability with family members. Some information about the scientific literature in FTD genetics is offered for context.

Research shows that the proportion of FTD cases with a strong genetic component is small, with approximately 10% having a clear autosomal dominant pattern of inheritance (the

disease is passed from grandparent to parent to child) (Pickering-Brown, Rollinson, Du Plessis, et al 2008; and Rohrer, Guerreriro, Vanddrovcova, et al, 2009). Genes with mutations known to cause FTD include: *MAPT*, *PGRN*, *CHMP2B*, *TARDBP*, *VCP* and *FUS*. Additionally, in fall 2011 researchers identified *C9orf72*, a gene located on chromosome 9, which is now recognized to be the most common cause of familial FTD, FTD/ALS and ALS.

An additional 30% of patients with FTD have a significant family history of dementia and/or related diagnoses such as ALS or Parkinsonism, but without a clear autosomal dominant inheritance pattern. In these cases the disease is said to be “familial,” meaning that an increased, though not definitive risk is being inherited in that family. Much current genetic research is focused on identification of the genes that confer this heightened risk or susceptibility to developing FTD (Goldman, Rademakers, Huey, et al, 2011).

The genes already identified as conferring risk for FTD account for less than half of the total familial cases (Goldman, Rademakers, Huey, et al, 2011). Nonetheless, clinical testing for some genes identified with FTD is now available in the United States and Europe and therefore is considered more often by people concerned about their potential genetic risk. There remain strong reasons why clinical testing should not be routinely recommended for people with FTD: it is very expensive (up to \$1,200 for a full sequencing of each gene) and often fails to identify a mutation. According to Goldman, Rademakers, and Huey, et. al, (2011) careful clinical, pathologic and family history information can and should guide testing decisions.

Because the situation is complex, the best way to determine genetic risk in a family is by working with a trained health professional (a genetic counselor or a specialist in neurogenetics) and by gathering accurate information from family members. An accurate assessment of an individual’s genetic risk requires 1) accurate diagnosis of the identified patient, 2) collection of detailed family and medical history and 3) construction of a three-generation pedigree by a professional.

It is important to note that the goal of genetic counseling is not to perform genetic testing, per se, but rather to accurately interpret an individual’s risk for inheriting FTD and to

provide education and counseling as to the benefits and limitations of genetic testing for that individual. The goal of genetic counseling therefore is to help the individual determine the course of action (to test or not) that will best support their physical, emotional, and mental health. It must be noted that genetic testing is not performed on children—especially when the condition of concern is of adult onset. However, heritability is an issue that the well parent should be prepared to discuss with the growing adolescent, as most will have questions long before they reach the age of emancipation when they can consider providing informed consent for genetic testing.

Needs of parents and children

“Unfortunately, I did not cope well with my feelings and did not know how to behave around my mother. Although I found activities we could do together sometimes, I mostly felt frustrated and unable to interact with her in any meaningful way.” – Woman, mid 30’s, recalling teen years with mother, now deceased.

The Task Force employed several methods to assess the education and support needs of the well parent and children and teens. The group wanted to solicit and reflect the concerns of affected families and what they would find most helpful. Anecdotal input was gathered from professionals and caregivers on the Task Force, and from their extensive contacts within the FTD community. The Task Force considered the complexity of directly engaging minors for this project. The group explored conducting several age-matched focus groups or on-line surveys and decided it lacked the immediate resources to conduct such a study well. Ethical considerations regarding informed consent and external review and approval of procedures were a concern. There were also concerns about not knowing participants’ individual stresses and particular challenges; one or more professionals trained to work with children would be needed to assist children who may need support as a result of participating. Further, past experience led some task force members to conclude that in such settings it can be difficult to know the full context of answers from a child or teen.

The Task Force obtained input on the needs of parents and their children in four ways:

1. First-person experiences with spouses or partners of a person diagnosed with FTD who have children home as reported to professionals and caregivers on the task force. The input reflected contact with AFTD's HelpLine, medical center clinic patients, family research study participants, FTD support group facilitators, and AFTD's parents' phone support group members. Task force discussions took place over four monthly meetings and were documented.
2. A survey of young adults who were under 18 and living at home at the time a parent developed FTD. "Reflecting Back: Experiences of Children and Teens," was a 41 question survey that elicited information about their experiences and the impact of their parent's illness.
3. Participants in AFTD's parent phone support group (N=10) invited input from their children in three areas of interest to the task force: their desire to interact with other children/teens, the most beneficial activities to help cope with the disease, and their most difficult challenges.

Input from task force members

Two lists were generated by the task force, one reflecting key issues and concerns of parents and one reflecting concerns of children/teens. They were generated through discussion by task force members over four months and tested with the parent support group. The lists were grouped to three aspects of need: education/ information, emotional and daily living. These categories were established by consensus of task force members to reflect potential points of intervention.

Table 1 - Concerns of Parents

Education/Information	Emotional	Practical
What to say to children, how much and when - How to describe the diagnosis and	Grieving loss of intimate relationship with partner/co-parent	Managing monetary and financial changes -Supporting family and providing

prognosis to a child - How to describe behavior changes		care on less income
How to communicate to friends, neighbors, colleagues -What and how much to say	Social changes – loss and changes to adult friendships	Coordinating with school
Understanding potential genetic risk -Answering children’s questions -May be raised by even very young children.	Dealing with children’s’ feelings – anger, sadness, wishing ill parent was gone	Finding effective and knowledgeable child or family counselors
How to help children cope with the added stress -Help to “find their own voice” in dealing with the illness -How to uncover what concerns them most	Persevering through exhaustion and conflicting feelings about when it will be over	Managing all the household tasks / logistics of schedules for work, children’s activities, etc.
Rate and course of progression -How to manage uncertainty	Changing nature of the emotional structure of the family unit - Feeling responsible to maintain the family unit through many difficult transitions - Dealing with different reactions, different stages of acceptance, and family crises	Ensuring safety if / when judgment becomes impaired and the risk for young children
Constancy of change -Recognizing and adapting to changing symptoms, family dynamics, and emotional needs	Facing the known and unknown -Wondering if issues of adjustments will bring family closer or make more distant	How to balance desire for children to be active with peers and engaged in activities with need for help at home.
Handling later stages -Deciding about facility care; Needs of children may precipitate earlier placement -Finding facility that will be comfortable for kids; - How to approach children visiting or not	Feelings of isolation; feeling that no one else could possibly understand	
Dealing with end stages of FTD -Accessing hospice -Assessing grief /bereavement supports for children	How to make sure that as caregiver and parent you balance all the challenges; abrupt change when parent moves to facility	
Developmental needs of children - Strategies to deal w/children as they age and change over progression of disease	Emotions around all the different, difficult choices you have to make, alone	
Communication strategies when	Identifying and coping with big occasions and transitions	

patient's language skills are affected.	-Impact on the patient and children (birthdays, holidays etc.) -Day to day issues may be masked until an emotional marker is reached, especially for children	
How to approach and manage children in caregiving role	Stress of feeling need to do it all	

Table 2 – Concerns of Children

Education / Information	Emotional	Practical
Info about FTD presented in ways children/ teens can digest	Being anxious parents will divorce or that they're responsible when problems are evident but not diagnosed.	Letting children choose how to deal with it; be able to answer or not various questions.
How to talk to friends, others about the disease -Want to answer questions in way they are comfortable and feel some control over info and conversation	How to deal with embarrassment of behaviors; not wanting the ill parent at games, school events, etc.	What to do when they don't want to have friends over
How to deal with increased responsibilities to help well parent and as care providers -Need to know they can still be kids	Unique aspects of same sex and opposite sex relationship to the affected parent	How to provide options for support that they would be willing to try.
Genetics – information geared for children; especially older teens and if family risk is evident	Immaturity of person with behavioral variant; parent argues and picks on children	How to find others who understand because they have a parent affected
How to deal with language issues -How to communicate with the ill parent	Managing transitions over progression of disease	Motor issues; parent who can't hold hand and walk and what children can do
How to manage situations so the child has a say or choice	Dealing with special occasions – Father's day/ Mother's day	Providing personal care – taking father to men's room and feeling uncomfortable with that; what's appropriate as move into care giving role
What tools do children need to handle...(whole range of situations over course of illness)	How help kids find own voice in dealing with illness; find out what concerns child most.	Physical adaptation / changes that happen w/in family and home environment.
	How they can feel a bit in charge of the situation;	

	Grieving and loss experienced by children through all 5 senses as well as emotionally, cognitively, spiritually	
	Kids' perspective of time (i.e.: 8 yrs being long life expectancy)	

Parents phone group information

Input was gathered from members of the AFTD parents' phone support group. Members were asked to speak with their children and prioritize a list of needs compiled by the Task Force from their perspective and from the child's perspectives.

Genetics was expressed as a top concern by both children and parents. Children may not have evidence of increased risk of inheritance in their family history, but still identified genetics as an area of concern. It is important for all families' to have an understanding of the genetics of frontotemporal degeneration and how to assess individual risk. Given the prominence of concerns about inheritance among children and teens, additional information is needed to prepare parents to address this complex and emotionally sensitive issue.

Other concerns prioritized by phone group members included helping children to find their own voice in dealing with the illness; addressing grieving and loss; managing changes to the family unit and keeping the family together. Group members added several issues from their support group meetings and discussions:

- Needing practical suggestions for how to handle the ambiguous status of the affected person being part of the family, but not part of the family, for example: How do you sign cards? Do you list both parents in the school directory?
- Handling the confusion of the affected spouse being the parent, but not actively parenting; being a spouse, but not an active partner.

- Children feeling more grown up as they become caregivers, and feel they don't need parenting as much; resisting parenting from the well parent.
- Families needing access to information about and for children early on in the diagnostic process or added to what is immediately available for people newly diagnosed.
- Needing ways to create an adequate support system and reduce feelings of isolation. Children said they wanted to know there's someone else going through the same thing.
- The importance of highlighting the value of having a community of people for support (such as the phone group) and that caregivers cannot create that community unless they ask. There are many reasons why caregivers find it difficult to ask.

Input from children in the parents phone group

"My father was diagnosed with this degenerative brain disease when I was ten; however, he started showing symptoms when I was six. I was sixteen when he moved into a nursing home and last spring he was moved into hospice care... It is a challenge to watch, year after year, as this slowly debilitating disease takes more of my father each and every day."-Male, high school senior

Parents in AFTD's phone support group offered their children a chance to provide informal input to the task force. The children and teens were invited by their parent to respond to three questions regarding: 1) Their interest in interacting with other children of people with FTD; 2) What they found to be the most supportive activity during their parent's illness; and 3) What has been most difficult in dealing with the illness.

Responses were received from 12 children in four families. They were compiled by the parent and forwarded to the Task Force members in the support group. Five (41.7%) said they wanted to talk to others about their situation, but did not know the best way to arrange that. Social networking and on-line resources are often suggested. When asked, many in this sample did not think that connecting via a social network, such as Facebook, would appeal to them. The children in this informal sample indicated that their most effective coping and support came through maintaining involvement with friends, activities, sports, and professional therapists. The most difficult aspects included dealing with some behaviors, such as when they think the affected parent is lying. Also mentioned were the challenge of handling the parent

moving out of house to a care facility, dealing with the well-parent's emotions, and fear of what happens if the well parent gets sick, which was perceived to result in more of a crisis.

Reflecting back on experiences with an affected parent

“Not all teens are willing to acknowledge that they want or need help, but they need to be reached out to, and made to know they are not alone. Like me, they may resist, but they especially need to know there are resources available.” – Woman, mid-30's

Many young adults confront a diagnosis of FTD in a parent and are affected by the physical, emotional, and financial demands of caregiving. They seek assistance specific to their perspective from AFTD and other health providers in increasing numbers. As one way to elicit input and engage this portion of the community, the Task Force developed an on-line survey for young adults who experienced the onset or progression of FTD symptoms in a parent when they were children or teens in the home.

People who were under 18 at the time a parent developed FTD were invited to complete a 41-question survey. The survey asked them to reflect back and consider the impact or value in their lives today of caring for their ill mother or father. The survey was conducted in September 2010. Notice about it was posted on AFTD's website, forwarded to FTD support group leaders and shared with others through the Task Force membership. The majority of the questions were open-ended, inviting short narrative answers. Responses were anonymous, unless participants voluntarily provided contact information for follow-up about the project. Responses were compiled and reviewed by the Task Force to identify themes and cull recommendations.

Twenty-four people completed the survey over a three-week period. 70.8% (17) of respondents were female and 29.2% (7) male; they ranged in age from 18 to over 35, with 54.5% between 18 and 25. The father was the diagnosed parent for 56.5% (13) of participants, mother for 34.8% (8), one person indicated a step-father, and one a step-mother. 78.3% (18) of the identified patients are still living, 21.7% (5) are deceased. The majority of respondents, 65.2% (15) were 16-18 years old when the parent was diagnosed with FTD; 21.7% (5) were 13-

15. Not surprisingly, symptoms were first noticed earlier, with 36.3% noticing symptoms when they were between 6-12; 45.5% at 13-15; and 18.2% at 16-18.

Questions elicited information about illness education (how and what they learned about their parent's diagnosis), emotional support, caregiving activities, coping skills, and suggestions for others. Within this sample roughly half the people answering indicated they had been told the name of their parent's diagnosis: 47.6 (10) had been told and 52.4% (11) had not. When asked "Where or to whom did you turn with questions about the diagnosis or your mother/father's condition?" the answers given most frequently among 21 responses included the well-parent (23.8%, 5 responses), the parent and Internet (23.8%, 5 responses) and the Internet alone (19.0%, 4 responses). Five people (23.8%) responded they had no one to turn to or did not want to talk about it.

Comments included:

"Didn't want to talk about it."

"I never asked questions. I just accepted it"

"We had no one to talk to. My father did the best he could, but just wasn't a communicator and no one else wanted to step over him and talk to us. It was very difficult for us."

"Nobody. As I got older, I looked toward the Internet for answers."

The section on emotional support provided a window into the range of responses and approaches to coping with a parent's diagnosis. People were asked what emotions best describe how they felt about their parent's diagnosis. They could enter responses into as many as five text fields. Eighteen people responded; of them 12 listed "sad"; 11 "angry"; six "scared" and six "confused." Those responding indicated overwhelmingly that the most supportive people to them were the well-parent and other immediate family, especially siblings. When it came to telling classmates and friends about their parent's diagnosis, 47.4% (9) of those answering the question did tell classmates while 52.6% (10) did not. Fewer people told their teachers; 31.6% (6) did inform teachers, while 68.4% (13) did not. And still fewer had access to a professional counselor or therapist for support or assistance; 26.3% (5) did, while 76.7% (14) did not. When asked to briefly describe the reaction of classmates or teachers and if they were supportive, comments included:

"I didn't tell many people for a long time. Unless someone was coming over to the house and he was acting differently, then I would briefly mention something about the disease to explain and never discussed details. But, they were all supportive /understanding when I later began to openly talk about it."

"They kept quiet about anything they knew and didn't ever say really much of anything to us. It was like it was not allowed."

"I eventually started sharing with people, once I developed enough knowledge and vocabulary to describe it. People are generally sympathetic and emotionally supportive; however, it pretty much falls on the immediate family."

"I dropped out of high school. Thankfully, returned to further my education at a later time. I left the area, no one knew, I just kind of disappeared."

"Most of them were sympathetic; often those with grandparents who have Alzheimer's will say they understand because of this relation. In truth, those comments are usually the most frustrating because unless your grandparents are raising you, the roles are completely different."

The activities people found to be most supportive while they were living at home during a parent's illness included: being with friends, sports, music, "staying busy," "escaping into video games," physical exercise," and "staying away from the house." When asked how their relationship with the diagnosed parent changed, respondents commented:

"I am more supportive and understanding."

"I took on more of an adult/care taker role. I became responsible for more things."

"Yes. I couldn't stand him."

"I became the 'parent' and he became the 'child.' I would be the one tying his shoes or taking him out to the grocery store with me."

"In some ways I developed more compassion as he became more helpless."

"Over time, the relationship became less and less gratifying, to the point where seeing him and taking him out is more of a dreaded obligation."

The relationship with the well parent also changed. Five of 18 respondents indicated they became closer, but that experience was not universal. Others said:

"My mother became less available to me because she spreads herself so thin caring for him and her mother. Sometimes I resent the amount of energy the situation drains from her and I worry about something happening to her."

"We became partners in her care...It took a lot of work for over 2 years to get back to a parent-child relationship once mom went into assisted living. We had stopped talking about anything besides mom."

“Unfortunately, I did not manage my feelings about my family falling apart very well. I saw my father falling into a depression, which I resented. I felt that he did not understand or care about me and I acted in accordance with those feelings. On the other hand, he became my sole parent, and I had to rely on him for everything, so we also became closer in that we had to make household and decisions about my future together.”

Survey participants also considered how their role and activities at home changed as a result of a mother or father’s illness with FTD. Of 19 people who answered the question, 57.9% (11) said they provided regular or significant care for the parent while they were a child or teen living at home; 26.3% (5) said they did not; and 15.8% (3) were unsure. The most commonly mentioned types of care included providing companionship, entertainment, and driving for errands. However, five of those who answered indicated they helped their parent with significant personal care tasks, such as toileting, bathing, eating, and maintaining a feeding tube.

A larger percentage of participants, 73.7% (14), said they provided regular or significant assistance with household chores or care of siblings during this time; 15.8% (3) said they did not and 10.5% (2) were unsure. Cleaning, cooking, grocery shopping, laundry, and yard work were the most common tasks mentioned. The majority of people answering these questions, 64.7% (11), did not feel the demands of helping at home had an effect on their school work; 23.5% (4) did. However, the opposite effect was seen when asked about their relationships with friends. 53.3% (8) of those answering said home responsibilities affected friendships, while 33.3% (5) said they did not and 13.3% (2) were unsure. It is difficult in this context to assess the degree to which involvement in these tasks exceeded the assistance children and teens might normally be expected to provide around the house. When asked to describe how they felt about these responsibilities at home, people said they felt: “stressed,” “annoyed,” “angry,” “like it was [their] duty”, “exhausted,” “confused,” “frustrated” and that it was “unfair.” Some however, responded differently, indicating they felt: “responsible,” “helpful,” “caring,” “happy,” “delighted,” “more grown up,” and that they “didn’t think twice about it.” These reflect the ability of many caregivers, including children and teens, to recognize some benefits that accrue from difficult situations.

Participants were asked what aspects of the disease were the most difficult to deal with.

They entered up to three text responses and were invited to briefly explain those responses. The task force reviewed responses and grouped the answers into several categories: 1) behavior symptoms, 2) loss of established relationship, 3) cognitive and communication symptoms, and 4) caregiving responsibilities. Examples of responses that illustrate each area of concern are compiled in Table 3.

Table 3

Behavior symptoms His interaction with others,embarrassment, sudden temper flares, inappropriate shout outs in public, aggressive behavior, erratic behavior; noises he makes, hoarding, shop-lifting; Never knowing what to expect	Loss of relationship Different father, not having my partner in crime, watching him struggle at things he once did without fail, knowing I no longer have an involved mother; not having someone who could relate; She was like an infant and that was very weird for me to see; Him not recognizing things were changing; Watching her forget how to care for herself ; Loss of social interaction; Arguments between my parents; Not knowing what was going on with her and why
Cognitive and communication symptoms Forgetfulness, apathy, loss of comprehension; avoidance; not listening; His inability to say what he wants; The first thing that she lost was her voice - It was hard not to ever hear her speak again	Caregiving responsibilities Bathroom issues, added responsibilities; Having locks on the inside of the doors so she wouldn't escape was an adjustment

The impact of these experiences is conveyed in some of the comments:

“All the above behaviors [were hard], plus poor hygiene, without understanding the underlying cause, led to a lot of social embarrassment.”

“My mom and sister were close and most alike while my dad [the affected parent] and I were most alike. He would often be my savior or logical partner among family discussions. Added responsibilities included the things that my dad always did around the house...and the things that my mother expected of my dad - such as buying birthday/Christmas gifts for my mom from my dad.”

“We would both end up crying and she would promise to do as the doctor told her, but the next day she would just do what she wanted. She would also get very aggressive, especially when she got frustrated.... She never hit us, but she would grab my dad by his arm and shake him. It was just scary and unsettling because we did not know if she was going to get abusive or just yell at us. I did not want her to go to college information sessions with me or even going to the grocery

store ...She would sing children's songs at any time, she would ask people with darker skin where they were from. I never came up with a strategy to handle the situation, I would just walk away."

One goal of the survey and the Task Force Starting was to identify mechanisms and styles for coping. Family was again identified as a critical support to children and teens living at home and mentioned by 42.8% (6) of those who answered the question: What was most supportive or helpful for you during your childhood and teen years at home? Listening to music and school were also listed, as were different ways to be away from the situation at home, and placement in a care facility. Additional comments included:

"Having a safe haven to go to at my boyfriend's house and his family. A place where I could go where I could still be a kid, I didn't have to take care of my mom."

"Being able to be in charge of the household care and maintenance helped me to feel like I had control over something, and gave me a sense of responsibility."

"Spending a lot of time with my dad. Finding activities that we could still do together. Treating the role reversal as me being his little assistant. Looking back, it would've been more helpful to openly talk to others about it."

When asked if there was anything in their family or that their family did that helped them cope, respondents identified honest conversation, empathy, and involvement of extended family as important.

"Extended family accepted everything with understanding and support"

"Talking about it.....giving lots of hugs"

"My family in Florida would take us in the summer to get away from everything. That was nice."

"My dad's side of the family became very active in our lives, my sister and I became very close to our aunt."

The absence of that support was also notable:

"We didn't really deal with it. I guess that was our way of coping with it. Later on, when there were very obvious changes, our family started to seek help from outside of the immediate family. That really helped take the burden off of us. Also, openly talking to others helped and not trying to hide the disease."

"We have a very small family, so the burden rests with my mother and myself. My mother is extremely supportive and tries to spare me any added burden. But, it's difficult to watch her take all of this on."

"Had no one, it really was not discussed with my sister."

Two other questions addressed personal qualities that facilitated coping and what the impact has been on the person's sense of self. Some noted the importance of being an optimistic person by temperament, or viewing themselves as resilient and strong.

"I focused on the positive aspects. Getting complete access to my dad's car was a very nice positive that allowed me to see the positive that came from it. I was a teenager, wanting independence."

"My ability to excel in other areas and to use sports as a vent for frustration."

"Just getting through day by day. Trying to accept the situation for what it is and not comparing my progress (or lack of it) to my peers."

Thirteen people answered the question "What impact did caring for your mother/father have on the way you see yourself? Common responses included appreciating and fostering the closeness of family relationships, and growth in strength and confidence to handle life's challenges.

"I know I can face anything in life. I know more about myself than most adults. I have a very good way of judging people's characters."

"I know that I can handle just about anything that life can throw at me, I know the true meaning of patience."

"I am responsible and I can handle a lot more stress than other people my age whose biggest worry is that they accidentally dyed their hair the wrong shade of blonde."

"I am very patient and I am great at explaining things to people. I am appreciative of things in my life and often aware (more than others) that nothing lasts forever. "

"It is everything and every part of me. It is how I decide if someone is going to be there and be a friend or if they will be an acquaintance. If someone listens and tries to understand they will be a friend vs. someone who makes it about themselves will be an acquaintance. Also, I know that I can get through losing my mother, I can get through anything."

Several people commented that they could find no positives to come from the experience:

"I see myself as more selfish because when I'm with my friends, I feel guilty like I should be spending this time with my Dad...I might be missing out on opportunities I could have now with him and not later."

"I don't know if there are any positives, because now my sister is affected by the same sickness."

The survey asked people to reflect on what would have helped them cope better or feel more supported as a child or teen. From the perspective of looking back at their adolescent years, 72.2% (13) of respondents said they would have been interested in meeting other children or teens who had a parent with FTD; 11.1% (2) said they would not; and 16.7% (3) were unsure. When asked what mechanism(s) would have been most appealing (on-line, telephone, one-on-one, an event bringing families together, etc.), 61.5% (8) people listed an in-person family event first, followed by phone or support groups; 38.5% (5) people mentioned on-line supports first, followed by group events or support groups for children/teens. The idea of getting together with others was embraced by young adults looking back at their earlier days. Insights from this group could be explored further to help develop resources that are effective and engaging for children and teens affected now. Related comments offered in the responses included:

"Knowing what he had earlier would have helped."

"Having more information about what would happen later on, down the road. ...Asking my dad to tell me stories about his childhood and earlier years before he couldn't speak anymore. Having discussions within the family with my dad about the disease. Saying goodbyes before it was to the point where goodbyes couldn't be said or communicated in some way."

"My family being there for me more. I think people thought that talking about it or bringing it up would make it worse. I needed to talk about it. They were all so busy in their own lives and scared I think. I think more people should've been there for us."

"More professional follow up for the whole family at the time of diagnosis. A support group or activities for teens / young adults coping with the same thing."

"Seeing a psychologist or psychiatrist by myself when I was still living at home. Family members and friends calling me."

"The availability, coping mechanisms (not to hold everything in), small articles/things that would explain what was going on in the parent's brain during each stage, give the person the feeling that they are not the only one going through this."

“Listening to the people who went through it. Making sure that it is something that children and teens would want to do and have access to. Something like a family event but with activities just for the children and teens so they have a place to go and be a kid but did not have to travel there by themselves.”

Existing Resources and Program Models

Prior anecdotal evidence indicated a clear lack of programs for this population. The Task Force conducted a scan of the environment to see what services exist that may provide examples or models for FTD-specific supports. A search for resources and clinical or support programs for children and teens was conducted via the Internet and through contact with professional colleagues in the United States, Canada and the United Kingdom. The main search was conducted between June and September 2010. Key words were: child(ren), youth/young caregivers, bereavement support, and dementia.

Programs in the United Kingdom

The concept of “young carers” – children providing care for a parent or grandparent with chronic illness or disability -was first formed in the United Kingdom in the early 1990’s and has taken root in Australia and Canada. The development and coordination of services within the young carers movement in the United Kingdom is reflected the work of The Children’s Society’s Include Project (www.youngcarer.com) which offers information, training, and support to people working to support children and young people who care for parents. A National Young Carers Initiative, funded by the Department for Education, is developing a National Focus for Young Carers, their families and those who assist them, that will promote common standards for services and promote services that encourage a whole family approach to support. The National Health Service has a website for young carers: www.nhs.uk/carersdirect/young/Pages/Youngcarershome.aspx and The Mental Health Foundation has a booklet for children on dementia: www.mentalhealth.org.uk/publications/?EntryId5=38715

Barnardos is the United Kingdom’s leading children’s charity. The organization runs 15 projects across the United Kingdom which support young carers and their families in a variety of ways. It started in 1996 and now offers 12 young carers groups in the region. Barnardos

strives to integrate the concept of building resilience with children in all the services. For more information: www.barnardos.org.uk/what_we_do/our_projects/young_carers.htm

Princess Royal Trust for Carers – storytelling project. There are some YouTube videos on line of this creative project that show children telling stories of caring for a parent. The project is very resilience oriented, and the results show how the stories help to alleviate the burden of care. It was shown to help kids to be kids, not miss school, etc. The groups included some discussions that helped them express feelings they had not previously expressed. For more information: <http://www.youngcarers.net/>.

Programs in Australia

One example of available resources is the South Australia Young Carers Services, www.carers-sa.asn.au/how-can-we-help/young-carers, which offers a website and on-line newsletter that updates service providers on issues related to young carers.

The International Young Carers Report compiled in 2009 is a resource directory that presents worldwide programs that provide support to children who have parents with a mental illness. Funded by the Australian Government under the Mental Health Respite Program, this directory seeks to make it easier for people to find ways to support young carers and to facilitate collaboration between agencies within Australia and internationally.

Programs in Canada

In 2003, 14 community agencies in Ontario, Canada created the Young Carers Initiative in Niagara (YCIN) (www.youngcarers.ca). It has its roots in the Alzheimer Society of the Niagara Region and includes agencies that serve children, youth and adults with diverse health conditions, such as such as HIV/AIDS, multiple sclerosis, brain injury, dementia, autism, developmental disabilities and children's mental illness, and are united by a common concern of support for children in caregiving roles. YCIN recognizes that the young carers movement in

Canada is in its infancy. A 2007 literature review references the history of the young carers movement in United Kingdom, and outlines efforts in Canada. The broad clinical and anecdotal experience of the YCIN member agencies forms their position that children in caregiving families have needs that are not being met by the current social and healthcare systems. Their efforts are aimed at increasing public awareness of these needs and providing information for children, families and providers.

ALS Society of Canada serves people with amyotrophic lateral sclerosis (also known as Lou Gehrig's disease) and their families. ALS is a neurodegenerative disease that impacts families in ways similar to frontotemporal degeneration. It causes progressive deterioration of neurons in the spinal cord and brain that lead to increased dependency on care; it can affect people in the prime of their family years; and the disease is fatal with no known treatment or cure. The ALS Society of Canada has developed resources specifically for children and teens that are available through a dedicated web page www.als411.ca. The information available and interactive nature of this site make it a creative and effective resource for reaching the intended audience.

When Dementia is in the House is a website for launched in late 2011 by the Canadian Dementia Knowledge Translation Network (CDKTN) for parents and teens of people with young-onset dementia or FTD. The project was spearheaded by Tiffany Chow, MD, Senior Scientist at Baycrest in Ontario and Katherine Nichol a former FTD caregiver. (<http://www.lifeandminds.ca/whendementiaisinthehouse>).

Programs in the United States

American Association of Caregiving Youth (www.aacy2.org) started in Florida in 1998 to support students who provide care for a family member facing disability or illness. It is a national resource for caregiving youth that seeks to recognize, support, and promote awareness of the dual role that many youth perform as students and caregivers. It works in cooperation with existing education, healthcare, and community organizations to implement the local Caregiving Youth Project (CYP), and seeks to establish an affiliate network of CYPs throughout the US.

Camp Erin is a nationwide network of bereavement camps for children and teens aged 6-17 who have experienced the death of a loved one. Camp Erin was created in 2002 by The Moyer Foundation (www.moyerfoundation.org). The program is locally organized in more than 25 states and offers a weekend-long camp that combines traditional camp activities, grief education, and emotional support. Participants learn tools to help address their feelings and memorialize loved ones at camp and long after they leave. In 2010, 35 camp sessions served more than 2000 children and teens.

Camp Building Bridges (<http://www.freewebs.com/campbuildingbridges08>) is a summer camp program for children affected by early onset Alzheimer's or FTD. Currently in its 3rd year, the camp was founded by a woman with a reported diagnosis of FTD and AD for her teenage son. The camp is now offered through The Oklahoma/Arkansas Chapter of the Alzheimer's Association. The Building Bridges program essentially involves a one hour meeting each morning as part of a larger Christian camp for 200 kids. The hour program mixes lecture and interaction, including a talk, discussion, and a 20-minute activity, such as making friendship bracelets, masks, memory boxes, or quilting. The camp is open to any child or teen caring for someone with dementia. During the summer of 2010, 12 children registered and five attended (three new/two repeat) from different states; two had grandparents with AD, three had parents w/early onset AD.

Needs and Opportunities

"If we can find ONE person who will be there for each kid, who will cheer them on, applaud their efforts, listen to their struggles, they can get through. Think of all the stories of people who thrived because one person reached out to them and believed they could shine bright and succeed" - Mother of two; caregiver for her husband

Families who have children at home as they confront frontotemporal degeneration are consumed not only with the demands of caregiving for the affected spouse or partner, but with the added challenges of child rearing. The average life expectancy across subtypes is eight years from the time of diagnosis, but may extend for more than 10 or 12 years. Over time, the children mature, while the parent's condition inevitably declines. Children grow up shaped by a

parent's behavior, language and cognitive decline, and eventual death. Parenting in the context of a normal family can be demanding; parenting in the context of FTD creates stress on a family that is poorly understood and largely not addressed.

The stress level on families is significant. Lack of awareness and knowledge of FTD coupled with the typically young age at onset and characteristic behavior and language symptoms present distinct challenges for the primary caregiver and children in the home. A patient's needs change over time as the disease engulfs more areas of functioning, while simultaneously, children grow, develop and reach milestones. Siblings within a family will be at different places developmentally and emotionally, and each person will understand the disease and process grief differently as they grow. The well-parent constantly juggles these shifting sands, attempting to provide physical and emotional support for all.

The disciplines and experiences explored by the Task Force suggest a framework for supporting families with a parent with FTD and children at home. The role of anticipatory grief, and ambiguous loss in dementia caregiving, and the importance of helping children manage their grief make grief management practices relevant to improving support for families affected by FTD with young children. Sandler, Wolchik and Ayers (2008) propose a framework for adaptation following bereavement that bears consideration for applicability to FTD.

"Contextual resilience" emphasizes adaptation as the concept that best describes the process of change following a death, with positive or healthy management of grief as the goal. Adaptation is a process that occurs over time. It is shaped by individual and environmental risk and protective factors. The cumulative effect of risk factors and the cumulative effect of protective factors, rather than any single one, determines the overall outcome. Rather than focusing on negative outcomes and pathology, resiliency focuses on what factors contribute to children doing well. Resilience and developing flexibility and new ways of coping is the goal rather than a previously held "recovery" model which implies grief is a disorder from which one returns to health.

The dynamic process of adaptation seems to accommodate the constantly changing interplay between the progression of FTD in a parent and the developmental needs of children in the home. Acknowledging that multiple factors contribute to the ability to adapt to stresses,

loss, and grief over time means that many points of intervention are possible. Svanberg's (2010) research in children living with a parent with young onset-dementia identified three stages of adaptation to the disease that may help the family cope: grieving for the lost relationship; detaching emotionally and understanding the disease as responsible; and allying with the well-parent to become more autonomous and responsible.

Each individual will experience grief through his or her own lens, which includes looking at how his or her environment and relationships change. Supporting each member of the family within the context of the entire unit is critical, especially given the prolonged and changing nature of FTD progression. Supports must address a range of needs, from providing accurate, age appropriate disease information, and promoting positive emotional relationships to assistance with practical daily management and successful engagement in school and work. Efforts must focus on assisting the entire family system to adapt and build resilience over time.

Recommendations

Parents need to have information available early when a diagnosis is first identified that will help them build a foundation for adapting to the constant changes ahead. They need access to reliable information about frontotemporal degeneration and on-going research into its causes, genetics, and potential treatments; education about ambiguous loss, how children grieve, bereavement, and processes of adapting to grief; and encouragement to seek the support and services they need. Adequate emotional and practical support for the primary caregiver, and access to appropriate medical and community supports for the patient are critical aspects of supporting children in the family.

A parent who watches for opportunities to engage children in learning or discussing the diagnosis, rather than compel them to attend doctor's visits or family meetings will receive a better response. Some anecdotal data suggests there may be a window of opportunity - at younger ages and earlier in the parent's course of progression - when children are interested and willing to talk about the parent's illness. Nearly 75% of young adults who looked back on their years at home would have been interested in meeting other children or teens in the same

position. Understanding the characteristics of children receptive to connecting with others, and designing services responsive to their interests could increase opportunities for education and support.

But the anecdotal reports gathered here indicate that children who have a parent with FTD find it very difficult to talk about what is happening in their families with others who do not understand, and support groups for children or counseling to help children and teens manage grief are rarely embraced - structured talk sessions trigger discomfort, performance anxiety, and fear of strong emotions. As a result, to help children in the general community, the use of approaches that do not involve talk may work. Opportunities for creative expression could be used to bring children together and allow them to direct disclosure from there. Music, art or theater events, service projects to help others, and involvement in a fundraiser for their issue, are examples of alternate approaches.

The following are some specific recommendations that emerged from the Task Force's work:

- It is important for each child to have a relationship with at least one other adult in addition to the primary caregiver for support and as a role model. If they have no extended family in the area, a church, synagogue or other organization where the family is already involved can be a great support and also be a source of mentors for the children. The non-FTD parent should also seek support which can come through small groups at church; through relatives via phone; and through caregiver support groups and counseling. The most prominent gaps to be filled will be the unique emotional role played by the ill parent.
- Understanding developmentally appropriate expressions of grief in children is helpful for the well-parent. Grieving and loss are experienced through all five senses as well as emotionally, cognitively, and spiritually by kids as well as adults. Recognizing changes in children as related to grief provides a context for understanding and intervention; engagement through activities rather than big discussions is most effective.

- Open, age-appropriate dialogue is important to enable the children to understand the parent's FTD. The well-parent should model self-care and maintain appropriate boundaries so children do not feel responsible for the emotional support of the main caregiver. Sharing information with children as the parent feels comfortable, not too much at a time, and with calibrated levels of detail is best.
- Support-seeking behaviors have been shown to be predictors of positive outcomes, so people who make efforts to build community do better than families that tend to isolate. Families vary in how and when they share information about the affected parent's FTD with others, but being open with family, friends, neighbors, and schools about the disease eases the stress.
- Children feel empowered when they experience some "control over the message." Help them develop ways to describe the situation that feels comfortable to them and helps meet their needs. Ask for help with transportation and other logistics that will enable children to attend sports and school activities and remain engaged with interests and the normal life of children their age. Children often don't feel acknowledged for what they are doing and achieving; engaging them around strengths and accomplishments can build healthy coping.
- Generally, parents perceive that the mutual support of other peers is a big need. The children of parents with FTD are often hesitant initially to reach out to other kids via email or Facebook. Even though the caregiving parent suggests these options, children are reluctant to openly share the issues they have with the FTD parent. Often in families with multiple children, the children rely on each other for support and become very close as they deal with the disease.

Next Steps and Future Direction

The mandate of the Task Force was to learn and to lead. It employed methodology that was informed, broad, and descriptive with an overriding bias for action. The immediate goal

was to learn what families need and develop new resources. As a result, two priority program initiatives have been approved by AFTD's Board of Directors for implementation in 2011. In April 2012, AFTD published *What About the Kids*, an educational booklet for parents that provides guidance on how to address FTD with their children and navigate daily issues at home, in school, and with friends. The booklet is being distributed to medical centers and community provider, and is available on the AFTD website. Easy access to information at the time of diagnosis will maximize opportunities to support the family as a unit and address the needs of each individual member- adult, child or teen.

Secondly, an engaging educational website for children and teens is in development. It will provide age-appropriate information about FTD, interactive elements, tips and tools for coping with everyday challenges, and ways for them to share with peers also affected by a parent's FTD. This will be linked to AFTD's well-established domain and is expected to become a clearinghouse for additional resources for the portion of the FTD with families with young children and teens. AFTD's website currently records an average of over 6000 visits per month. Analysis of traffic to the site, page hits and referring sources will be initial parameters used to evaluate the effectiveness of the new page and that of partner projects in the future.

An additional goal of the Task Force is to stimulate greater attention to the needs of this portion of the FTD community among academic, medical and community providers. There are limitations to the informal approach to data gathering, and reduced rigor in qualitative and quantitative analysis of results obtained. However, the findings reflect broad input and contain the seeds of many potential avenues for further academic research and program development. This report offers valuable perspective on the issues surrounding young families facing FTD and how they cope with the experience. Areas warranting further exploration include grief, bereavement and coping over the progression of FTD, better understanding of specific risk and protective factors in FTD families, and a framework for holistic services and supports.

Areas for future work may include:

- Lack of awareness of frontotemporal degeneration significantly increases the burden families and children carry. Continued expansion of public awareness efforts and the

education of medical, social service, and school professionals are essential.

- Study of the benefits of support group participation for FTD caregivers, including groups for parents of children and teens. Preventing the isolation of people coping with these rare diseases appears to be a powerful protective factor.
- Foster cooperation and collaboration among disciplines that work with children, i.e.: education, counseling, and health. Efforts to understand children as providers of care in FTD families, and promote supports across key contacts in the environment that develop the resiliency of individuals within each family.
- Expand appropriate community services for families facing challenges of FTD. Access to knowledgeable, compassionate physicians, respite, home health, day programs, care facilities and hospice providers can help to moderate stress on a family and promote or restore balance in parent-child relationships.
- Advocate for social policies that support a holistic approach to assessing family needs when a person is diagnosed with FTD or other neurodegenerative disease.
- Help families sort through the complexity of FTD genetics to understand and address the anxiety among relatives and children regarding the potential heritability of disease. Genetic testing is not an issue in children, but increasingly it is becoming one relevant to teens and young adults. A parent's access to accurate, understandable information on basic genetics and the role of genetic counseling is critical so they can be prepared when children ask.
- The young carers movement in the United Kingdom and Australia inspired changes in public policy to create more effective systems for assessment of families with a

chronically ill or disabled parent. What opportunities exist for advocacy with U.S. policy makers that might improve access or coordination of services for affected families?

Conclusion

This report summarizes the findings of the AFTD Task Force on Families and Children. The need for improved information and support for both parents and children in families affected by FTD is demonstrated. A framework for services is suggested that draws from concepts of contextual resilience and reinforces the development of coping skills, competency, and confidence rather than adopting a pathology or deficit approach to adjusting to grief and loss. Some recommendations are given that show how this framework can be incorporated into family life. Two key initiatives have been identified and embraced by the AFTD Board of Directors for implementation as the organization begins to address the needs, and a number of ideas for future directions in research and service development are offered.

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AFTD Task Force on Families with Children

Membership

Gail Andersen, BS, ChE
Caregiver for FTD Spouse
Mason, Ohio

Paul J. Higgins, MEd
School Counselor
Keller Independent School District
Keller, Texas

Sharon Denny, MA
Program Director
The Association for Frontotemporal
Degeneration
Radnor, Pennsylvania 19087

Linda Nee, LCSW-C
Family Studies Unit
National Institute of Neurological Disorders
and Stroke
Bethesda, Maryland 20892

J. Elise Gaul, MS, LPC, CT
Children's Bereavement Coordinator
David Bradley Children's Bereavement
Program
Director, Camp Erin-Philadelphia
Penn Wissahickon Hospice
Bala Cynwyd, Pennsylvania 19004

Darby Morhardt, MSW, LCSW
Research Associate Professor / Director –
Education
Cognitive Neurology and Alzheimer's Disease
Center
Northwestern University Feinberg School of
Medicine
Chicago, Illinois 60611

Paul Lester, BSIE
Caregiver for FTD Spouse
Raleigh, North Carolina

For further information about the AFTD Task Force on Families with Children contact:

Sharon S. Denny, Program Director
sdenny@theaftd.org
267-514-7221.