WHEN DEMENTIA IS IN THE HOUSE:
Creating Early-Onset Dementia Education for Kids

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BACKGROUND:

Frontotemporal dementia (FTD) is a neurodegenerative illness with early onset, before the age of 65. Symptoms of FTD include marked behavioral, frontal executive, language, and motor changes. Caregivers at home with the patient often include children of school age. There are currently no resources for older children or for parents to know how to discuss the illness and its implications to their younger children.

Because the needs of children of different ages are not intuitively obvious to clinicians, researchers and service providers, we held focus groups with children of patients with FTD to learn about their experiences and what they needed at various points in the patient's diagnostic process and course of illness.

We intended for analysis of the focus group data to inform the creation of webpages, one for adolescent caregivers to patients with FTD and another for parents who need to discuss the illness with younger children who would not access the Web themselves.

METHODS:

Caregivers from the US and Canada have identified themselves as parents of children affected by FTD and have requested that they be contacted by author (TWC) if an opportunity for their children to voice opinions arises. This list received an invitation for children aged 8-19 to volunteer their participation in one 2-hour focus group that would be held through Skype or regular telephone. Participants were able to invite other eligible young FTD caregivers that they knew to participate. Any respondents to the invitation contacted the focus group leader directly, as Dr. Chow was the treating physician for the parents of some subjects.

Inclusion criteria were: self-identification as an 8-19 year old caregiver to someone with a frontotemporal dementia (behavioral variant or primary progressive aphasia or corticobasal syndrome or progressive supranuclear palsy), English-speaking, and able to access the internet or teleconference line to participate in the focus group. If under 18, must have co-consent from a parent or legal guardian.

The semi-structured interview with a common list of open ended questions or topics given to both groups was administered by a medical journalist (Leader) who is herself a parent to two teenagers in a family touched by FTD. The focus group interview script is available from PI Dr. Chow.

14 participants contributed to two focus group sessions. They ranged in age from 11-18. They had an average of 3 years of living in a household with someone identified as a person with FTD. 10/14 were girls.

Thematic Analysis

The focus groups were digitally captured (audio) and transcribed. We used a thematic analysis approach, which allows for the identification of themes in qualitative material by means of a coding scheme. A coding scheme was derived in vivo, rather than a priori, and a coding dictionary (with definition of and proscribed uses for codes) was developed to ensure consistent application of the codes. The qualitative software package Atlas.ti facilitated the application of codes and organization of theme groups, as well as creating the theme-based query outputs (quotations from the text). All data, save for areas where the interviewer was wrapping up sessions or explaining the study process, were eventually categorized within one or more theme areas, which offers confidence that saturation of theme areas was achieved.

CONCLUSIONS

Focus group participants appreciated the incorporation of their commentary into the design of the website. We have received supportive praise for the look and feel of the site. Parents and child-caregivers have commented that the website has been useful to their discussions and planning. Healthcare professionals have seen the website as a useful tool, and sample letters "To Whom It May Concern" in the neighborhood or at the airport have been downloaded for adaptation in others' practices. Next steps include an interactive colouring book for children too young to access the internet, building interactivity to bring child-caregivers together for support, and a parallel resource for children whose grandparents have Alzheimer's disease or other late-onset dementias.

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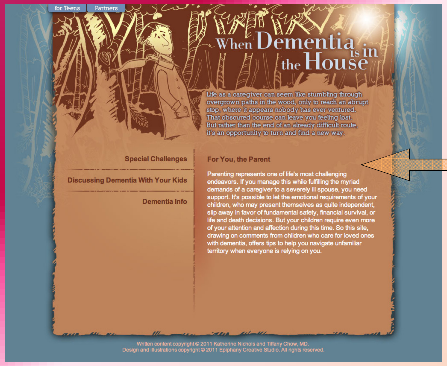
www.lifeandminds.ca/whendementiaisinthehouse launched on November 15, 2011.



Life as a caregiver can seem like stumbling through overgrown paths in the wood, only to reach an abrupt stop, where it appears nobody has ever ventured. That obscured course can leave you feeling lost. But rather than the end of an already difficult route, it's an opportunity to turn and find a new way.

For You, the Parent

Parenting represents one of life's most challenging endeavors. If you manage this while fulfilling the myriad demands of a caregiver to a severely ill spouse, you need support. It's possible to let the emotional requirements of your children, who may present themselves as quite independent, slip away in favor of fundamental safety, financial survival, or life and death decisions. But your children require even more of your attention and affection during this time. So this site, drawing on comments from children who care for loved ones with dementia, offers tips to help you navigate unfamiliar territory when everyone is relying on you.

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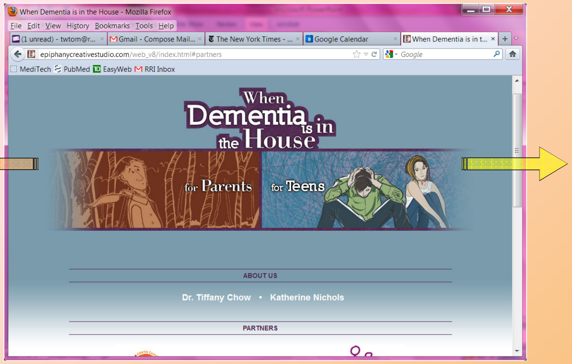

You're here because someone you love, quite possibly one of your parents, suffers from an illness that differs from anything you've ever experienced. Other serious diseases, such as cancer, tend to affect patients physically; in that case it can be easier for you to see and understand the changes. But when the illness resides in the brain, everything is a mystery. Knowing what's happening - and what you can do to help - can make a painful challenge in life a little easier.

It's important to remember that while much confusion may surround the exact naming of your loved one's disease, the label is far less important than the actions you can take to reduce your loss. There's a lot you can do to help yourself and your family throughout this time.

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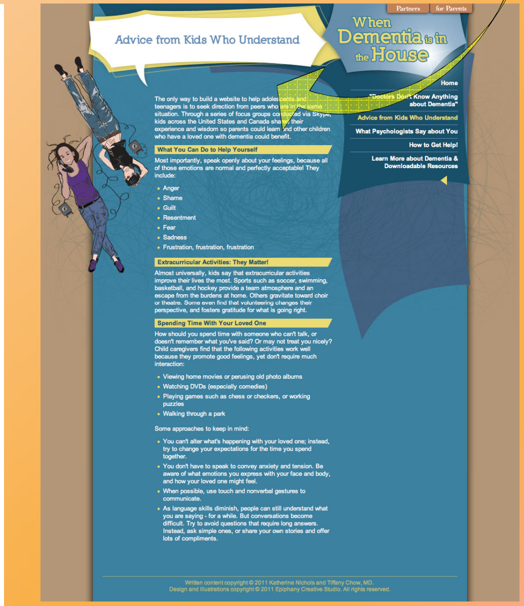

Advice from Kids Who Understand

The only way to build a website to help adolescents and teenagers is to seek direction from peers who are in the same situation. Through a series of focus groups conducted via Skype, kids across the United States and Canada shared their experience and wisdom so parents could learn and other children who have a loved one with dementia could benefit.

What You Can Do to Help Yourself

Most importantly, speak openly about your feelings, because all of those emotions are normal and perfectly acceptable! They include:

- Anger
- Shame
- Guilt
- Resentment
- Fear
- Sadness
- Frustration, frustration, frustration

Extracurricular Activities: They Matter!

Almost universally, kids say that extracurricular activities improve their lives the most. Sports such as soccer, swimming, basketball, and hockey provide a team atmosphere and an escape from the burdens at home. Others gravitate toward choir or theatre. Some even find that volunteering changes their perspective, and fosters gratitude for what is going right.

Spending Time With Your Loved One

How should you spend time with someone who can't talk, or doesn't remember what you've said? Or may not treat you nicely? Child caregivers find that the following activities work well because they promote good feelings, yet don't require much interaction:

- Viewing home movies or perusing old photo albums
- Watching DVDs (especially comedies)
- Playing games such as chess or checkers, or working puzzles
- Walking through a park

Some approaches to keep in mind:

- You can't alter what's happening with your loved one; instead, try to change your expectations for the time you spend together.
- You don't have to speak to convey anxiety and tension. Be aware of what emotions you express with your face and body, and how your loved one might feel.
- When possible, use touch and nonverbal gestures to communicate.
- As language skills diminish, people can still understand what you are saying - for a while. But conversations become difficult. Try to avoid questions that require long answers. Instead, ask simple ones, or share your own stories and offer lots of compliments.

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RESULTS: The analysis revealed six overarching theme areas.

1. Caregiving

Caregiving challenges included trying to strike a balance between being a child and being a caregiver, struggling to exercise with the patient, and concern for the patient's safety. Caregiving took an emotional toll on the participants. They described the reward over sharing a sentimental moment with the patient but also expressed guilt and self-blame during instances in which their patience with the patient wore thin. In a few cases, the participants found that their experience brought them closer with family and made them better people. There was notable overlap with the areas of relationship with the patient and strategies for coping with FTD.

2. Coping

Spending as much time as possible with the patient and reminiscing about old memories helped child-caregivers to cope. Providing support for the family and healthy parent was important and could be accomplished by taking increased responsibility around the house and sharing household chores. They also found it helpful to channel their energy outside the home through sport, dance, choir , and even volunteering.

Participants commented on problem-solving necessitated by difficulties that arose with outsiders to the FTD patient and their family. Participants found that outsiders had very little knowledge of FTD and often assumed that behavioral or personality changes were the result of the patient simply being belligerent or unpleasant. Coping strategies ranged from simply ignoring outsiders who were judgmental or unsympathetic toward the condition to openly sharing information about FTD with those willing to listen.

3. Symptoms of FTD

Participants talked about specific symptoms of FTD, their experience with these and the impact these symptoms have on their relationship with the patient and others. Communication difficulties were highlighted as one of the most difficult symptoms to cope with in FTD, precluding meaningful interaction with the patient. In some cases, this was due to the patient's tendency toward social isolation and reticence.

4. Diagnosis

Virtually all participants were told of the diagnosis through discussion with the healthy parent, and in some cases, the patients themselves helped explain. Participants unanimously agreed that sooner was better in terms of breaking the news. However, there was some debate about disseminating the information in its totality, especially concerning the prognosis. Children should have the option of learning as much about FTD as they feel comfortable with, and that in some cases, details about the progression and overall prognosis should be provided in a stepwise manner rather than at once.

5. Relationships

Although communication was often one-way, some participants found that spending quiet time with the patient was still mutually rewarding and beneficial. Other caregivers felt that just seeing the patient smile or laugh provided its own sense of reward. An important part of the new relationship was having compassion and acceptance for the patient. Acceptance of the patient was made easier by attributing the changes to the disease rather than the patient. Participants recognized the immense increase in responsibility falling on the healthy parent and the emotional and physical burden that resulted.

6. Support

The majority of participants identified their healthy parent as the chief means of family support followed by siblings then extended family. Most participants found it useful to talk to friends as an outlet. Although most friends had a very limited understanding of FTD, they were typically empathetic and willing to listen. Unlike support from family members and friends, participants felt somewhat disconnected from health professionals. Participants preferred conversations in-person but accepted that technology was an alternate means of support that could be used in specific circumstances. And as a result of the interview, some of the participants discovered that speaking about their situation was a positive experience. Several expressed interest in joining an online forum where they could share their experiences with other peers.

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