

Telehealth-facilitated caregiver support group for spousal caregivers of individuals diagnosed with atypical dementias

Included in this package are some potentially useful web-based resources; including basic information, support forums, and practical suggestions. Finally, attached is a handout on Managing Challenging Behaviours in Frontotemporal Dementia that may be universally helpful.

Canadian Caregiver Coalition - <http://www.ccc-ccan.ca/>

From their website “The Canadian Caregiver Coalition is the national body representing and promoting the voice, needs and interests of family caregivers with all levels of government, and the community through: Advocacy and leadership; Research and education; Information, communication and resource development”

“The Coalition's Strategic Plan is a roadmap for where we need to go, how to get there, and with whom, in order to bring about policy changes that will improve the lives of family caregivers.”

“Building Partnerships and Expanding the Voice of the CCC

Building a strong partnerships base and sharing our message with all levels of government, the corporate sector and caregiving networks

Embracing a Grass Roots Approach

Facilitating education and sharing of best practices for Family Caregiving

Informing Policy and Direction

Undertaking an annual planning process to identify / confirm strategic priorities, in collaboration with individuals and organizations who share our vision.”

<http://www.caregiver.org/caregiver/jsp/home.jsp> - Family Caregiver Alliance (FCA); US-based

From their website “FCA is a public voice for caregivers. Our pioneering programs— information, education, services, research, and advocacy—support and sustain the importance of families nationwide caring for loved ones with chronic, disabling health conditions.”

This website is a vast resource and includes information about Huntington’s disease

http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=574, vascular dementia

http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1995, and the variants of

frontotemporal dementia http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=573

They also have an online discussion forum for Huntington’s disease

<http://lists.caregiver.org/mailman/listinfo/hdmd-group> lists.caregiver.org.

Finally, this website has a document that provides very good information on websites related to caregiving for any chronic health conditions, including dementia – see

<http://caregiver.org/caregiver/jsp/content/pdfs/FCA-Harford-Practical%20Tools-Caregivers.pdf>.

Also in this list are resources on self-care for caregivers, most of which is located on their own site.

UK organization that provides very good information

<http://www.pdsg.org.uk/>

From their website “Caring for people with frontotemporal dementia is hard, there are few facilities tailored for the younger sufferer and those are not always appropriate for people with frontotemporal dementia. Also there are no specific treatments yet for frontotemporal dementia. All this adds to the distress, isolation and burden of caring. The PDSG tries to decrease the burden by providing information and support.”

http://www.pdsg.org.uk/clinical_information/ This link has some wonderful tidbits of information on different variants of frontotemporal dementia such as semantic dementia http://www.pdsg.org.uk/clinical_information/semantic_dementia/, progressive non-fluent aphasia http://www.pdsg.org.uk/clinical_information/progressive_aphasia/, and frontal or behavioural variant http://www.pdsg.org.uk/clinical_information/frontotemporal_dementia/. Most importantly, this link http://www.pdsg.org.uk/clinical_information/ provides links to information on ‘swallowing problems,’ ‘communication,’ ‘challenging behavior,’ ‘obsessions,’ and ‘apathy and how to deal with it.’

In addition, this site provides a section titled ‘helpful tips’ includes some information about travel, awareness cards, etc.

This group also has a well linked on-line support forum

<http://www.ftdsupportforum.com/>

From their website, a discussion of the forum”This FTD and Pick's support forum is an international support group set up by carers of people with various types of fronto-temporal dementia. This includes, but is not limited to, Pick's Disease(PiD), Frontotemporal Dementia (FTD), Primary Progressive Aphasia (PPA), Frontotemporal Lobe Degeneration (FTLD), Dementia with Lewy Bodies (DLB) and Corticobasal Ganglionic Degeneration (CBGD). The membership is made up predominantly of caregivers, but we also welcome people who suffer from FTD. Because the focus of the group is mainly on the caregiver, FTD sufferers may find the discussions difficult to take. If you have FTD and would like to join, please understand that conversations are blunt and may be painful at times. The primary purpose of this group is to communicate with one another in a supportive and friendly environment. Many people in our lives outside of the forum have never heard of the types of dementias that we deal with on a day to day basis. We find value in talking with one another about the challenges we face as caregivers and the changes we see in our loved ones.”

Books recommended on their site <http://ftdsupport.com/side-ideas-books.htm>

Templates of information cards (cards to give to others to quickly explain the disease) <http://ftdsupport.com/side-ideas-buscards.htm> or templates of letters to give to relatives/loved ones <http://ftdsupport.com/side-ideas-letters.htm> <http://ftdsupport.com/side-ideas-miscell.htm> ideas that may be helpful including door alarms, sound monitors

Yet another very good website, US-based

<http://www.ftd-picks.org/support-resources/finding-support/caregiver-support-groups>

From their website “Upon receiving a diagnosis of frontotemporal dementia, individuals and families often enter a world of new and confusing medical, social, legal and financial systems. They may have some experience assisting an elderly or ill parent, but the typically earlier onset of FTD can mean additional challenges. It can seem overwhelming to care for someone with FTD. In addition to managing daily needs, there are new terms to learn, acronyms to decipher – PPA, TDP-43, FTLD- and services to find. Roles within a family often shift and people may not feel at all prepared for the tasks they face. You need not travel this road alone. Accessing reliable information and compassionate support can help you to feel confident as a caregiver.

These pages will point you toward some of the people and places that can provide what you need. Be persistent, be creative, and be proud of all that you accomplish.”

They have a nice listing of specific information under ‘caregiving challenges’ <http://www.ftd-picks.org/support-resources/caregiving-challenges> including “Treasuring This Moment in Time” & “Three C’s followed by three P’s, which is “From one of my wise mentors I had learned a method for regaining perspective called “the three C’s:” I didn’t *cause* it. I can’t *change* it; and I can’t *control* it.” This link also includes sections on ‘dealing with oppositional behaviors,’ “structuring the day,” “driving privileges,’ and “children and teens.”

Books and resources <http://www.ftd-picks.org/support-resources/resources/books-publications> in addition to other resources <http://www.ftd-picks.org/support-resources/resources/links>

Baycrest FTD resources

http://www.baycrest.org/Health_Information/Conditions/AZ/11045_11085.asp

Also the source of the final pages on managing challenging behaviors

Alzheimer Society of Canada resources/Alzheimer Society of Saskatchewan resources

<http://www.alzheimer.ca/english/disease/dementias-frontotemp.htm>

University of California, San Francisco Frontotemporal dementia information

<http://memory.ucsf.edu/ftd/>

Mayo Clinic

<http://www.mayoclinic.com/health/frontotemporal-dementia/DS00874>

A copied section on caregiver stress from the Mayo Clinic website

Caring for a loved one can be a strain on even the most resilient individuals. If you're a caregiver, take steps to preserve your own health and well-being.

By Mayo Clinic staff

When you hear the word "caregiver" you probably picture someone caring for a parent with Alzheimer's disease. But a caregiver is anyone who provides help to another person in need, whether that's an ill spouse or partner, a disabled child, or an aging relative. Indeed, more than 65 million Americans provide care to a loved one.

If you're among them, you know that taking care of someone who needs your assistance can be very rewarding. But it can also exact a high toll, and caregiver stress is common. Caregiver stress is the emotional and physical strain of caregiving. Individuals who experience the most caregiver stress are the most vulnerable to a decline in their own health.

Many caregivers fall into the trap of believing that they have to do everything by themselves. Don't make that mistake. Take advantage of the many resources and tools available. Remember, if you don't take care of yourself you won't be able to care for anyone else.

Signs of caregiver stress

As a caregiver, you may be so focused on your loved one that you don't realize that your own health and well-being are suffering. Watch for these signs of caregiver stress:

- Feeling tired most of the time
- Feeling overwhelmed and irritable
- Sleeping too much or too little
- Gaining or losing a lot of weight
- Losing interest in activities you used to enjoy

Too much stress, especially over a long time, can harm your health. As a caregiver, you're more likely to experience symptoms of depression or anxiety. In addition, you may not get enough physical activity or eat a balanced diet, which only increases your risk of medical problems, such as heart disease and diabetes.

Tips for dealing with caregiver stress

The emotional and physical demands involved with caregiving can strain even the most capable person. That's why it's so important to take advantage of available help and support. These tips have helped others deal with caregiver stress:

- **Accept help.** Be prepared with a list of ways that others can help you and let the helper choose what he or she would like to do. For instance, one person might be happy to take the person you care for on a walk a couple of times a week. Someone else might offer to pick up groceries for you.
- **Don't give in to guilt.** Feeling guilty is normal, but understand that no one is a "perfect" caregiver. You're doing the best you can at any given time. Your house does not have to be perfect, and no one will care if you eat leftovers three days in a row. And you don't have to feel guilty about asking for help.
- **Get informed.** Organizations such as the Red Cross and the Alzheimer's Association offer classes on caregiving, and local hospitals may have classes specifically about the disease your loved one is facing.
- **Join a support group.** A support group can be a great source for encouragement and advice from others in similar situations. It can also be a good place to make new friends.
- **Stay connected.** Make an effort to stay in touch with family and friends. Set aside time each week for socializing, even if it's just a walk with a friend. Whenever possible, make plans that get you out of the house.
- **Commit to staying healthy.** Find time to be physically active on most days of the week, and don't neglect your need for a good night's sleep. It's also crucial to eat a healthy diet.
- **See your doctor.** Get recommended immunizations and screenings. Make sure to tell your doctor that you're a caregiver. Don't hesitate to mention any concerns or symptoms you have.

Respite care

It may be hard to imagine leaving your loved one in someone else's care, but taking a break is one of the best things you can do for yourself as well as the person you're caring for. Most communities have some type of respite care available, such as:

- **Adult care centers.** Many adult care centers are located in churches or community centers. Some care centers provide care for both elderly adults and young children, and the two groups may spend time together.
- **Day hospitals.** These hospitals provide medical care during the day. In the evening, your loved one returns home.
- **In-home respite.** Health care aids come to your home to provide companionship, nursing services or both.
- **Short-term nursing homes.** Some assisted living homes, memory care facilities and nursing homes accept people needing care for short stays while caregivers are away.

The caregiver who works outside the home

Two-thirds of caregivers work outside of the home. Juggling work responsibilities and caregiving isn't easy, and employed caregivers experience high levels of caregiver stress. If you're in this situation, try these tips for balancing your work and personal responsibilities:

- Learn to delegate. Share your work — and home — responsibilities with others.
- Ask your human resources department about resources your company offers, such as support lines or referral services. Then make use of these assistance programs.
- Keep an open line of communication with your supervisor and co-workers.
- Ask your loved one's doctor to send a letter to your company explaining the seriousness of your loved one's condition.

You aren't alone

If you're like many caregivers, you have a hard time asking for help. Unfortunately, this attitude can lead to feeling isolated, frustrated and even depressed. Rather than struggling on your own, take advantage of local resources for caregivers. To get started, contact your local Area Agency on Aging (AAA) to learn about services in your community. You can find your local AAA online or in the government section of your telephone directory.