



Family Caregivers' Grapevine

A publication by NSCR's
Caregiver Support Program

renew strength, gain knowledge

Coping with Change: When Your Loved One Is Diagnosed with Dementia

By Cassandra Van Dyck

A dementia diagnosis comes with a wash of emotions. Feelings of grief, shock, and fear are common. Such feelings are natural when you know that your loved one's abilities will continue to change, and that your relationship with them will also shift as time goes by. If you are a caregiver, your loved one's diagnosis of dementia may also bring an outlook of understanding or relief. You may have been noticing signs and symptoms for quite some time, such as their inability to learn and retain new information or their struggle with routine tasks, but you were unsure if what you noticed was significant. Perhaps you were quite confident that their symptoms fit a dementia diagnosis, but you were unsure of how to best support them through this transition. A diagnosis can provide you and your loved one with additional support and resources, which can drastically improve the quality of life for you both.

Supporting Your Loved One's Emotions

One of the great challenges of caregiving is balancing the needs of your family member with your own. Supporting this person through a dementia diagnosis is no exception. They are likely feeling much of what you are: fear, shock, grief, and maybe relief that they now have an explanation for their symptoms. How can you support them, while also taking care of yourself? Addi-



tional resources are key. Make sure that you have someone (or a group of people) to check in and debrief with regularly, so your experiences are acknowledged, allowing you to be present for your loved one. A trusted family member or friend is a great option, but it is worthwhile to also have access to a caregiver support group or counsellor. Over time, you may find the two latter supports indispensable because of the unbiased and attentive support they provide.

Talking to your loved one about their diagnosis can be challenging. Support your care partner's emotions by using empathy and reflective listening. If you're not sure how to respond to your spouse or parent's feel-

-ings of frustration and sadness, try the following statements:

"It sounds like you're feeling really scared. I'm here for you, and we will work together to get you the support you need."

"You seem really sad, and I understand that hearing you have dementia must be really hard for you. Can you tell me more about how you're feeling?"

Creating Your Support Team

After diagnosis, it might feel like things happen quickly after weeks, months, or years of noticing small or big changes in your loved one. Appointments with doctors and specialists will be scheduled. You will be presented with a plethora of resources. Advice and support will stream in from lots of people. While much of what's offered will be helpful, it can also be overwhelming. Remember to be gentle with yourself as you adjust to this new journey with care partner. While there are consistencies in how abilities change, people living with dementia change in different ways and at different paces. Pay attention to their cues. Learning how to best support them will depend on their individual needs.

Having a solid support team is (arguably) the most important thing you can do for yourself and your loved one. Who's on your list of valuable resources will shift depending on what you and your loved one need, but you will need names, numbers and services available no matter what. Even if you feel that you don't need extra support right now, create a "just in case" list. Who will drive your family member to appointments if you fall ill or go on vacation? Where/who will they stay with when you need a break? Who else can support your loved ones emotional and physical needs? Who can support yours? What organizations are leading in dementia research? These are all questions to ask yourself before making a list. If your loved one is able,

involve them in the process of identifying and writing down resources.

A New Journey: Redefining How You Relate, In the Now

"Something has gone, something bad has gone. We've reached the limit of our soul of misery and we're now poof! We're just doing the best we can. We're not feeling like that, we just do, we just are. I think that's just the way it is." – Cathie Borrie, "The Long Hello"

There are many practical things that you can do to support your loved one and yourself while on the dementia care journey. Sometimes the less practical advice, the subtle changes in attitude or outlook or routine are what make the greatest difference in your well-being. I recently read a profoundly moving article, "Love and Renovations," on the blog Welcome to Dementialand, by Elaine M. Eshbaugh. Elaine describes a conversation she had with a man who explained that his recent move with his wife wasn't a big deal because she got the same countertops. The man had installed the same countertops in their new home so that she would transition to their new space with ease. Of course, not everyone has the carpentry skills needed to tackle such a big project with ease, but what struck me was that the husband just did what he thought needed to be done, because he loved his wife and because he could. He was considerate of doing everything he could to make her comfortable. So much of being a caregiver is accepting where your loved one is at, and accepting and adjusting accordingly.

As you embark on this new journey with your loved one, be gentle and kind to yourself. Take things one day at a time. Get support. Remember that even when you feel alone, you are not. Reach out when you need to.

January 2018

Sun Mon Tue Wed Thu Fri Sat

	1	2	3	4 Network Group 7-9PM	5	6
7	8	9	10 Network Group 10:30AM- 12:30PM	11	12	13
14	15 Medications for Dementia Care 3-5PM	16	17	18	19	20
21	22 Walk & Talk 1:30-3PM	23	24	25	26	27
28	29	30	31			

Network Groups

Thursday, January 4th and February 1st, 7-9PM
 Wednesday, January 10th and February 14th,
 10:30AM-12:30PM Room 203 in Capilano Mall

Sneak peek—Jan 4 & 10: Soothe your system with
 Emotional Freedom Technique

Are you curious about how EFT works? Tapping is an
 effective way for many people to gain relief from
 stress and feel their emotions calm. For part of the
 meeting time we'll practice self- tapping techniques
 with guest speaker Christine Wheeler. Christine is a
 published author and passionate EFT practitioner.
<http://www.christinewheeler.com/what-is-tapping>

Medications for Dementia Care

Monday, January 15th, 3-5PM
 Silver Harbour Seniors' Activity Centre 144 East 22nd
 St., N. Vancouver

Is a loved one living with dementia or memory loss?

Understand more about:

- what the term dementia truly means
- types of medications commonly prescribed
- how to manage medication routines
- how changes in the brain affect behaviour and ability

An informative presentation with Dr. Arvind Kang, MD
 and Psychiatrist.

Walk & Talks

Monday, January 22nd & February 26th, 1:30-3PM

Join us for company, fresh air, and some gentle exer-
 cise. We walk at a pace that is comfortable for every-
 one. Meet us in front of the washrooms at John Law-
 son Park, rain or shine!

For registration and information on all sessions, contact Karyn by email at karyn.davies@nscr.bc.ca or by phone at 604-982-3320.

Wellness Corner



Dementia Care Resources

Books

The Long Hello, By Cathie Borrie | “A beautifully written meditation on memory loss, suffering, hope and love.” - Jed A. Levine

Ten Thousand Joys and Ten Thousand Sorrows, By Olivia Ames Hoblitzelle | A memoir about a couple’s journey with Alzheimer’s and the power of spirituality to carry them through.

Managing Transitions: Making the Most of Change, By William Bridges | Though not specific to dementia, this book helps readers manage and adapt to change—an essential skill for the caregiving journey!

Validation Techniques for Dementia Care: The Family Guide to Improving Communication, By Vicki de Klerk-Rubin | Tips and tricks for effective communication.

**All of these books can be found in NSCR’s Caregiver Library.*

Web

Alzheimer Society of Canada | Offers resources for caregivers on a variety of issues faced by caregivers, such as communication techniques, planning for the future, and grieving. www.alzheimer.ca

The Caregiver Network | TCN offers webinars on a variety of topics, from care planning to dementia care to mental health. <https://thecaregivernetwork.ca>



How to Talk to Your Care Partner's Doctor

By Cassandra Van Dyck

On your caregiving journey, you are likely to accompany your loved one to many doctor's appointments. From check-ups with their GP, to specialist consultations, ongoing appointments and everything in between, you will spend a lot of time in medical rooms. As a primary support person, you may begin to feel that your own experience at the appointments is as valuable as your loved one's. As a caregiver, it's important for you to be in the loop. Understanding your loved one's condition and treatment options will help you support them to the best of your abilities. Chances are, you will have a lot of questions and concerns of your own to bring up with the health care professional you're seeing. It can be a challenge to also remain respectful of a family member's sense of privacy, dignity, and right to personal choice.

Depending on your loved one's needs, your level of involvement at doctor's appointments will vary and so will your ability to contribute questions and concerns. Given the time constraints of doctors, trying to balance the need to voice your questions and concerns while respecting the autonomy of your family member can be challenging, to say the least.

Talk to your loved one.

If you regularly accompany your care partner in to the room with their doctor, you're in a great position to advocate for them. You will want to make sure that your family member feels good about you asking questions. The more you can talk to your loved one about your concerns before the appointment, the more comfortable they will feel.

The closer you and your spouse or parent are to being on the same page before a doctor's appointment, the easier it will be for you both to clearly communicate your needs. Voice to them your questions and concerns. Ask their permission to contribute. Invite them to sit down with you to make a list to take with you to the appointment.

Make a list.

Because of time constraints and the possibility of getting distracted during your appointment, it is very common to be on your way home before you remember the question you'd been meaning to ask for weeks. The most tried and true way to make the most of short doctor's appointments is to pre-write a list of questions and concerns. Resist the urge to store the list only in your head! Write it down and bring it out before the doctor enters the room. Before your doctor leaves the room, take one last look at the list to make sure you covered all you wanted to.

Prepare information the doctor will need.

What symptoms has your loved one been experiencing? What is their pain level, on a scale of 1-10? What medications are they taking? What is their lifestyle (food/drink intake, activity level) like? How is their mood? How are they sleeping? The more awareness you have, the easier it will be for you to answer questions and for your doctor to conduct a thorough assessment.

Trouble shoot.

Let's say that you are deeply involved in the care of your loved one. You are around them enough to notice something is off that perhaps they are not aware of or that they do not want to talk to a doctor about. Maybe they're struggling with incontinence and embarrassment is preventing them from opening up to their doctor. Perhaps you've noticed that they seem depressed, but when you ask them about it they don't want to talk. They could be skipping medication doses. These are tough situations to navigate, and it's common to feel like you're stuck if you can't discuss what's going on with your loved one in front of their doctor.

What to do:

First, talk to your care partner again. Let them know that you're concerned about their well-being, and you're wondering how they'd feel about you talking to their doctor. Ask them if they'd mind you booking an appointment or speaking to their doctor on the phone, without them there if they're not comfortable being a part of the conversation.

If your loved one still does not want you to speak to their doctor, consider making a phone call or sending a fax with your concerns. If you're unsure of how to communicate your concerns to your loved one's doctor, call the Medical Office Assistant and ask them how best to proceed. Doctors are often grateful to receive information that can help them to better diagnose or support their patients. While the doctor will not be able to disclose confidential details to you, they are able to receive information. They can ask a patient questions related to the caregiver's concerns, but not disclose where the questions came from.

Some final tips from Nancy Calhoun...

- Ask how you can best help. For example, you can use the prepared list to remind the person of questions for their doctor.

- Encourage the person to talk honestly about his or her symptoms.
- Ask what you should do if there are complications [with medications].
- After the visit, discuss the visit with your loved one.
- Do something nice for yourself!

5 Minutes for Self-Care

Did you just get through a stressful conversation with your loved one, or a challenging doctor's appointment? Are you feeling stressed today? Now's a great time to practice some self-care! Here are some ideas on ways to take care of yourself in 5 minutes or less.

- *Sing along at the top of your lungs to a song in the car*
- *Dance to a song you love in your living room*
- *Set a timer for 5 minutes and write in a journal*
- *Stretch! Lift your arms above your head. Roll your head from side to side. Try gentle lunges or rotate your wrists and ankles.*
- *Take some deep breaths! Fill up your lungs and stomach with as much air as you can. Pause, and push it all out. Pause, and repeat.*

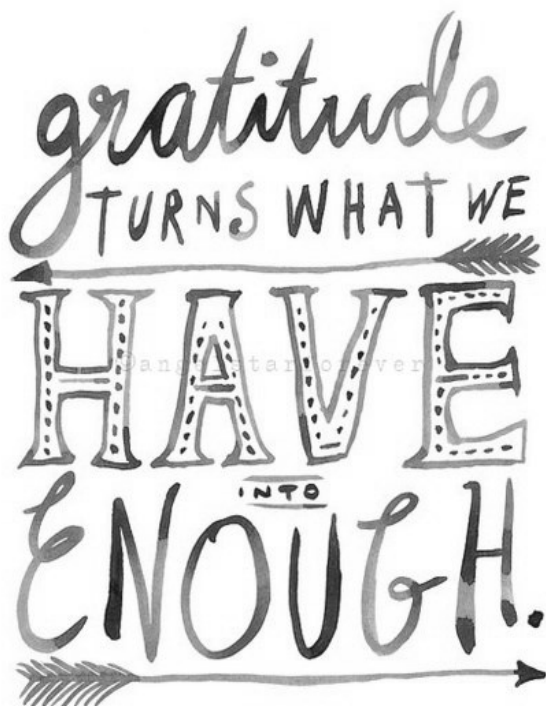
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Gratitude Corner

New Year`s Gratitude



Instead of writing New Year`s Resolutions this year, why not write New Year`s Gratitude. Take this time of renewal as an opportunity to reflect on all you`re grateful for, and perhaps to implement a gratitude practice in to your life.

Ask yourself the following questions to get some clarity:

Where could I use more gratitude in my life this year?

Who am I grateful for, and how can I spend more time with them? How do I express my gratitude to them?

What am I grateful to myself for? What are my strengths?

Am I using them?

Get cozy and spend some time answering these questions in a journal. How did you feel after? Differently than when you wrote resolutions last year?

The Elderly and Their Adult Children

By Calm Pond



I'm an adult children of my two 80-something parents. As such, I have a dual role: at times, I am a leader: taking charge, delegating, coordinating. At other times, I'm still their little girl, or at least, they see it that way. It can make for some pretty interesting (and challenging!) moments.

Are you also an adult child? Here's some facts and ideas I found from Eric Digests:

<https://www.ericdigests.org/pre-925/adult.htm>

The population of what they call the 'oldest-old' (85 years+) is rising. Adult children provide about a quarter of the care to elderly fathers and a third of the care

to elderly mothers. Traditionally, it has always been up to adult children to care for their parents, indeed, in some cultures, children are seen as a kind of old age insurance. Adult children provide direct assistance to activities of daily living and also coordinate and monitor services. The 'baby boomer' population is becoming older, and this group tend to have fewer children to care for them. Caregivers are at times, under a great deal of strain. Some suffer from the emotional burden of care and tire out. Support groups play a large role in helping the caregivers deal with stress. As recently announced by our Prime Minister, caregiving is a tremendously valued social resource.

As a an adult child, I often remind myself of the gratitude I feel towards my parents who cared for me as best they could and provided me with opportunities. I see caregiving as an act of 'giving back'. Yes, it can be stressful, but also, it can be very rewarding. I savour the special moments I have with my parents (I call them my 'hummingbird' moments). One day I will look back and remember this time, and know that I made a difference in the lives of two very special people.

Perhaps you feel the same way?

Calm Pond is a caregiver and volunteer writer for our blog, North Van Caregivers.

*Read more posts like this at
www.northvancaregivers.wordpress.com*



NSCR Caregiver Support Program

201-935 Marine Drive, North Vancouver, BC V7P 1S3

Thank you to those who have already donated. We appreciate your generous contribution!

You can support the work we do by joining NSCR's donor program, *Caring Community*.

Contact Nancy Hollstedt to make a donation: (604) 982-3311 or nancy.hollstedt@nscr.bc.ca

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