

Conquering Your Fears at Every Stage of the Caregiver Journey

Webinar with Family Caregivers of BC, October 11, 2018

Presented by Author/Speaker Janet Dunnett

What kind of caregiver are you?

- Just starting out on the journey? well into it? coming to the end?
- A daughter or son? a spouse? a relative? a friend?
- 24/7 or just a few hours a day or week? (you are committed to it, and your help is needed).
- Caregiving without reservation? Harboring some resentment?
- Young? In a club sandwich of care? A senior citizen? Healthy? With your own health burdens?

There are as many kinds of caregivers as there are caregiver stories. But some things are the same. All caregivers become experts. Their role on the health team is essential and unique. Yet they may feel invisible and some may even feel disrespected or taken for granted. Fight that! We go through many phases as caregivers. This is one map, of my personal journey. What's yours?

The early days — “just helping out”

Caregiving might begin slowly, with just one or two activities of daily living where the cared for needs (or just appreciates) your help.

- Outside observers might say. “You are such a good daughter”
- You might reject the caregiver identity (you are just a good daughter, after all!)

Need Creep

“A few needs” here and there is giving way to more and more needs more and more hours of the day.

- You may or may not acknowledge that you are getting stressed, tired, pulled apart by competing expectations of spouse, job, family and the cared for person. If someone does ask, “how are you doing?” you might say, “I’m fine” because you don’t have the language to really explain!
- The surrounding health care system might not yet be ready to offer much support to you, as caregiver, stating family responsibility. And you might agree. “Families are supposed to take care of each other...right?”
- One challenge you might acknowledge is how hard it is to provide help in a way that does not rob the cared-for of dignity or independence. This gets harder to “pull off” as need creeps on.
- One opportunity is to focus support to the cared-for on activities that contribute to the need to still find purpose and meaning in life, a reason to get out of bed in the morning (eg. help to get out of the house? support to attend social encounters?).
- It is the time to look ahead. Research what care options are in your community. Learn about the course of conditions that are affecting the loved one, Begin the conversations around “what if this gets worse?” (advance directives).

It is a time to zero in on your own need for self-care. This means setting boundaries. This might lead to new battles— with your own caregiver guilt. Remember, though. You are not much good to anyone if you fall apart. So, your self-care is “part of the job”.

Crisis

Looking back on a particularly bad time, you will see it as a turning point, where your caregiving has rapidly escalated (you were so busy driving, you didn’t look in the rear-view mirror). This will be an intense time, but now you might have more support from the health care system.

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- It now helps to find and cultivate the non-judgmental and willing ear/s to let you download your feelings of fear, anger, frustration, sadness...even guilt. Someone you already know? A support group? A meet up group on line?
- In BC – call the Family Caregivers of BC Caregiver Support Line toll-free @ [1-877-520-3267](tel:1-877-520-3267). The staff at Family Caregivers will listen, help you think through a challenging situation, connect you to resources and make sure you are looking after yourself.
- Come to terms with the reality that friends and acquaintances might back away at this point. (ie. “Not THAT story again!”) This will surprise you and may hurt your feelings.
- Understand that self-care is harder than ever but more important than ever.

The Denouement

If your caregiving story were a novel, it would be the time when “the action” has been resolved and loose ends are being tied up. Caregiving in *The Dwindling Time* ends as nature intends, in the death of the cared for.

- As caregiver you are less challenged than ever before to “do”. But, you are more challenged than ever before to just “be”. Your presence is most important.
- Some ideas for this time:
 - How can you support physical comfort? (the time for “cure” has passed).
 - Can you be open to conversations that are more spiritual? It’s time for this.
 - Can you help tie up loose ends, the business side of living so that in dying, there is less of a burden left to the family?
- As caregiver, expect to contend with practical, emotional and financial burdens. Expect to have feelings of sadness. Anticipatory grief is normal and just the other side of the love coin.

When Caregiving is Over

- Expect to be exhausted, physically, emotionally and spiritually perhaps - for quite a while.
- Expect to ruminate, “did I do it right? did I do enough?” This is a normal response.
- Don’t be surprised if you have an element of relief that it’s over. AND DON’T FEEL GUILTY ABOUT THAT!
- Expect to need grief support, someone, or a group, that will still be ready to listen and review as you process, long after everyone else has “got back to normal” and doesn’t want to go over old news.

In Sum?

Caregiving: “The hardest job I ever loved.”

Expect to be transformed. You will never be quite the same (and that’s growth, a good thing!)

Janet Dunnett is the author of a memoir of caregiving, called *The Dwindling: A Daughter’s Caregiving Journey to the Edge of Life*, 2017. It is available (or can be ordered) in any Canadian bookstore, is on Amazon and is also available as an e-book on Kindle.

You may find out more about Janet Dunnett on her website. www.journeyspress.ca