



Family Caregivers
of British Columbia



Planning for a Future with Parkinson's

Family Caregivers of BC

- Non-profit charity dedicated 100% to the wellbeing of family caregivers
- 28 years, first of it's kind in Canada (Family Caregivers' Network Society until 2015)
- Serving all of BC since 2010, past 4 years with Ministry of Health Patients as Partners Initiative funding
- 60% of Board members and 100% of Staff have caregiving experience



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To learn something new

To identify ONE thing you are going to start doing – the same or differently

To reflect on, "What's most important to me as I age and what do I need to do to make it happen?"

To laugh – with me or at me, either one is fine!

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Definition of Family Caregiver



Family member or friend who gives unpaid care to an adult either at home or in a facility, who has a physical or mental health condition, chronic illness or frailty due to aging.

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Quick Poll

How many of you are familiar with Family Caregivers of BC (previously known as the Family Caregivers' Network Society)?



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Mission

To improve the quality of life for family caregivers through information, support and education.

We provide leadership to strengthen the voice of family caregivers and the significance of their role.

Vision

Family caregivers are recognized, valued and supported as partners in care.



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Why Do Family Caregivers Matter?

- 89% care > than 1 year
- 27% of British Columbians are caregivers
- 80 – 90% of care at home
- Majority are women
- 35% are employed

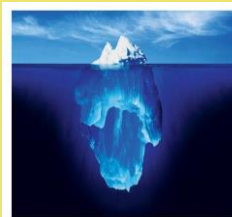
Sinha, M. (2012). Portrait of caregivers. Catalogue no. 89-652-x—No.001. Statistics Canada. Analytical Paper. Spotlight on Canadians: Results from the General Social Survey.



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Why Do Family Caregivers Matter?



- 3/4 of family caregivers help with transportation including helping to attend medical appointments,
- Almost 1/4 help with medical treatments and personal care
- 1/3 schedule and coordinate appointments

(Sinha, 2012)

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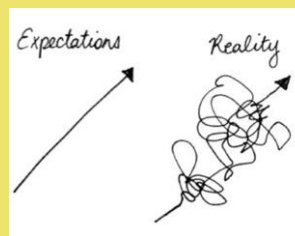
Future Planning: It's Common Sense Right?

- Peace of Mind
- Decreases Stress in time of Crisis
- Time to Explore Preferences
- Better Quality of Living
- More control and independence

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"Make reality your friend not your enemy"



Planning for Transitions



Taking Stock

Challenge/Need

I want to stay in my own home

Personal Capacity

Do I have the functional ability to stay here? If not, who will help me? Do they have the ability?

Financial Resources

What will it cost me to stay here as my needs change? i.e., renovations, accessibility, can I afford private care and support in home, etc

Informal resources

Do I have family or friends that can help me stay in my own home when I can't? What can they help with? How much are they willing and able to do?

Formal Resources

What programs and services exist to help me stay in my own home? i.e., public health care system, government programs and private services

10 Questions to Start the Conversation

1. If faced with an unexpected change in health or mental capacity, are they financially and legally prepared? This would include taking steps with: advanced health-care directive including a DNR [do not resuscitate], representation agreement, power of attorney, a will, etc.
2. Will they want or expect a lot of involvement from their children if they need care?
3. At what point would they consider asking for or accepting help?
4. How do they feel about having private care come in to help with household tasks, personal care and home maintenance?
5. Have they done research on how much care and housing options cost?

10 Questions to Start the Conversation

1. How would they feel about you checking that bills are being paid?
2. If at some point they are no longer able to live at home, what kind of living arrangements would they prefer? Living with you? Building a home or moving to be closer to you or other family? Move to an assisted living facility? Residential care?
3. Have they made any long-term plans? If yes, could they share those plans with you?
4. Do they have a good understanding of how the health care system works in providing care and support to seniors?
5. Who is willing to step up in the family caregiver role?

Watch For The Signs!



Documentation

- When having to make future decisions or in a crisis, having information and documentation at your fingertips is KEY.
- Anyone who is involved in your care and support should know where the information is kept or have a copy.

EMERGENCY CONTACT SHEET

Name of Elder: _____
 Address: _____
 Telephone: _____

FIRST CONTACT
 Name of Primary Caregiver: _____
 Address: _____
 Telephone: _____ Mobile: _____
 Email: _____

Relationship: Child
 Other family specify _____
 Friend, specify _____
 Other, specify _____

OTHER EMERGENCY CONTACTS

Name: _____ Tel: _____
 Address: _____ Has a spare key? Yes No
 Email: _____

Relationship: Child
 Other family specify _____
 Friend, specify _____
 Other, specify _____

Name: _____ Tel: _____
 Address: _____ Has a spare key? Yes No
 Email: _____

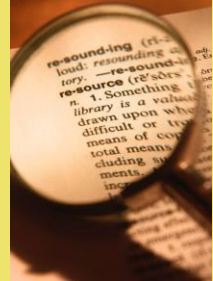
Relationship: Child
 Other family specify _____
 Friend, specify _____
 Other, specify _____

Health Care Appointments

- **Write down the reason on a piece of paper** with the date and time of the appointment and with whom (if with a specialist).
- **Write down symptoms**
- **Write down a list of questions** for the appointment
- **Bring a list of all medications being taken.**
- Having an **extra set of ears and eyes** during a health appointment can be helpful.
- If you need more time for yourself or the person you are caring for to deal with a medical issue, **ask for an extra long appointment** when booking the visit.
- **Follow-up is key!**

Top Documents

- Key People & Important Documents
- List of Power of Attorney; Health Representative; Levels of Intervention
- Where are the documents located?
- List of key medical specialists, care managers, other support personnel
- **VERY LITTLE USE IF NOT CURRENT!**



Journal/Observations

Date and Time	Health Event or Change in Physical or Emotional Health	Length of event or change What made it worse/better	Other Notes
April 15, 10:00 am	Felt dizzy in the morning; Mom nearly had a fall	Lasted about 45 min Lying down made it feel better	Will keep observing and make an appointment to see Dr. next week.

The person beside the patient needs care too.



Caregivers Need Care Too!

Almost one in four British Columbians is providing eldercare to a parent, caregiving a spouse or partner, or providing care to another adult family member or friend. Many of these people are doing so while holding down a job, looking after children, or dealing with a health issue of their own. Family caregivers need recognition and inclusion as partners in care, but they also need care themselves. Make them part of Family Caregivers of British Columbia for resources and support.


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of British Columbia
— Let us help —

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Effects of Caring

- 1/3 of family caregivers in British Columbia are in distress (Mackenzie, 2015)
- Over half (55%) of caregivers in Canada felt worried or anxious as a result of their caregiving responsibilities
- Approximately 1/3 felt overwhelmed or experienced disturbed sleep due to caregiving (Sinha, 2012). General Social Survey)

Impact of Caregiving on Health

Chronic health conditions
twice the rate
of general population



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10 Signs of Caregiver Stress

1. Denial – about disease & effect
2. Anger
3. Social Withdrawal
4. Anxiety about the future
5. Depression
6. Exhaustion
7. Sleeplessness
8. Emotional reactions – crying & yelling
9. Lack of concentration

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Impact of Caregiver Stress

- Caregiver gets sick and/or burns out
- Caregiver is unable to continue supporting their care recipient in the community
- Already strained community services are required to fill the gap
- Care recipient loses out by not having the value added a family/friend caregiver provides
- May lead to increased utilization of acute care and facility based resources

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Services

Caregiver Support Line in BC 1 877 520 3267
Mon-Fri: 8:30am-4:00pm

- One-to-one emotional support
- Help navigating the health care system
- Access to support groups
- Newsletter with timely articles
- Referrals to other community resources

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Services

Visit the Virtual Resource Centre:

- Educational webinars, workshops and online modules on topics such as:
 - Caregiver health and wellness
 - Family dynamics and caregiving
 - Communication and assertiveness skills
 - Sharing the care
 - Navigating the health care system

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Thank You

Caregiver Support Line:
toll free 1-877-520-3267

Education & Resource
Center:
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Family Caregivers
of British Columbia



Our ears and minds are open

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