



## Caring for aging parents

**T**ake a huge helping of baby boom, mix in a dash of better health, add a few cups of trends like population aging, later childbearing, and health care restructuring – that’s the recipe for the increasingly common phenomenon of caring for aging parents. Some call it the ‘sandwich generation’ – caring for parents while also caring for children – but it goes beyond that. With more people living into their 80s and 90s, many seniors are now caring for their parents well into their own retirement years.



Most informal (unpaid) care for seniors comes from family. This issue of *Expression* discusses the planning and decisions involved when adult children care for aging parents.

There are few ‘right’ or ‘wrong’ answers. Each family has different ways of dealing with issues and making decisions. Each parent is affected by aging differently. And each adult child has a different capacity to lend support.

Figuring out how to meet diverse needs and accommodate varying capacities takes open communication, careful planning and co-operation among family members. The process is challenging – physically, emotionally, financially – but it can also be tremendously rewarding, solidifying family bonds and deepening relationships in ways few other experiences can match.

**Joyce Thompson**  
NACA Member



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The National Advisory Council on Aging consists of up to 18 members from all parts of Canada and all walks of life. The members bring to Council a variety of experience and expertise to advise the federal Minister of Health, her colleagues and the public on the situation of seniors and the measures needed to respond to the aging of the Canadian population. Current NACA members are:

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## ■ Proceed with care

Caring for an aging parent can be as complex as providing round-the-clock care for a chronically or terminally ill parent or as simple as keeping in touch and minding your own business. One end of the spectrum represents a full-time commitment; the other is a hands-off approach. In between lies a range of possibilities:

- help with errands, appointments and household maintenance
- emotional support, e.g. regular contact through visits, phone and e-mail
- financial contributions
- arranging for and co-ordinating services provided by professionals.<sup>1</sup>

The right path for your family depends on many factors: your parents' state of health and ability to care for themselves; the capacity of you and your siblings to provide care of the type and extent your parents need; and the availability and suitability of other kinds of support. That's why it's so important to plan. Thinking about these questions before the need arises lets you talk things over calmly and explore options unhurriedly, making decisions based on what seems best for everyone, instead of in the heat of a crisis or medical emergency.

## ■ Laying the groundwork

As delicate as the subject might be, encourage your parents to discuss with you their wishes and preferences should they eventually be faced with physical or mental limitations. Some parents want to talk, so be ready to listen, but many belong to a generation that finds it hard to ask for help. On the other hand, they may be relieved you've raised the subject, realizing that planning lessens the strain on everyone.

<sup>1</sup> P. J. Wade. *Your guide to...caring for your aging parents*. Toronto: Coles Publishing, 2001.



No matter who initiates the conversation, you can facilitate the process by gaining a better understanding of your parents' views: listen and ask questions, try to avoid 'you should' statements; and keep the conversation flowing for as long as necessary – don't expect to resolve all the issues in an evening. Involve siblings and other family members, so that everyone's clear about your parents' wishes.

You'll need to do some homework: gather information, talk to friends and colleagues, enlist the help of a doctor, social worker or religious leader – someone whose opinion your parents respect. This is the time to ask if legal arrangements are in place – wills, powers of attorney, advanced health care directives and so on (see *Expression* Volume 14, Number 3). If none are in place, you may want to recommend professionals (an estate planner, lawyer, financial adviser, etc.) or an agency that co-ordinates these services.

As a potential caregiver, perhaps your most important preparation is personal: deciding how much you can take on, given your time, financial position and other responsibilities; rearranging commitments to accommodate caregiving; and lining up resources to support your caregiving efforts and your physical and emotional health.

If you're an employed caregiver, inquire about your employer's eldercare policies, discuss your situation with your employer

## What if...

Ability, rather than age, is the best indicator of need. Whatever your age, playing the 'what if' game can help decide in advance what level of intervention is desired. To facilitate discussing these issues with your caregivers or with your parents, try to imagine what you see as the desirable level of intervention in each of the following situations:

- Difficulty with basic tasks – walking, dressing, cooking
- Reduced cognitive skills – getting lost while driving, can't remember familiar names
- Neglecting hygiene or grooming
- Forgetting to pay bills, overdrawing a bank account
- Abruptly losing weight or appetite
- Losing interest in friends, social activities or hobbies
- Showing behaviour changes – depression, substance abuse, paranoia, combativeness

*Adapted from P. J. Wade  
(see page 8)*

and look for strategies to manage work and caregiving. Not all employers will be willing and able to accommodate your needs, but it's worth discussing.

As Canada's population continues to age, employers may become more receptive to providing work/life balance solutions.



## Preparing a caregiving plan

A detailed caregiving plan provides parents with the opportunity to express their wishes and preferences, encourages adult children to evaluate their own caregiving capacity, and helps establish priorities for the near future and the longer term. A caregiving plan can be revisited over time to ensure that it still reflects the wishes of parents and caregivers.



### For the adult sons and daughters:

If the planning task seems daunting, break it into manageable chunks. Start by making a list of the information needed for a plan and ask your parents to help you gather the information (you can also do the same for yourself!):

- location of documents, records and accounts (will, power of attorney, durable power of attorney for health care, health and other insurance policies, bank and investment accounts, funeral and burial arrangements)
- medical details (e.g., allergies, drugs being taken, chronic conditions, blood type)
- names and contact information for professional advisors: family doctor and specialists, dentist, lawyer, accountant, investment advisor, insurance broker, bank manager, religious leader
- names and contact information for social network: you and your siblings, other

relatives, neighbours, close friends, clubs, associations or place of worship where your parents are/have been members or volunteers

- services related to your parents' home – cleaning, snow removal, yard maintenance, building superintendent, property manager
- Home and community care supports – home care services, seniors' centres, meals on wheels, community care centres, support groups, local social services listed in the municipal pages of your phonebook
- Supports for caregivers – respite programs (in- and out-of-home), adult day centres, transportation services, support groups, counselling, information and education programs, workplace supports, tax relief, etc...

### For the parent:

Once the information gathering is complete, let your children/caregivers know about your preferences by providing clear written or oral directives about desired level of care and intervention for the situations described in the "What if..." textbox on page 3. Doing so will give you peace of mind and allow your loved ones to know in advance and prepare to give you the best of care according to your wishes.



## ■ Family ties

Playing a new role in your parents' lives takes adjustment on everyone's part. This isn't role reversal – you're not 'parenting' your parents. Your parents are adults with a lifetime of experience and opinions; as long as they're competent to make decisions and aren't endangering themselves or others, they're in charge. Treating them like children makes caregiving harder for everyone. Your criteria for decisions may differ from your parents' – you may value safety and health, while they prize independence.<sup>2</sup> Old age often brings losses; what you may perceive as stubbornness could be a normal response to loss and the desire to preserve dignity and autonomy.

Prepare for the emotional impact of caregiving: emotions can run high on both sides if parents fear losing independence or becoming a 'burden' on their children. Adult children may feel resentful of the extra responsibility and guilty about feeling resentful. Watching your parents age can be an unwelcome reminder of your own mortality. You may feel overwhelmed by the conflicting demands of parents and your other family responsibilities (spouse, children, grandchildren). Everyone needs to be clear about expectations – parents about what kind of help they want, and children about what kind of help they can give.

### Caring long-distance

If you live far away and your parents have no close relatives living nearby, you can work with them to set up a network of friends, neighbours and professionals that they trust and can rely on for help as needed. Give some thought to how to nurture that network from afar so that it continues to respond to your parents' changing needs as they age. As needs become more numerous and complex, you can enlist help from the local community health agency or a specialized eldercare agency. Family members living far away can share responsibility by doing jobs such as bill-paying, taking care of legal matters, or researching issues and services; they can also offer emotional support through regular phone calls, letters, cards and e-mails.

**Bart Mindszenty and Michael Gordon** caution that sometimes in their zeal to help their parents, children make decisions that are well intentioned but actually serve to disrupt tried and true lifestyles, resulting in increased family tension and parental angst.<sup>3</sup>

Accommodating your parents' decisions will not only smooth relations with them

<sup>2</sup> The Healthy Caregiver Magazine, 21 January 2002, [www.healthycaregiver.com](http://www.healthycaregiver.com).

<sup>3</sup> Bart Mindszenty and Michael Gordon. *Parenting your parents*. Toronto: Dundurn Press, 2002.



but may also bring benefits. Giving up the struggle to be ‘right’ helps resolve old conflicts and forge new bonds. The result can be a deeper connection, offering all the rewards of ‘giving back’ care and support you received as a child while establishing a new relationship based on understanding and sharing information.



## ■ Be good to yourself

While caregiving has compensations, it can also be a very difficult and draining experience. You’ll find it much easier to cope with the mental and physical strain if you take care of your own emotional and spiritual health. And you won’t be able to provide care at all if your physical health breaks down. To be a good caregiver, you have to take good care of yourself: set limits on what you’re prepared to do; schedule regular time for yourself; be alert to emotions such as guilt and anger and the possibility of depression; reach out for support.

If you have siblings, work with them and other family members to apportion responsibilities, taking their resources and capacities into account. Ask friends for understanding – you may not have as much time to spend with them as before, but you still value their support through phone calls or e-mails. Seek out community resources – meals on wheels,

daycare, respite care for a day or a weekend off from caregiving, help with transportation to appointments, and emotional sustenance from a caregivers’ support group.

When you share your experiences in a support group, you’ll feel less isolated and you’ll gain practical advice about caregiving.

## ■ Caregiving 101

Caring for aging parents is a process, not an event: patterns of caregiving change as physical, health and financial pressures exert their influence. A caregiving plan might kick into action gradually at first, starting with helping your parents while they still live in their own home – running errands, checking for and eliminating safety hazards, and doing home maintenance.

As parents’ abilities change, care might expand to include help with personal hygiene, preparing or delivering meals, driving to and from appointments and activities. Changing mental abilities may require yet another level of care – such as help with finances. Parents don’t need to give up all responsibilities at once; options such as ‘companion’ credit cards and joint bank accounts can ease the transition.

But the transition could also be rapid or unexpected. Even if your parents are in perfect health when you start planning,



statistically one or more health problems is likely to arise after the age of 65 – cardiovascular disease, stroke, Alzheimer’s, various cancers, injuries from falls, and disabilities associated with aging or chronic conditions such as arthritis and diabetes. Understanding these conditions is an important element of caregiving; whether the condition is life-threatening or chronic, learn what can be done to prevent, control or manage it (see *For more information...*).

Knowledge helps you support your parents’ decisions about their care or take on more responsibility for decisions as parents become less able to make them. Look for support through partnerships with health professionals you all trust.

Caregiving changes when staying at home is no longer an option; now your role is to support your parents as they consider options. Should they move in with you? Or should they consider assisted living facilities, supportive housing, seniors’ residences or a nursing home? Many publications offer tips on choosing among the options (see *For more information...*). Discuss the issue before the need becomes urgent, so everyone will agree when it’s time.

## ■ Caring until the end

Planning also helps families care for parents, at home or in hospital, as they are dying. Arrangements made in advance –

health care directives for medical treatment and life support, discussions about how much medical intervention is enough – let parents influence decisions when they’re no longer capable of expressing their wishes. They also reduce the likelihood of disputes among family members, so caregivers can concentrate on saying goodbye and helping the parent experience a ‘good death’, as the parent defines it. Similarly, having plans in place for organ donation, a funeral, and burial or cremation eases the pressure at a time when grief and fatigue strain decision-making powers to the limit. Caregivers and close family can then focus on comforting each other.

## ■ A valuable experience

Like many of life’s challenging experiences, caring for an aging parent can help us grow in our understanding of ourselves and our compassion for others. A parent’s death leaves a void. The hours you spent in caregiving can now be devoted to something else – re-evaluating your dreams and goals for your own life, reconnecting with those you may have neglected while caregiving, thanking those who supported you, thinking about the legacy your parent has left you, reaching out to a caregiver who’s going through what you did, and last but not least, thinking about your own future need for care and starting to plan for yourself.



## For more information...

Alzheimer Society of Canada. *Alzheimer Disease: A Handbook for Care*. Toronto: Alzheimer Society of Canada, 1991.

Henderson, Karen. "The dichotomies of caregiving: Mental health challenges of informal caregivers" in *Writings in Gerontology, Mental Health and Aging* (18). National Advisory Council: Ottawa, 2002.

Mindszenty, Bart and Michael Gordon. *Parenting Your Parents*. Toronto: Dundurn Press, 2002.  
A thorough guide: vignettes illustrate typical family situations; an excellent planning guide is provided as well as resource lists by province and territory.

Molloy, W. *Caring for Your Parents in Their Senior Years: A Guide for Grown-Up Children*. Toronto: Firefly Books Limited, 1998.

National Film Board of Canada. *Labour of love*. A video presenting five intimate profiles of caregivers and their families, filmed over a one-year period (includes a guide). 1998. 45 minutes.

Wade, P.J. *Your Guide to...Caring for Your Aging Parents*. Toronto: Coles Publishing, 2001.  
Offers practical advice on managing day to day and tips for finding the best residence or institution.

## Online

Local chapters of the Alzheimer Society of Canada, the Canadian Cancer Society, and the Caregiver Network are a good place to find support groups. If you can't get to a meeting, online forums are available.

Alzheimer Society of Canada 1-800-616-8816  
[www.alzheimer.ca](http://www.alzheimer.ca)

The Arthritis Society 1-800-321-1433  
[www.arthritis.ca](http://www.arthritis.ca)

Canadian Cancer Society 1-888-939-3333  
[www.cancer.ca](http://www.cancer.ca)

Canadian Home Care Association (613) 569-1585  
[www.cdnhomecare.on.ca](http://www.cdnhomecare.on.ca)

The Caregiver Network (416) 323-1090  
[www.caregiver.on.ca](http://www.caregiver.on.ca)

Hints for caregivers (New Brunswick Department of Family and Community Services)  
[www.gnb.ca/0017/Seniors/hints-e.asp](http://www.gnb.ca/0017/Seniors/hints-e.asp)



**Joyce Thompson** has broad knowledge and experience across a number of areas of the health care system, including medical services, public health, home care, and long-term care. She is currently manager of Insured Medical Programs with the Prince Edward Island Department of Health and Social Services. Ms. Thompson is past president of the Nurses Association of Prince Edward Island and the New Brunswick–Prince Edward Island Branch of the Canadian Public Health Association, and continues her involvement in many professional and community organizations. She has a keen interest in seniors and a sound understanding of issues surrounding aging. Ms. Thompson was first appointed to NACA in 1997, then appointed again to Council in September 2002.