



Preparing For The Future: Where There's A Will, There's A Way[®]

Tuesday July 10, 2018





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MS Society of Canada

- **Mission Statement:** To be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.



Long Term Care
PLANNING NETWORK

***Preparing For The Future:
Where There's A Will, There's A Way©***

Presented by Karen Henderson

For The MS Society

July, 2018

Agenda

- Long Term Care/Planning
- The 10 – Step Long Term Care Planning Process
- Resources



Limitations Of This Presentation

- Since this is a national webinar:
 - Terminology may be different from what you know
 - Care/equipment/housing costs/rates cannot be specific to any province
 - Resources cannot be specific to any province
- I know I am speaking to a mixed audience **BUT** long term care planning applies to all Canadians regardless of present health status
- Some questions were sent in ahead of today; I will do my best to address what I can at the end





What Is Long Term Care?

- A variety of services provided to people with a prolonged illness, disability, or cognitive impairment such as Alzheimer's disease
- Intended to help a person maintain present level of functioning - not cure medical problems: **care not cure**
- Takes place at home, in hospital/rehabilitation centre or a long term care facility.



What Is Long Term Care?

- Most long term care is not medical; it provides assistance with the basic everyday tasks of life, called the Activities of Daily Living (ADLs):
 - Bathing
 - Eating
 - Dressing
 - Toileting
 - Transferring
 - Continence



How Long Does Long Term Care Last?

NOT:

- The number of years of care in the home—no-one tracks family caregiving here
- The number of years in a care facility (average nursing home stay is 2-3 years)

THE REAL ANSWER? No-one knows



Who May Need Long Term Care?

- **Age** – As you live longer, your risk generally increases
- **Marital Status** - Single people are more likely to need care from a paid provider
- **Gender** - Women are more likely than men to need long-term care, primarily because they tend to live longer
- **Disability**
- **Lifestyle** - Poor diet and exercise habits can increase your risk
- **Health and Family History** – A family history of poor health may increase your risk
- **Living Arrangements** - living alone



What Is Long Term Care Planning?

A 10 – step process through which you:

1. Determine how you will look after your health
2. Decide how/where you want to live – a workable home environment
3. Understand the health care system where you live
4. Understand the role of governments in the provision of care services, accommodation and funding
5. Decide who you can count on for help
6. Organize, manage and store all information
7. Have a plan for emergencies
8. Create an advance care/end-of-life plan
9. Communicate and update the plan regularly
10. Celebrate the good days



Step 1: Determine How You Will Look After Your Health/Self

- Knowledge: how you will keep up with MS research/developments
- Attitude/emotions: how you will deal with the grief, denial, sadness or anxiety—how you will cope with the disease
- Brain: help your memory with tools like a digital recorder, cell phone camera, calendar
- Stress: learn what works for you
- Exercise: build a program (with a physio) that works for you/try and stick with it
- Diet: eat a balanced, healthy diet-Mediterranean
- Assistive devices: use appropriately



Go for it!



*A guide to choosing and
using assistive devices*



Public Health
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Agence de la santé
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Canada

Step 1: Determine How You Will Look After Your Health/Self—Other Coping Skills

- Anticipate potential problems before they happen e.g. if you like to food shop, but the store is too big or chaotic, choose smaller shops or shop in the early morning/late at night
- Plan for things outside of your regular routine e.g. know when people are coming for a visit so you can prepare
- Be proactive about medical apts; ask for special times so neither you or your caregiver have to rush
- If you have a communication problem, prepare a sheet on how best to communicate with you
- Don't be afraid to reschedule



Step 2: Decide How/Where You Want To Live—A Workable Home Environment

- Do you live in a two-story house with the only bathroom upstairs?
- Do you have a massive yard that requires regular care?
- A small apartment or condo might allow you to live independently longer
- However—take the time to evaluate your present home environment before considering a move
- Consider home modifications
- Remember: It helps to work through some of these issues before a crisis comes and forces a quick response



Step 2: Decide How/Where You Want To Live—Home Modifications

- Eliminate throw rugs
- Ease entrances and exits
- Replace door knobs with levers
- Simplify stairs
- Make room to maneuver
- Plug in and turn on without hassle
- Install an intercom system to make room-to-room communication easier






Public Health
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THE SAFE LIVING GUIDE

A black and white illustration within a circular frame. An elderly woman with glasses, wearing a patterned dress and a hat, is walking on a wooden floor. She is carrying a tray with a teapot and two cups. She is tripping over a dog that is lying on its back on the floor. The dog's head is in the foreground, and its body extends towards the woman. The woman's legs are in the air, and she has a look of surprise or concern. The background is a simple floor with some lines suggesting perspective.

A guide to home safety for seniors

Canada

Step 2: Decide How/Where You Want To Live —Plan For Transportation Options

- Get an accessibility parking permit as soon as possible
- Sign up for your provincial Wheeltrans service as soon as possible
- If applicable, investigate car modification



Step 3: Understand The Health Care System Where You Live: The Care Continuum

1. Home care
2. Retirement home living
 - Independent living - self-contained apartment-style accommodation geared to seniors who are able to live autonomously
 - Assisted living/supportive housing/enhanced residential care
 - Memory care
3. Long term care/Alzheimer care
4. Hospice/palliative care



Step 3: The Care Continuum—The Realities of Home Care

- Home care is not an insured service under the Canada Health Act
- There is a glaring lack of investment in home care and home supports
- Public system offers a limited number of hours
- Private pay home care hourly: \$25+; nursing care \$60



Step 3: The Care Continuum—Care Equipment Costs

Wheelchairs

- \$200-\$5000

Electric hospital beds

- \$3,000 to \$5,000

Scooters

- \$2,400 to \$5,000

Walkers

- \$100 to \$450

Bath lift

- \$1,200

Ramps

- \$200 to \$8,000

Medication dispensing machines

- \$25-\$300



Step 3: The Care Continuum—Independent Living/Retirement Homes

- Privately-run facilities that provide accommodation, social events, meals, housekeeping etc.
- NO government subsidies
- Minimal care provided; you pay extra for more care
- Tenancy arrangement; monthly costs: \$2000-\$7000 depending on whether it's a private room or suite.



Step 3: The Care Continuum—Assisted Living/Supportive Living

- Personal care provided for a fee
- May be a nurse on staff
- Meals provided in the dining room
- Rates: more expensive than retirement home living



Step 3: The Care Continuum—Memory Care

- Enhanced security
- Care/specialized programs for seniors with dementia
- Rates: similar to retirement homes



Step 3: The Care Continuum—Long Term Care Facilities

- Owned/operated by municipalities, religious organizations or for-profit organizations BUT regulated by provincial governments
- Fees and waiting times vary by province



Step 4: Understand The Role Of Governments In The Provision Of Care Services, Accommodation And Funding

- Provincial governments cover physician, hospital and various diagnostic/treatment services
- All taxpayers entitled to **basic** care in the home
- Co-payment for facility care
- No Canadian will be turned away from a long term care facility due to inability to pay.



Step 4: Understand The Role Of Governments In The Provision Of Care Services, Accommodation And Funding

- No compensation for family caregivers even though they provide 80+ per cent of home care
- No national standards for facility care
- No national home care program
- No national pharma-care program.



Step 5: Decide Who You Can Count On For Help—The Care Planning Conversation/Family Meeting

Why?

- Concerns about the health/safety/independence of a family member

When?

- **Before a crisis occurs**

How?

- Create an agenda
- Gather family members concerned—who can/will do what
- Make decisions - reach a consensus
- Continue to communicate/update.



Step 5: Decide Who You Can Count On For Help—Plan For Personal Care

- Develop a daily routine, especially if you suffer from cognitive difficulties
- Invest in adaptive clothing, as buttons/zippers/shoe laces become more problematic
- Be honest about communication challenges; discuss what is changing and what continues to be possible, or not
- Talk about about what each person wants, expects—what is realistic



Step 5: Decide Who You Can Count On For Help—Plan For Effective Caregiving

Research and make use of helpful community services:

- Adult day services
- Hired companions and homemakers
- Meal programs
- Case managers
- Physical, occupational, speech therapists
- Respite care workers
- Transportation services

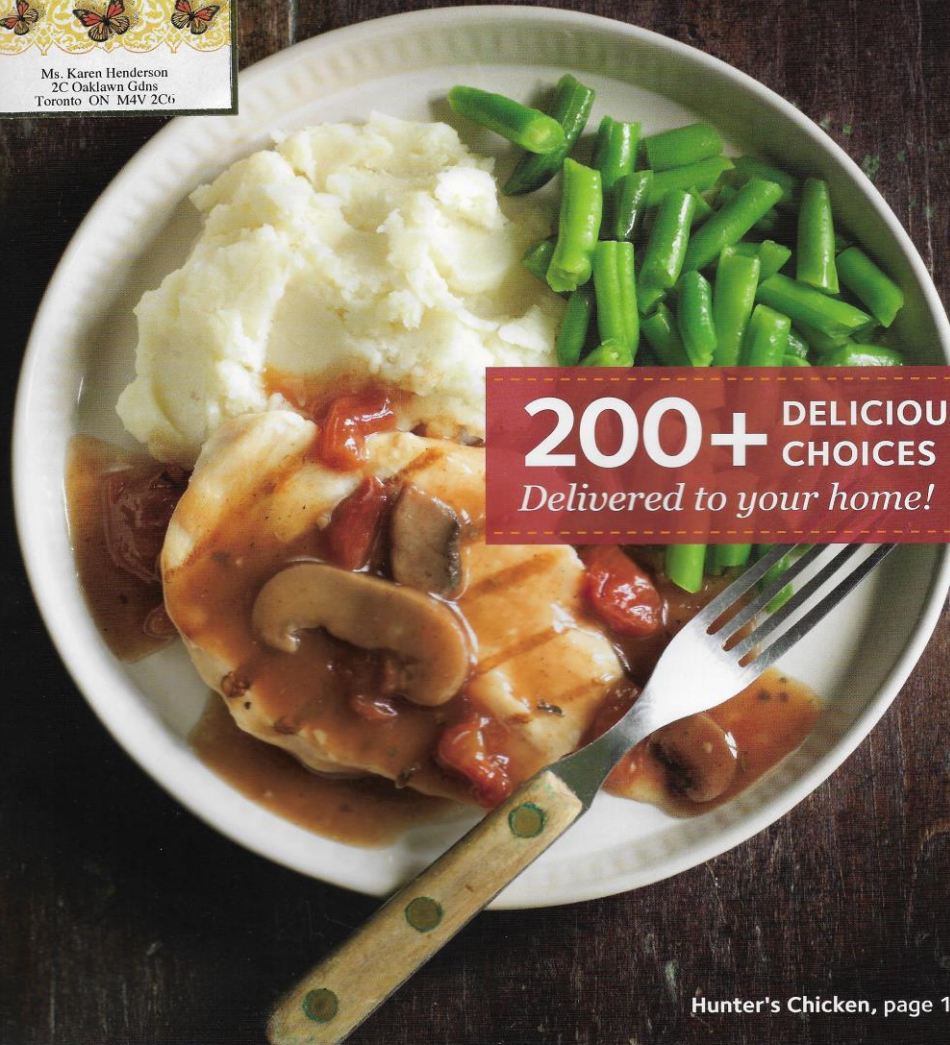



**HEART TO
HOME MEALS**
DELICIOUS MEALS MADE FOR SENIORS™

FALL 2017
WINTER 2018

My Menu


Ms. Karen Henderson
2C Oaklawn Gdns
Toronto ON M4V 2C6



200+ DELICIOUS
CHOICES
Delivered to your home!

Hunter's Chicken, page 18

Step 5: Decide Who You Can Count On For Help—Plan For Effective Caregiving

You and your caregiver should:

- Keep a health journal-work together
- In the journal write down appointments, phone numbers, medications, contacts, and questions you want to ask the doctor
- Keep track of symptoms and any reactions to medications
- Date all entries so you can both remember what happened a month ago, a year ago
- Your caregiver's observations are key because nobody knows you better than your caregiver.
- Be proactive about medical apt. times



Step 5: Decide Who You Can Count On For Help—Plan For Effective Caregiving

If you are a caregiver:

- Take time for yourself, keep doing the things you love
- Take things one day at a time
- Don't beat yourself up if something doesn't work
- Realize you cannot be a caregiver for everyone in your family; if you have aging parents who need/will need care, decide how you can help without endangering your own health/well being
- You can only do your best



Step 6: Organize, Manage And Store All Information: Personal Information

- Personal information – social and family
- Family medical history
- Biographical notes
- Medical Information



Step 6: Organize, Manage And Store All Information: Financial Information

- Work with a financial advisor—talk about the end of earned income and the possibility of retiring involuntarily
- Analyze and adjust spending habits
- Downsize home/cars if necessary
- Plan for your spouse/possible insurance options
- Review life insurance policies to see if they have disability riders; ensure that premiums are paid and that the beneficiaries are correct.



Step 6: Organize, Manage And Store All Information: Financial Information—Joint Bank Account

- A bank account in which two or more people have ownership rights over the same account. These rights include the right for all account holders to deposit, withdraw, or deal with the funds in the account, no matter who puts the money into the account
- Joint accounts may include the right of survivorship. This means that if one of the account holders dies, the surviving account holder becomes the owner of the account, with the right to deposit, withdraw, and deal with the funds in the account



Step 6: Organize, Manage And Store All Information: Financial Information—Long Term Care Funding Options

- Provincial government
- Personal savings/investments
- Supplementary health insurance
- Downsizing
- Reverse mortgage



Step 6: Organize, Manage And Store All Information: Financial Information—The Disability Tax Credit (DTC)

- Work with an accountant who understands how to take advantage of all available disability credits like the DTC
- A non-refundable tax credit that helps persons with disabilities or their supporting persons reduce the amount of income tax they may have to pay
- Mandatory first step which opens doors to other federal, provincial or territorial programs such as the registered disability savings plan, the working income tax benefit, and the child disability benefit.



Step 6: Organize, Manage And Store All Information: Legal Information—Your Will

- Every adult should have a current will, regardless of marital status or existence of children
- Request your lawyer to make your will probate ready (name the beneficiaries, joint tenancy bank accounts with right of survivorship), so when you pass away, funds can be transferred more quickly



Step 6: Organize, Manage And Store All Information: Legal Information—Your Powers of Attorney (POA)

- Two types of POA—one for finance and one for personal care
- If not completed already, do the paperwork with your lawyer as soon as possible
- Cognitive difficulties can sneak up gradually; if you cannot answer a lawyer's questions to his satisfaction, he may refuse to create the documents



Step 7: Have A Plan For Emergencies

- Keep a first aid kit in your home, car, cottage
- Always know where the nearest hospital is
- Keep Ontario Poison Centre number handy: 1-800-268-9017
- Keep a card in your purse/wallet with emergency numbers
- Post vital information for paramedics on the refrigerator, including:
 - Name of your substitute decision maker/POA For Personal Care
 - Details of your health condition(s)
 - Information (signed by your doctor) that you have a DNR if you have chosen this approach

DNR: Do - Not – Resuscitate



Step 7: Have A Plan For Emergencies —If You Have To Go To The Hospital

- **Check your wristband.** Make sure the information on your wristband—your name plus any drug allergies—is accurate
- **Insist on clean hands.** Expect anyone who touches you—including your visitors—to first wash his or her hands with soap or an alcohol-based solution
- **Make a drug list.** Make sure your attending doctor knows that you want to be told the name of each new medicine given to you as well as its intended purpose and possible interactions



Step 7: Have A Plan For Emergencies —If You Have To Go To Hospital

- Have a family member/friend there at all times if possible
- Keep a notebook/pen by the bed; ask all staff to record their name/title
- Record all questions/answers in the notebook
- Be proactive about discharge planning; ask to speak to a social worker/case manager ASAP
- Find out what your insurance covers
- Make sure you understand all medications and equipment needs *before* leaving the hospital



Step 8: Create An Advance Care/End-of-Life Plan

- Advance care planning helps ensure you get the medical care you would want, if you are unable to speak for yourself and doctors and family members are making the decisions for you
- These preferences are often put into an advance directive, a Power of Attorney for Personal Care (ON), a Representation Agreement (BC) or Personal Directive (AB)



Step 8: Create An Advance Care/End-of-Life Plan

- Advance care planning is about conversations, decisions, and identifying:
 - who will look after your financial affairs/property
 - how you would like to be cared for
- It reflects life changes, and so may reflect a person's wishes for care over time
- The person(s) you choose to act on behalf of you/your wishes is your substitute decision maker/agent/representative



Step 8: Create An Advance Care/End-of-Life Plan—Power of Attorney for Property

- Your attorney can act for you in financial dealings, such as banking, signing cheques, buying or selling real estate, and buying consumer goods
- You must be mentally capable at the time of signing
- Each province and territory has its own laws relating to Powers of Attorney. You need to follow the law in the province or territory where you live.



Step 8: Create An Advance Care/End-of-Life Plan—Power of Attorney for Personal Care/Personal Directive/Representation Agreement

- Document through which you appoint your substitute decision-maker(s)/agent
- Can only be used if you become incapable
- Details your wishes about anything related to your personal care:
 - where you want to live
 - what you want to eat/wear
 - kind of health care you want
 - grooming preferences
 - how you want your safety ensured.



Step 8: Create An Advance Care/End-of-Life Plan—Care Decisions That Could Come Up

- CPR (cardiopulmonary resuscitation)
- Ventilator use
- Artificial nutrition (tube feeding) and artificial hydration (IV, or intravenous, fluids)
- Comfort care at end of life
 - physical comfort, mental and emotional needs, spiritual issues, and practical tasks.



Step 8: Create An Advance Care/End-of-Life Plan—Planning For Organ Donation

- Although people with multiple sclerosis can't give blood or donate bone marrow, the donation of organs is allowed
- Reasoning: the recipients of organs can be told about the donor and are in a position to accept any associated risks—with blood transfusions this is not possible.



Step 8: Create An Advance Care/End-of-Life Plan—Keep Your Health Directives Up To Date

The American Bar Association Commission on Law and Aging suggests that you re-examine your health care wishes whenever any of the following "five d's" occurs:

- Decade: When you start each new decade of your life.
- Death: When you experience the death of a loved one.
- Divorce: When you experience a divorce or other major family change.
- Diagnosis: When you are diagnosed with (another) serious medical problem.
- Decline: When you experience a significant decline or deterioration from an existing health condition, especially when it diminishes your ability to live independently.



Step 8: Create An Advance Care/End-of-Life Plan—Understand MAID – Medical Assistance In Dying (June 2016)

- Because families often struggle with financial matters during an extended illness, it is important to plan beforehand
- Total MAID deaths as of June 2018: 3714
- Who is eligible (18+)
 - Has a serious and incurable illness, disease, or disability
 - Endures physical and psychological suffering that is intolerable to them
 - Their natural death has become reasonably foreseeable
 - Must be capable of providing informed consent at the time that MAID is provided.
- Average age: 73. Oldest: 104
- Main causes: cancer, neurological, cardiovascular



Step 9: Communicate And Update Your Plan Regularly

Creating your plan will take time and effort, but once it is completed, you will have accomplished two very important goals:

1. You will have added the missing piece to any retirement planning you may have done
2. You will have removed a huge burden from your family; over time you all will be thankful that you took the initiative to plan ahead



Step 10: Celebrate The Good Days

- Take things one day or week at a time
- Find things to do together
- Create a 'good day' list of things you can do on a good day
- TVO features wonderful documentaries
- Listen to music together
- Use a Kobo/Kindle reader; share a book and talk about it



What Long Term Care Planning Gives You...

- The ability to act and make effective decisions while you are still able
- Control over:
 - How much care you receive
 - The quality of care you receive
 - Who delivers that care
 - Where that care is delivered
 - For how long that care can be delivered
- INDEPENDENCE DIGNITY CONTROL

Priceless.



Long Term Care
PLANNING NETWORK

Remember Two Things...

- 1. TO RETAIN YOUR INDEPENDENCE, YOU MUST LEARN TO ASK FOR AND ACCEPT HELP**
- 2. THE BEST TIME TO PLAN FOR LONG TERM CARE?
BEFORE YOU NEED IT**



Resources – Federal Government

- **Blood, Organ and Tissue Donation**

www.canada.ca/en/public-health/services/diseases/blood-organ-tissue-donation.html

- **The Safe Living Guide: A Guide to Home Safety for Seniors**

Health Canada

phac-aspc.gc.ca/seniors-aines/publications/public/injury-blessure/safelive

securite/index-eng.php

- **Go for it! A guide to choosing and using assistive devices**

Health Canada

www.veterans.gc.ca/eng/services/health/promotion/fallsp/goit



Resources – Federal Government

- **Disability Tax Credit**

www.canada.ca/en/revenue-agency/services/tax/individuals/segments/tax-credits-deductions-persons-disabilities/disability-tax-credit.html

- **DTC: Opening Doors**

www.investmentexecutive.com/newspaper_/building-your-business-newspaper/dtc-opening-doors/

- **Registered Disability Savings Plan**

www.canada.ca/en/revenue-agency/services/tax/individuals/topics/registered-disability-savings-plan-rdsp.html



Resources - General

- **The Care Guide** www.thecareguide.com
- **Long Term Care Residential Rates**
www.thecareguide.com/residence-options/long-term-care/costs/cost-of-long-term-care
- **From Patients Who Know: A Hospital Handbook**
http://uhnopenlab.ca/wp-content/uploads/2016/10/Hospital-Handbook_eBook_2016-08-24.pdf
- **Speak Up! Advance Care Planning** www.advancecareplanning.ca
- **Alternative Home & Vehicle Modification Programs**
www.marchofdimes.ca/EN/programs/hvmp/Pages/NationalProvincialHMPrograms.aspx



Resources - General

- **The AdvoConnection Directory** - To locate private patient advocates
<http://advoconnection.com>
- **Age Comfort** agecomfort.com. Home care/assistive devices
- **When Love Gets Tough: The Nursing Home Decision** by Doug Manning
- **Caring For Loves Ones At Home** legacies.ca
- **Home and Long Term Care Magazine** <http://homeandlongtermcare.ca>
- **Heart to Home Meals** www.hearttohomemeals.ca
(Ontario and Alberta)



Resources – General

- **Getting Funding for Accessibility Equipment in Canada**
www.silvercross.com/getting-funding-for-accessibility-equipment-in-canada/
- **Adaptive Clothing Canada** www.adaptiveclothingcanada.com
- **Silvert's Adaptive Clothing/Footwear** www.silverts.com
- **I need to find a more satisfying way to live with MS**
<http://trk.cp20.com/click/e7a4-qkqo9-fehsh-912608s4/>
- **Seniors tell us what it's really like to live in long term care**
www.cbc.ca/radio/whitecoat/seniors-tell-us-what-it-s-really-like-to-live-in-long-term-care-1.4450594



Karen's Long Term Care Planning Educational Tools And Resources

- **Long Term Care Planning Network** www.ltcplanningnetwork.com
- ***It's never too early to start the care conversation...A Guide For Adult Children & Their Parents***
- **Long Term Care: A Practical Planning Guide For Canadians**
- **The Critical Illness/Long Term Care Planner**
- **The 10 - Step Long Term Care Planner.**



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Specialists in helping Canadians understand the implications of long term care on personal, professional and financial well-being.

