

**Disconnecting
from change
does not
recapture the past.
It loses the future.**

—Kathleen Norris



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PLANNING AHEAD

Perhaps you have put off writing a will, or preparing other legal tools that will help your family deal with decision-making when you are no longer able to make your own decisions. However, a diagnosis of any serious health problem can bring you face-to-face with your own mortality. A diagnosis of dementia highlights the need to think clearly about the short and long-term future. The time to plan is now!

IN THIS SECTION YOU WILL LEARN ABOUT:

- “Planning for the Future”: this timeline will help familiarize you with some important health care decisions.
- “Ready Set Plan”: a checklist to help you decide whether you and your family have dealt with some important planning issues.
- “Medical Profile - Admission to Hospital”: a place to document important medical and personal information that can assist in your care in the event that you need to go to the hospital.
- A section outlining some important considerations regarding driving.

Taking care of future planning is a gift that we can all give to our family and friends.

You need to inform someone in your immediate circle of family and friends about your decisions when you have made them— especially since you may be relying on them for help in the future.

Nothing in this workbook can replace you seeking independent legal and financial advice about your particular circumstances.

PLANNING FOR THE FUTURE

Planning for the future is a positive step you can take towards helping yourself and your family cope with the diagnosis of Alzheimer’s Disease or a related dementia, and prepare for what lies ahead. You may still be independent, but as the disease progresses, your ability to make your own decisions will decline.

Planning for Health Care Decisions

PLANNING FOR SAFETY	FINANCIAL PLANNING	PLANNING LIVING ARRANGEMENTS	END-OF-LIFE DECISIONS	FUNERAL
Driving assessment Home safety Getting home again if you get lost	Tax credits Insurance Joint names on bank accounts, safety deposit box Name someone you trust to look after your financial interests	Accessing Services Placement Relationship with Long-term Care Case Manager	Write down your wishes for end of life decisions Name substitute decision-maker to make health care decisions for you Make legally-binding end-of-life decisions	Funeral Plans (Pre-Arranged) Will
TIMELINE				
			PERIOD OF INCAPACITY	DEATH

Ready Set Plan

This checklist will help you to decide whether you and your family have dealt with some important planning issues.

Have you thought about..... Financial and Legal Affairs?

Financial and Legal Affairs	Yes	No	Where to get more information
Ensuring that someone you can trust can access your bank account and safety deposit box			Bank or credit union, Lawyer, Notary
Making and registering an <i>Enduring Power of Attorney</i>			Legal Information Society of Nova Scotia, Nova Scotia Public Trustee, Lawyer, Notary
Making and registering a will/ review executor (s)			Lawyer, Notary
Appointing a guardian for minor children			Lawyer or Notary
Reviewing beneficiaries in life insurance, RRSP's RRIF's, pensions, etc.			Financial or Investment Advisor
Informing your family of wishes/ plans to avoid potential disputes. Making a list of personal items and who you'd like to receive them.			
Completing the <i>Authorizing or Cancelling a Representative</i> form for CRA (T1013 - gives permission for someone else to access your tax information)			Canada Revenue Agency
Applying for applicable tax credits			Canada Revenue Agency
Developing a financial plan. If you own a business, develop a business management succession plan.			Financial Advisor
Reviewing insurance needs (e.g. house, life, car or long-term care insurance)			Lawyer, Notary or Financial Planner
Including a charitable gift as part of your estate planning.			Lawyer, Notary or Financial Planner

The content of the handout is provided as an information resource only and does not provide legal advice. Please consult your lawyer, notary and/or financial advisor to ensure your financial, estate, and health care planning is appropriate for your needs.

Have you thought about.... Health Care and Personal Affairs?

Health Care and Personal Affairs	Yes	No	Where to get more information
Making a Personal Directive			www.gov.ns.ca/just/pda
Communicating end-of-life care choices to your representative and family			
Filling out the form: Medical Profile for Admission to a Hospital			Alzheimer Society of NS (a copy is in this workbook)
Labeling your keys and ensure there is a duplicate set in a known location			
Discussing with family plans for ceasing driving now or in the future			DriveABLE, Your Physician, www.notifbutwhen.ca
Preparing a file with your important papers and information such as:			
<ul style="list-style-type: none"> • your birth date and ID numbers (e.g. SIN, MSP, driver's license) 			
<ul style="list-style-type: none"> • names of financial and legal advisers, representative(s) under power of attorney and/or personal directive, executor(s) 			
<ul style="list-style-type: none"> • your health professionals such as doctor and dentist 			
<ul style="list-style-type: none"> • prescriptions, medical conditions, allergies and medications 			
<ul style="list-style-type: none"> • phone numbers of family and other important people 			
<ul style="list-style-type: none"> • location of will, power of attorney, etc. 			
<ul style="list-style-type: none"> • list of assets, deed(s), insurance policies 			
<ul style="list-style-type: none"> • bank account and investment account numbers, location of safety deposit box, security codes for home safe, credit card numbers and expiry dates 			
<ul style="list-style-type: none"> • passwords (e.g. email, computer, voicemail, other secured information) 			

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Medical Profile – Admission to Hospital

The following pages (labeled Medical Profile - Admission to Hospital) provide a space for you to document important medical and personal information that can assist in your proper treatment and care in the event that you need to go to the hospital. You can copy or remove these pages from your **Shaping the Journey: living with dementia™** workbook and/or share their location with your family members.

BASIC INFORMATION

Name:		MSI Number:	
DOB (mm/dd/yyyy):		Home Address:	
Home Phone:		Home Contact (Name):	
Other Family Contact (Name):			
Relationship:		Phone:	
Specialist	Phone Number	Fax Number	
Community Nurse:			
Occupational Therapist:			
Physiotherapist:			
Other:			
Specialist:			
Specialist:			
Case Worker:			

PERSONAL CARE / POSITIONING / OTHER RESOURCES

Health Issues: (Medical/ Surgical/ Emotional/ Psychiatric/ Allergies/ Tendency to Wander):

Medical Profile – Admission to Hospital

The following pages provide a space for you to document important medical and personal information that can assist in your proper treatment and care in the event that you need to go to the hospital.

Special Considerations for Treatment: (e.g. - is the person with dementia likely to be particularly anxious and confused by a visit to the hospital—explain)

Positioning: (attach pictorial guidelines if complicated)

Information about particular sleeping positions or seating issues

Other important people involved in this person's life:

Name: _____ Ph: _____ Relationship: _____

Name: _____ Ph: _____ Relationship: _____

Name: _____ Ph: _____ Relationship: _____

Name: _____ Ph: _____ Relationship: _____

EATING / COMMUNICATION / SIGHT / HEARING

Does this person have any food allergies? Yes No

If yes, please list all allergies: _____

Does this person have coughing/choking episodes during meals? Yes No

Do they have swallowing difficulties? Yes No (if yes, what are the mealtime guidelines)

Food Texture: Regular Cut up Minced Pureed

Other Information: _____

Does this person require a special diet? Yes No

Regular Cardiac PKU High Fibre Anti-reflux

Fluids: (if not regular) Regular Thickened Thickening agent: _____

How does this person communicate?

Verbal Non-verbal Yes / No Response Communication Aid

Please describe communication methods in detail: _____

Medical Profile – Admission to Hospital

The following pages provide a space for you to document important medical and personal information that can assist in your proper treatment and care in the event that you need to go to the hospital.

Describe any unique way of communicating or behaving and the best way to respond:

Behaviour

Response

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

Hearing Impairment: Yes No

Hearing Aid: Right Left N/A

Visual Impairment: Yes No

Glasses: Yes No Contacts: Yes No

Medical Profile – Admission to Hospital

The following pages provide a space for you to document important medical and personal information that can assist in your proper treatment and care in the event that you need to go to the hospital.

HEALTH ISSUES / CONSENT FOR TREATMENT / CURRENT MEDICATION

Lifts and Transfers Required: Independent Requires Assistance

Mobility Aids: Wheelchair Walker Cane Other: _____

Bathing: Independent Requires Assistance Dependent

Dressing: Independent Requires Assistance Dependent

Oral Hygiene: Independent Requires Assistance Dependent Dentures

Bladder Function: Continent Incontinent Incontinence Products:

Bowel Function: Continent Incontinent Diarrhea Constipation

Elimination Routines: Regular toileting every __ hours Incontinence Pads
(day night)

Sleep Patterns: Nothing unusual Sleep disturbances:

Safety Requirements: Information

Skin Care: Pressure areas:

Wounds or sensitive areas:

Skin Products:

*** Representative or Committee:**

*** The name of the person appointed TSDM in a Personal Directive if this person cannot give informed consent for treatment:**

Name _____ Ph: _____ Relationship: _____

Current Medications—Keep this up to date

MEDICATION	DOSE	ROUTE	FREQUENCY	LAST DOSE	SPECIAL CONSIDERATIONS

Name: _____ Signature: _____ Date: _____

DRIVING

Dementia causes changes that will, eventually, affect a person's ability to drive safely. Driving requires concentration, judgment, and the ability to reason and make decisions. All of these become impaired in people with dementia.

Dementia is a journey of losses. As one of the first major losses, driving is perhaps one of the most difficult to cope with. Managing this loss well can set the foundation for dealing with the other losses resulting from this disease.

If you have dementia, or support someone living with dementia, the following will provide information to help you manage this important safety issue.

Prepare to stop driving

Often stopping driving is one of the first losses you will deal with. Preparing yourself and those around you for this loss is key to handling this issue well.

In the early stages of dementia some people may continue to drive safely, others cannot. The following steps will help you prepare for the day you have to give up your keys:

- **Talk** – Many people feel angry or sad about having to stop driving. Discussing driving from the very beginning is important to handling this loss. Talk to your doctor, your caregivers, your family and friends. Let them know how you feel if giving up driving is going to be difficult for you.
- **Assess** – If you plan to continue driving, know that the illness may affect your ability to assess your own driving. Ask your family, friends and doctor to monitor your driving and to let you know when your driving abilities change. Your doctor can do a simple screening test and send you for a driving evaluation. A driving evaluation will let you know if it is time to stop driving.
- **Plan** – Plan for your retirement from driving. To ease the transition, plan for alternative ways to get around. Talk to your family and friends about driving you; and look at alternative transportation available to you. Try out the plan before you have to stop driving. This way you can see what works and what doesn't before you need to rely on others.

Know when to stop driving

It is common for people to modify the way they drive as their abilities are affected by the physical changes of aging. But for people with dementia, it's different.

Unlike the typical aging process, dementia affects your ability to know your own limitations. You may or may not be aware of changes in your driving that suggest you are at risk such as:

- Getting lost on familiar routes
- Being unaware of driving errors
- Missing traffic lights or road signs
- Having near misses
- Finding it difficult to stay in your lane
- Noticing scrapes or dents on your car

One incident may not warrant concern. But over time, an increase in the frequency of unsafe driving behaviours requires attention. Often, because of changes due to your illness, you will not be aware of your own driving abilities. You might deny, make excuses or blame others for your unsafe driving behaviour.

You can ask your family members or friends to use the checklist on the following pages to look for warning signs that indicate driving may no longer be safe. Because your illness is progressive, it is important to keep track of changes over time, so repeat this quick check often.

If you have concerns about your own or a family member's ability to drive safely:

- Talk to your family about your concerns.
- Ask your doctor to do a screening test.

Driving warning signs

A diagnosis of mild dementia alone is not an automatic reason to stop driving. Families can use the list on the next 2 pages as an objective way to monitor any changes in driving skills over time. Written notes of observations can help you make informed decisions and may be useful in conversations with healthcare providers. Consider the frequency and severity of incidents. Several minor incidents or an unusual, major incident may warrant action. Look for patterns of change over time. Isolated or minor incidents may not warrant drastic action. Avoid an alarming reaction. Take notes and have conversations at a later time, instead of during or right after an incident.

Driving Behavior Warning Signs	Yes	No	When Noticed, How Often
Decrease in confidence while driving	<input type="checkbox"/>	<input type="checkbox"/>	
Difficulty turning to see when backing up	<input type="checkbox"/>	<input type="checkbox"/>	
Riding the brake	<input type="checkbox"/>	<input type="checkbox"/>	
Easily distracted while driving	<input type="checkbox"/>	<input type="checkbox"/>	
Other drivers often honk horns	<input type="checkbox"/>	<input type="checkbox"/>	
Incorrect signaling	<input type="checkbox"/>	<input type="checkbox"/>	
Difficulty parking within a defined space	<input type="checkbox"/>	<input type="checkbox"/>	
Hitting curbs	<input type="checkbox"/>	<input type="checkbox"/>	
Scrapes or dents on the car, mailbox or garage	<input type="checkbox"/>	<input type="checkbox"/>	
Increased agitation or irritation when driving	<input type="checkbox"/>	<input type="checkbox"/>	
Failure to notice important activity on the side of the road	<input type="checkbox"/>	<input type="checkbox"/>	
Failure to notice traffic signs	<input type="checkbox"/>	<input type="checkbox"/>	
Trouble navigating turns	<input type="checkbox"/>	<input type="checkbox"/>	
Driving at inappropriate speeds	<input type="checkbox"/>	<input type="checkbox"/>	
Not anticipating potential dangerous situations	<input type="checkbox"/>	<input type="checkbox"/>	

Driving Behavior Warning Signs	Yes	No	When Noticed, How Often
Uses a “copilot”	<input type="checkbox"/>	<input type="checkbox"/>	
Bad judgment on making left hand turns	<input type="checkbox"/>	<input type="checkbox"/>	
Near misses	<input type="checkbox"/>	<input type="checkbox"/>	
Delayed response to unexpected situations	<input type="checkbox"/>	<input type="checkbox"/>	
Moving into wrong lane	<input type="checkbox"/>	<input type="checkbox"/>	
Difficulty maintaining lane position	<input type="checkbox"/>	<input type="checkbox"/>	
Confusion at exits	<input type="checkbox"/>	<input type="checkbox"/>	
Ticketed moving violations or warnings	<input type="checkbox"/>	<input type="checkbox"/>	
Getting lost in familiar places	<input type="checkbox"/>	<input type="checkbox"/>	
Car accident	<input type="checkbox"/>	<input type="checkbox"/>	
Failure to stop at stop sign or red light	<input type="checkbox"/>	<input type="checkbox"/>	
Confusing the gas and brake pedals*	<input type="checkbox"/>	<input type="checkbox"/>	
Stopping in traffic for no apparent reason*	<input type="checkbox"/>	<input type="checkbox"/>	
Other signs:	<input type="checkbox"/>	<input type="checkbox"/>	

*** Stop driving immediately**

Alternatives to driving

Look at your needs. Each person's transportation needs are different. Consider:

- Where do you generally want to go (e.g., appointments, shopping, social engagements)?
- How often do you need rides?
- At what time(s) do you generally need rides?
- How much can you afford/are willing to pay to get from place to place?
- Do you have any special needs regarding the transportation? (e.g., Do you use a wheelchair or walker? Do you need help right from your couch to a chair at your end destination?)

Then look at your options:

- Family and friends – You may know people who can help you get from place to place. The price is right and it could be a very convenient way to get around.
- Public transportation – For some, public transportation may be an alternative. Is there a bus stop near your home? There is a seniors' fare discount for those 65 and older. Many buses are now wheelchair accessible. Persons with physical or cognitive disabilities who are unable to use public transit without assistance are eligible to use Access-A-Bus. Find out what's available in your community. Again, the price is right, but availability and convenience will depend on where you live and when and where you are going.
- Taxis – Convenient, but expensive. However, some cab companies permit special rates when there is a contract between the company, taxi driver and the customer. It is worth calling to ask about if you plan to use taxis often!
- Special transportation services – Private, individualized, special transportation and accompaniment services are available in some communities. Service is often very convenient, available at any time, but more expensive than other options.
- Walking – Want to stay fit and go green? Do you live close to shopping, appointments, and other places you want to get to? Walking is a great way to keep fit and healthy. Check first with your doctor if you aren't used to walking those distances. You can't argue with the price.

- Community/Senior's Centres – Many centres have pick-up transport services run by local volunteers. Some have planned outings with transportation included. Transportation costs are usually very reasonable but the services are not individualized (e.g. they may not be available on demand).
- Your own car – Just because you retire from driving doesn't mean you have to sell your car. You might want to keep it so that it's there for others to drive you wherever you need to get to. If you have a disability that impairs your mobility, you may be eligible for a special parking permit for people with disabilities.
- Deliveries and online shopping – Many grocery and other kinds of stores will deliver to you free of charge or for a small fee. Today, "catalogue" shopping has become easier with the arrival of internet shopping. It doesn't get you where you want to go, but may help you acquire the things you need. Delivery charges are usually very reasonable.
- Other alternatives – Other options exist in some communities. For example, there may be transportation alternatives that will take you to and from medical appointments. Some municipalities have instituted special transportation programs.

No longer driving?

It doesn't mean you can't still carry on an active, engaged life. Getting together with a friend for lunch, visiting family members, playing a round of golf or a game of bridge or spending the morning at the local seniors' centre are still important activities that you want to continue.

Continued mobility is the key

Some of us eventually choose to retire from driving. For others, it is no longer safe or possible to drive. And others may wish to continue driving part time. No matter what, most seniors want to remain active in their communities and that means they want to be mobile; able to get where they want and need to go at the right time.

If you would like more information about driving and Dementia visit www.notifbutwhen.ca There is a link for caregivers and one for physicians.