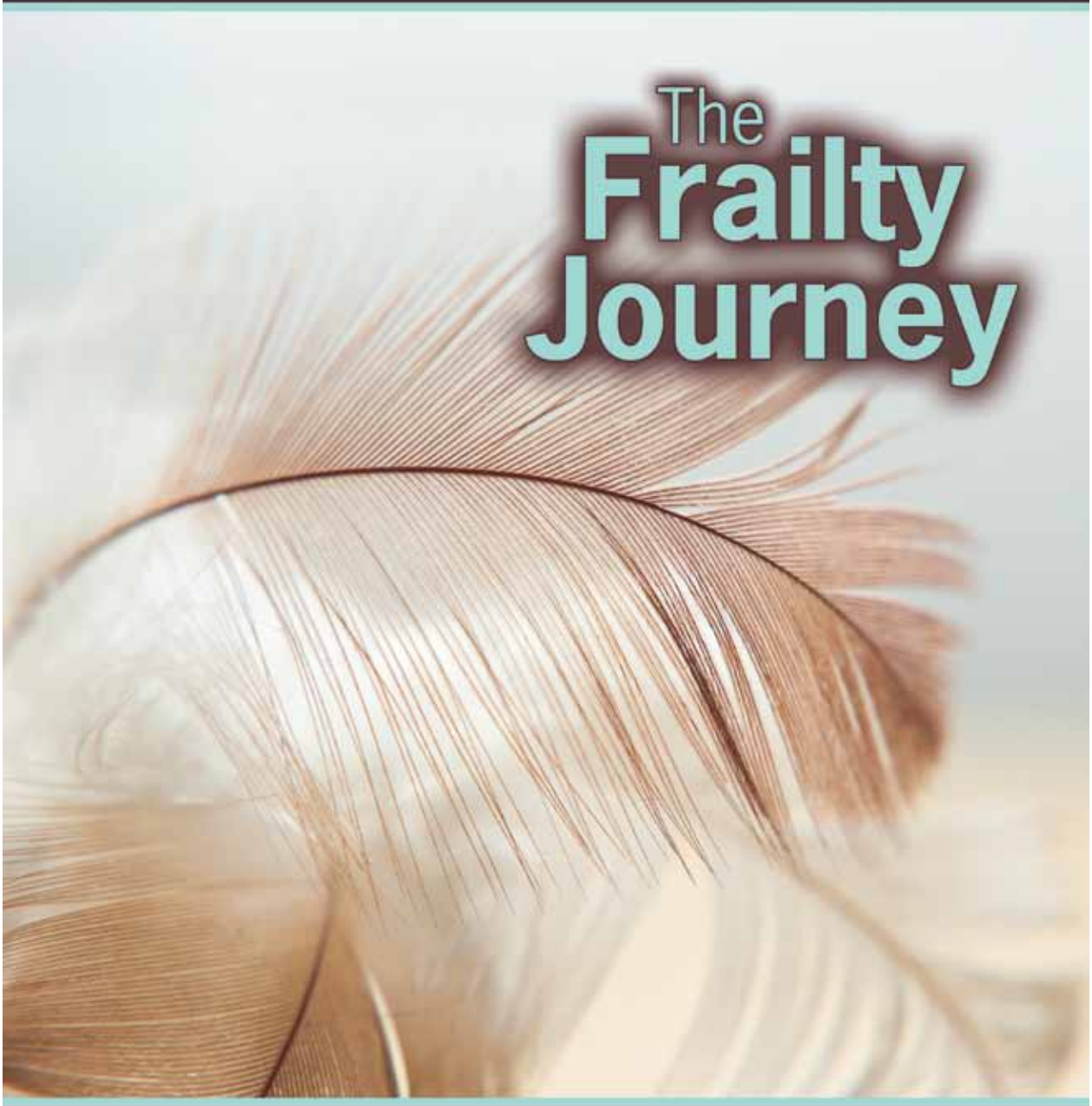

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The Frailty Journey

This is a Canadian resource about frailty. The following email address is ONLY for feedback about this booklet. It is not for patient specific questions. You will not receive a response from a health-care professional.

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Cette publication est également disponible en français.

Dedicated to all the remarkable people who have taught us to look past the frailty and see the person. It has been our privilege to learn with you.

Contents

PART 1

Why are we talking about frailty?

Everyone has a combination of abilities and weaknesses. When a person's weaknesses or disabilities and health problems overwhelm their ability to live independently, this is called **frailty**. A frail person may have problems with balance, strength and walking or be on many medications for serious health problems. They may have difficulty with memory, vision or hearing. It is often risky for a frail person to be alone for extended periods.

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Why is frailty important?

Frail adults are at higher risk of becoming sick and having difficulties during hospitalization or major medical procedures. A frail person will have more difficulty recovering after an illness and have a higher chance of losing the ability to walk and carry out day to day activities. Frail people have a shortened life expectancy. It is important to consider frailty when making health decisions and plans for the future.

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How do you know if someone is frail?

LIST I: If the answer is yes to any of the questions below, the person is frail.	Yes	No
Is the person in a nursing home or is a move to a nursing home planned in the near future?		
Does the person need help eating, dressing, toileting or getting into bed?		
Has the person been diagnosed with dementia and is not safe to be alone?		
Does the person have cancer that has spread in the body?		

Notes

LIST II: If the answer is yes for many of the questions below, the person is likely frail or at risk of becoming frail.	Yes	No
Does this person have memory problems or confusion?		
In the past year has the person been admitted to hospital two or more times?		
Would you rate their overall health as fair or poor?		
Do they need help preparing meals, shopping, driving, taking medications, and doing housework and laundry?		
Are they on more than five medications?		
Has the person recently lost weight? Do they have a poor appetite?		
Does this person often seem sad, lonely, depressed or anxious?		
Is this person having trouble walking or have they fallen recently?		
Do they suffer from bladder or bowel accidents?		
Do they have one or more of the following serious health conditions: cancer, heart failure, lung disease on oxygen, poor kidney function, history of stroke?		
If this person lives alone, do you have to check on them frequently? Would you be worried to leave town and be out of touch with them?		

If you know someone who is frail, the remainder of this booklet will provide important information on:

- health priorities and
- supportive plans for the future.

Notes

PART 2
Health Priorities

Medications and Common Diseases:

Most frail people are taking a lot of pills.
These pills may have been started years ago.
Some of the pills may no longer be needed.
Some may now be causing side effects like:

- decreased appetite
- tiredness and weakness
- feeling generally unwell
- muscle pain
- dizziness.

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If a person is on a lot of pills it may be difficult to sort out which ones are helping and which are making things worse.

Why do doctors have “targets” and follow “guidelines”?

Targets are the numbers doctors aim for when treating diseases. There are targets for blood sugar in people with diabetes and targets for blood pressure in people with high blood pressure. These targets are often summarized in guidelines. **Guidelines** are advice to doctors about how to treat diseases. These are written based on research. Most of that research is done in young adults who have one illness; for example, high blood pressure.

Treatment guidelines often do not take into consideration important things such as other medical problems or medication side-effects that are more common in frail adults.

Notes

Adjusting medications in frail people can be very tricky. **Any changes should be done with the supervision of your health-care team.**

Diabetes

For years doctors have recommended “tight” control of blood sugars. This is still recommended for newly diagnosed, younger people with diabetes. “Tight” control of diabetes can be dangerous for frail people because blood sugars can go too low. This is called **hypoglycemia**. Low blood sugars can be associated with:

- falls
- hospital visits
- confusion
- coma.

Notes

Often frail people are not aware that their blood sugar is dangerously low. The Canadian Diabetes Association Guidelines now have a special section discussing frail seniors. They emphasize that avoiding low blood sugar is the most important goal.

Three things to consider in frail people with diabetes:

1. Avoid blood sugars under 7 mmol/L, especially if on insulin.
2. A strict diabetic diet may no longer be needed.
3. Daily blood sugar checks are likely only needed for people on insulin.

See the Additional Information section of this book for links to helpful websites about diabetes.

Notes

High Blood Pressure:

For years doctors have recommended “tight” control of blood pressure. If frail people on pills for high blood pressure are over treated it can lead to symptoms including:

- dizziness
- falls
- fainting and lightheadedness when first standing up
- tiredness and weakness.

If a frail adult has any of these symptoms it is important to talk to their health-care team. The blood pressure may be checked lying down and again after standing up.

It is no longer considered a good thing for frail adults to have the “blood pressure of a teenager”. Some research shows frail older adults may be better off with higher blood pressure.

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Medications for other conditions

Although this booklet was not designed to discuss individual medications, it is worth mentioning a few specific classes of medications.

Blood thinners: These drugs are usually given for:

- irregular heart rate (atrial fibrillation)
- history of blood clots
- stroke prevention
- other heart diseases.

These drugs can require frequent blood tests and come with risks including:

- minor bleeding (i.e. nosebleeds and bruising)
- major bleeding resulting in hospitalization.

Sometimes a blood thinner that does not require blood tests can be used. The

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decision to use blood thinners when someone is frail is not a simple one. You should have a conversation with your health-care team if you have questions about a frail adult on blood thinners.

Cholesterol drugs (e.g. “Statins”): Some people have been on medications to lower cholesterol for many years. Doctors are starting to question if these drugs are beneficial for frail people. Often these drugs cause:

- muscle aches
- cramps
- weakness.

If a person is frail enough to require a nursing home level of care these drugs can probably be stopped. The side effects likely outweigh any benefits.

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Dementia

People with dementia are frail regardless of any other health problems. If frailty is primarily caused by dementia (memory and thinking problems) please consider reading the three booklets in the Dementia Trilogy series:

- An Introduction to Dementia
- The Dementia Compass
- Later in the Dementia Journey

More information on specific medical conditions

See the Additional Information section for links to helpful websites about specific diseases.

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Major Medical Decisions and Medical Emergencies :

Frail adults are at increased risk of medical emergencies. It is important to know that frailty will increase the risks associated with hospitalization and medical treatments. Sometimes, a frail person will have time to consider treatment options such as:

- dialysis for kidney failure
- chemotherapy and radiation therapy for cancer
- planned surgeries for the heart, spine and brain.

Other times a decision is needed immediately. Examples of these situations include:

- life support for lung failure
- cardiopulmonary resuscitation (CPR) for cardiac arrest
- emergency surgery when a person is unconscious.

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Family members or close friends often help frail adults make decisions. It is important to consider the values and priorities of the frail adult. Research shows that most seniors want to live as long as possible, **if** they can be active and are comfortable.

When you are participating in health care decisions, it is important to ask the following questions:	**Yes**	**No**
Could treatment worsen quality of life?		
Could the treatment worsen function or memory?		
Is it possible that the person will not be able to return home and will need to move to a nursing home after treatment?		
Are there options for minimizing symptoms including pain?		

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Being frail can decrease the likelihood of being active and comfortable following major medical events. For example:

- frail adults have a higher chance of losing their abilities to walk and manage on their own following a medical crisis.
- persons with frailty almost never have a good quality of life if they survive CPR. This is why many frail people decide not to have CPR during cardiac arrest.
- frail people have a shortened life expectancy.

Medical treatment does not stop if the decision is made to decline treatments that may not be well-tolerated (including CPR, surgery or chemotherapy). Instead, the focus shifts entirely to controlling uncomfortable symptoms including pain, shortness of breath or restlessness. Sometimes specialists working in palliative care become involved to help keep

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people comfortable. The goal of this care is to optimize quality of life.

What to expect as frailty progresses: Signs that the end of life may be near

Frailty is not reversible and gradually gets worse with time. There are many reasons why it is difficult to predict how long a frail person will live.

Some of the signs that a person is not expected to live much longer include:

- not being able to get out of bed
- choking when swallowing or not eating much
- high fevers or infections that keep coming back (including pneumonia or urinary tract infections)
- being drowsy most of the day and hard to wake up.

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Advanced Care Planning project

The Advance Care Planning project is a Canadian initiative attempting to get people talking about health and personal care decisions. For a free workbook please go to: www.advancecareplanning.ca.

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PART 3
Supporting a frail adult

Frail adults need help from others. Sometimes the help is in the form of a person paid to come to the house (a homecare worker). Here are some ideas that have helped other people accept this important change:

- It may be better to introduce help a few hours at a time and increase it gradually. If there is a crisis, a lot of help may need to be started quickly.
- Sometimes people don't like getting help with bathing and dressing from their family members but will accept help from someone who does this for a living.

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- Frail adults sometimes worry about becoming a “burden” on family members. Hiring someone to help can allow friends and family to continue enjoyable social visits.
- Many adults are worried about someone coming in and “taking over”. Being clear about how much help is needed can avoid this.

How do you know what help to ask for?

Homecare workers can be self-employed or work for an agency. Before hiring someone, clarify what work needs to be done. The following lists will give you an idea of services to ask for and other services that are usually not done by homecare workers.

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Services often provided and not provided by homecare workers

Table 1. Household chores

Often provided	Usually not provided
Sweeping, vacuuming and mopping floors	Cleaning high shelves and windows
Washing dishes and cleaning counters	Heavy lifting
Changing the bed and doing laundry	Snow shoveling and yard work
Cleaning bathrooms	
Preparing simple meals	
Providing reminders about exercises and companionship on walks	
Medication reminders or supervising the medications being taken	Giving medications or giving injections (i.e. insulin)
Transportation for appointments and outings (i.e. groceries)	Doing banking

Table 2. Personal care assistance

Often provided	Usually not provided
Helping with bath or shower	Changing bandages
Dressing and grooming	Foot care (unless specifically qualified)
Cutting food or feeding	Organizing tube feeds
Assistance using the toilet	Changing catheters
Help in and out of chairs and bed	

Notes

When hiring someone, be clear about expectations. It is important to have clear communication. If things are not working consider,

- adjusting the homecare workers hours of work to suit the frail adult's lifestyle
- contacting the person directly and ensure they understand your expectations
- hiring a different person. This does not mean the plan has failed.

If a frail adult is able to stay in their own home with services, it is important to have a back-up plan. There will be days when workers will not be able to get to the house. Some back-up strategies include:

- Asking the workers to call you if they are not able to come in, so you can make plans. Some frail adults do not call when their homecare workers don't come and this can be risky.

Notes

- Have a list of people who have committed to providing help at short notice. These may be alternate homecare workers or family, neighbors and friends.
- If the homecare worker is having frequent absences this may be a sign that the current worker is not a good fit and a change may be required.

In addition to homecare workers, it can be helpful to consider some of the following options:

- Meal delivery (sometimes called Meals on Wheels) - provides either warm or microwavable meals.
- Pharmacy delivery is often offered at no extra charge
- Grocery delivery
- Automated bank payments
- Hairstylists who come to the house

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- Nurses who do foot care
- Snow removal services and lawn care
- A personal help button worn around the neck or on the wrist in case of emergency. There are other “high-tech” monitoring systems available.

The addition of these services may help a frail adult remain at home longer.

If you are looking for more guidance about the supports or equipment needed, an **occupational therapist** may be helpful. **Social workers** can help coordinate plans for help and discuss available funding. Your health-care team may be able to put you into contact with these people.

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How plans for help change over time

As people become very frail, more help may be required than can be provided by family and homecare workers in the home. Some of the challenges, when caring for a very frail adult at home, can include:

- loss of bowel and bladder control
- balance problems and falling
- difficulty climbing stairs, walking and standing up
- health issues that require a trained nurse
- unstable health conditions requiring frequent visits to the family doctor or emergency room.

Often people with these challenges live in a nursing home but sometimes 24-hour care at home can be arranged. The goal of both of these options is to help the person be as comfortable as possible and avoid hospital stays.

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"24-hour care" at home

It is sometimes possible for a very frail person to remain at home until death. Often this is possible only if there is enough money to pay for help and equipment at home.

Some of the things to consider when having a very frail person live at home include the following:

- Help will often be required 24-hours a day, 7 days a week.
- Homecare workers will often help clean the person after a bowel or bladder movement and help the person move around safely.
- There is often a significant cost involved in keeping a frail adult at home until death. In addition to hiring people, special equipment is often required. Hospital beds and lift-chairs for the stairs may need to be purchased or rented.
- It is often challenging to find homecare workers who are willing to work overnight.

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Moving to a nursing home

Three of the benefits of nursing homes include:

- **24-hour staffing:** Because there is paid staff around the clock, 911 calls and visits to the emergency room can be decreased.
- **Staff members are trained and equipped to help people with mobility difficulties:** As frail adults develop problems getting into and out of bed they require assistance from strong people trained to help people move safely.
- **Prevention of caregiver burn-out:** It is challenging to provide 24-hour to a very frail adult. This can cause exhaustion for family members providing help at home on a full time basis.

Many people are slow to investigate nursing home options. Some peoples' concerns about nursing homes include:

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- A promise made in the past, "never to move to a nursing home". When a promise was made in the past, it may have been hard to imagine a time when assistance would be needed to get out of bed and wash after toileting.
- The feeling that other family members or friends want the person to stay at home. Sometimes an open discussion among family members may reveal that everyone agrees it is time to consider a nursing home. Other family members, who may be less involved, may not recognize how difficult things have become.
- Media reports of neglect or poor care in nursing homes. It is important to take a tour and ask questions about nursing homes in your area. By continuing to visit the person in the nursing home you can be reassured that the person is getting the best possible care.
- Stories of people getting worse after moving into a nursing home. When a very frail adult

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needs the help available at a nursing home they are usually in a phase of life when health can deteriorate quickly. This will, unfortunately, happen regardless of where the person is living.

Some practical considerations about a move to a nursing home include:

- "Assessment process" and wait times: The process to have someone assessed for a nursing home and the wait time for a spot can be lengthy. It is important to consider applying before you are in a crisis.
- Pets living with the frail person: It is important to have a safe plan for the pets.
- Some nursing homes cannot let people smoke: It may be important to talk to the family physician about "stop-smoking options" including the nicotine patch, gum or inhaler.

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How to advocate for a frail adult

It is important to remember that you continue to have a voice. Often staff will ask your opinion about how the person can be made most comfortable. Some opportunities for expressing your opinions include:

- scheduled family conferences
- resident and family councils
- informal discussions with staff.

Helping staff see the whole person

Here are three ways you can help a frail adult share information to improve relationships with staff:

1. **Create a life history poster** – Use a piece of poster board to help

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organize some pictures and factual information about the person's life. The poster can be placed on the wall at home or be taken to the hospital or nursing home.

2. **Outline a brief Life Story** – See the Appendix at the end of this booklet called "Life Story" to record the answers to questions about the person's life. This will help to improve the quality of conversation.
3. **Complete a Sensory Survey** – See the Appendix at the end of this booklet called "Sensory Preferences" to record preferences to help staff make the frail person as comfortable as possible.

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PART 4 Additional information

There are many online sources of information. We highly recommend the following:

- **AGS Foundation for Health in Aging**
  Healthinaging.org
  - A Guide to Geriatric Syndromes
  - Living with Multiple Health Problems: What older adults should know
- **Speak Up: Advance Care Planning Workbook**
  www.advancecareplanning.ca Start the conversation about end-of-life care. "It's about conversations. It's about decisions. It's how we care for each other."

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- **The Canadian Coalition for Seniors' Mental Health**: "Delirium in Older Adults: A guide for seniors and their families".
  - www.ccsmh.ca/en/default.cfm#.

For information about the impact of specific diseases on frailty please consider an online search for national organizations advocating for specific patient populations. For example:

- **The Kidney Foundation of Canada**
  - Choosing not to start dialysis
  - Choosing to stop dialysis
- **The Canadian Lung Association**
  - COPD and end-of-life care
- **The Heart and Stroke Foundation**
  - Health information
- **The Alzheimer Society**
- **Canadian Cancer Society**
  - Advanced cancer
- **Canadian Diabetes Association**
  - Clinical practice guideline: Diabetes in the Elderly
- **Diabetes Care Program of Nova Scotia**
  - http://diabetescare.nshealth.ca/sites/default/files/files/LTCFAQ.pdf
  - Long-term care guidelines

The following were used in the preparation of this booklet:

- **Encouraging Comfort Care: A Guide for Families of People with Dementia Living in Care Facilities**
  - http://www.alzheimers-illinois.org/pti/comfort_care_guide.asp
- **A Guide to End-of-Life Care for Seniors**
  - Regional Geriatric Program of Toronto
- **Reaching Out to the Spiritual Nature of Persons With Dementia**
  - www.baylor.edu/content/services/document.php/60623.pdf
- **Caring for Patients with Terminal Alzheimer's Disease**
  Ladislav Volicer. The Canadian Review of Alzheimer's Disease and Other Dementias.
- **PATH: A New Approach to End-of-life Care**
  Moorhouse and MalleryThe Canadian Review of Alzheimer's Disease and Other Dementias.
- **New Brunswick Association for Spiritual Care** www.nbasc.ca
- **Goodendoflife.com**

Website addresses current as of Septmber 2014.

Appendix 1 Life Story

(Fill in the parts that are applicable.)

My name is .....

Most of my
friends call me .....

I was born on ..... in .....

I grew up in .....
and came from a family of .....

I met my spouse .....

I married ..... on .....

I have ..... children. Their names are: .....
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I have ..... grandchildren and ..... great
grandchildren. Their names are: .....
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People I regularly see or talk about include:

I would like you to know I had many interests which included the following:

My favorite things to do in my childhood were:

My favorite things to do as an adult (include hobbies):

My favorite types of books and music are:

This is what I like to do to relax:

My favorite things are:

I worked most of my life as:

I belonged to various groups, committees, volunteer work, that included:

My spiritual beliefs included:

Three accomplishments/successes/ achievements that I am most proud of are (consider including education, certificates, courses etc.):

I have had these pets over the years:

Other things you should know about me include: (Please consider including military service. Is your military service something you like to talk about?)

Please indicate below:

❒ YES, I give consent for this information to be shared with the people around me so they know more about me.

❒ NO, I do not give consent for this information to be shared with the people around me.

Signature of patient or substitute decision-maker:

Date:

Appendix 2 Sensory Preferences

Favorite smells: examples include roses, pine, sea air, foods, soaps and perfumes, laundry detergent

Disliked smells: examples include specific foods cooking, soaps and perfumes

Favorite foods: examples include sweets, salty snacks, cold or warm (ice cream vs. oatmeal)

Disliked foods: examples include specific flavors like curry, cinnamon, fish

Favorite food textures: examples include crunchy, chewy, drinking through a straw, drinks with or without ice, milkshake thickness

I like to have something in my mouth: examples include chewing gum, peppermints, toothpick, straw of hay, cigarette

Preferred background noise: examples include favorite types of music, nature sounds, quiet, talk radio

What volume is preferred?

Favorite TV/radio shows:

Disliked background noise: examples include specific types of music, television, quiet

Room temperature preference:

What clothes are usually worn inside: examples include T-shirt, vest, long-sleeve shirt with buttons or without, sweater, shoes, slippers

Favorite fabrics: (wool, silk, cotton, polyester, rough textures, fuzzy textures)

Disliked fabrics:

Other:

Level of personal contact: (please circle)

Enjoy holding hands or a pat on shoulder? **Yes No**

Having hair brushed? **Yes No**

Having face or hand lotion put on? **Yes No**

Massage? **Yes No**

Favorite resting position: examples include rocking in a chair, reclining in a LazyBoy, sitting in a firm chair, lying down in bed

Preferred level of activity: walking, dancing, rocking, being still, changing position

Something in the hands?
examples include a rosary, cigarette, cell phone

Night time routine:

Normal bedtime

Before bed routine

Pajamas/night dress/other

Sheets tucked in or loose

Weight of blankets

Morning routine:

Time of waking

Time of getting out of bed

Breakfast? **Yes No**

Bathing routine:

Shower, bath, other

Preferred soaps or other products

Adapted from Life History and Sensory Preference Survey,
Tracy McGrath BPE, Recreation therapist


RÉSEAU DE SANTÉ
Horizon
HEALTH NETWORK