Bruce Peninsula Hospice

Stepping STONES

A Personal Conversation Planning Guide

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Stepping Stones has been adapted by Bruce Peninsula Hospice with much gratitude and with permission from Hospice Northwest's "Don't Duck the Conversation" guide created in Thunder Bay, Ontario in 2016. Stepping Stones is intended to be a companion to Advance Care Planning materials created by the Speak Up Ontario campaign hosted by Hospice Palliative Care Ontario. This guide does not provide full details/knowledge on Advance Care Planning and its relation to Health Care Consent -- readers are encouraged to please see inside for further resources.

Stepping STONES

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Why DO THIS?

THE PURPOSE OF THIS GUIDE IS TO PROVIDE YOU WITH "STEPPING STONES" TO *FURTHER CONVERSATIONS* ABOUT PLANNING FOR EMERGENCIES, LIVING WELL AND FUTURE HEALTH AND PERSONAL CARE.

Having conversations and preparing those that will need to help and care for us, reduces the stress of family members and community if we are ever faced with a life limiting illness. By engaging in conversations and planning ahead, crisis situations may be avoided or managed more effectively and our quality of life may be enhanced.

The more you walk down the path, the more comfortable it becomes. Many may already be comfortable speaking about later or future health and planning issues and this guide can serve as a useful reminder of what was discussed, or a place to jot down thoughts as you think of them.

You think it can wait? Here is my story.

"In May, 2015, my father died. He was 93. For the last several years of his life my brother and I were his Substitute Decision Makers. We were appointed powers of attorney for his property and his personal care. My father was clear about what he wanted and he certainly made it known. And what a gift that was in the end. My brother and I were able to have the important conversations with him and with our siblings regarding the next steps in his care as his health declined. He was very much in control until he could no longer take control. All calm, no surprises, no angst, nothing left unsaid.

Then the unthinkable happened. In August, 2015, I woke early with a tingling in my right hand that moved into my arm. I gave it a shake, thinking my hand was just going to sleep and I turned onto my back. But the tingling moved into my face and I had a bit of a head ache. I slid out of bed with a heaviness on my entire right side. Now, you have to know that I am slim and fit, not yet 60, have excellent blood pressure and pride myself on eating a very healthy diet. A stroke was NOT in the plan. But, there it was. Thankfully, the health care providers in Wiarton and Owen Sound acted quickly, and as a result, minimized the impact of the stroke. Those important conversations with my family are on-going. This precious life is fragile. There is much we cannot control; yet, there is much we can claim. **Don't wait, Advance Care Planning matters.**"

CHRISTINA MEREU, WIARTON

Benefits

WE TEND TO PUT OFF OR AVOID THOSE *IMPORTANT CONVERSATIONS*, HOWEVER WHAT BETTER TIME THAN WHEN WE ARE HEALTHY TO START THEM?

Setting the example for our friends and those we care about can be a beautiful thing. We do not have to be in our later years to experience an emergency, progressive life-limiting illness or a tragedy that makes these conservations relevant. Being prepared and ***making it a habit to have these conversations*** about our wishes, will serve not only us, but our friends, our children and our children's children. **Our preparation:**

PREPARES OUR FAMILY AND FRIENDS

REDUCES STRESS

SETS THE EXAMPLE
Insights & Learning will benefit others in the future

MAKES THE UNCOMFORTABLE, COMFORTABLE

"My mom knew, and shared with us, what she wanted and didn't want in terms of end of life care. When she found out that she had a terminal cancer, she intentionally shared her desires with all of us, and she was open to all our questions. Knowing what her wishes were helped us very much in navigating her last days. Nothing makes the pain of loss easier – but I am so thankful that I never had to question "Is this what mom would have wanted?". She thought about it, told us – and in telling us, she freed us from having to make these terribly difficult decisions on our own. While advocating her wishes, we were united. I can only imagine how painful it would be for families who do not have such guidance from their dying loved one."

LAUREL BAKER MARTIN AND THE BAKER FAMILY, LION'S HEAD

"My father prepared us by letting us know that he was ready to leave this world. He was always telling us we are born to die. He was ready spiritually and he had conversations with us to help prepare us too."

BERDINA JOHNSTON, NEYAASHIINIGMIING

THINGS TO THINK ABOUT AND DISCUSS

The information provided is not a legal document and is not intended to be a substitute for professional legal, financial or health care advice. We encourage all readers to seek further supports and resources including independent legal, financial and health advisors.

1. Who needs to be contacted if there's an emergency and I suddenly have to go to the hospital?

   Who will help look after the house, pets and who do I want notified?

   Who do I want to visit me when I am really sick?

2. Who is/are my Substitute Decision Maker(s) (SDM) who will speak on my behalf if I am no longer mentally capable to make decisions or direct my care? (such as in the event of an accident, a stroke, loss of verbal skills due to dementia or other illness).

   Do these individuals know my values and wishes for care, for quality of living and even personal hygiene?

   Does everyone close to me know and understand about my Substitute Decision Maker(s) and important wishes?

3. Where are my important papers kept? Who knows this location?

   Who can access them in case of an emergency including passwords?

4. What's still on my bucket list? What makes life meaningful for me?

   What simple pleasures will continue to make my life enjoyable as I enter my "sunset years"?

5. What hopes do I have for my “sunset years”?

   What modifications or home renovations may need to be made?

   What things do I still need to think about and put in place and what supports do I hope to have?

6. What are some of the things I want to be remembered for and what legacies do I hope to leave behind?

   Is there a list written down and where is it kept?

   Who is the executor of my will? Who are some of the people in my will and are they easy to locate?

7. What personal health care wishes and values about my future care have I shared with my family, friends, future SDM and/or health care provider?

8. What type of funeral or celebration of life have I envisioned?

   Who do I want involved in the planning?

   What arrangements have already been made? How will it all be paid for and what do I still need to think about?

9. What are some of the top things I hope to resolve before I die? (relationship, financial, property or spiritual matters or other important things I’ve been meaning to do…)

10. If I have a progressive life-limiting disease and my health seriously declines, in the final weeks or days…What have I thought about for this time?

    Where do I want to be if it is possible?

    What music, poetry or literature will soothe me? (as I will likely still be able to hear even if I can no longer speak), what spiritual care and social companionship will bring me comfort?

EMERGENCY

IF YOU WERE UNEXPECTEDLY ADMITTED TO HOSPITAL, THERE'S BEEN AN ACCIDENT, OR AN EMERGENCY THAT TAKES YOU AWAY FROM YOUR HOME FOR AN INDEFINITE PERIOD.

WHO NEEDS TO BE NOTIFIED?

Name: ______________________________ Tel: ______________________

Name: ______________________________ Tel: ______________________

SUBSTITUTE DECISION MAKER* (FOR HEALTH CARE DECISIONS):

Name: ______________________________ Tel: ______________________

WHO WILL LOOK IN ON MY HOME?

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CARE FOR PETS:

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VISITORS YOU MIGHT WISH FOR IF YOU WERE HOSPITALIZED:

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IF SERIOUS EMERGENCY -- SPIRITUAL CARE PERSON?

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*See page 9.

Who will
SPEAK FOR ME?

WHO WILL SPEAK ON MY BEHALF IF I AM NO LONGER MENTALLY CAPABLE TO MAKE THE DECISIONS REQUIRED ABOUT MY HEALTH OR PERSONAL CARE: (SUCH AS IN THE EVENT OF AN ACCIDENT, A STROKE, DEMENTIA OR OTHER ILLNESS).

Advance Care Planning is a process of reflecting, identifying and communicating your wishes for health and personal care in the future event that you ever become mentally incapable of directing your care yourself. *Please refer to definitions on page 23.*

Understanding who your default Substitute Decision Maker* (SDM) is, or if you wish to name someone in a Power of Attorney for Personal Care document (POAPC), who will speak for you if you were ever mentally incapable of doing so yourself, is one important aspect of Advance Care Planning. It will be this person, or people, who will provide consent for care and treatments, or refusal of consent, based on the wishes you shared with them when you were mentally capable.

Even if they do not know your specific wishes, for instance about a certain treatment decision you may not have thought about, they are required to act in your best interests, based on their knowledge of you and your values, as you would have wished.

A free, online workbook to help start the conversation about Advance Care Planning for Ontario residents can be found at: **speakupontario.ca** As well, the Speak up Guide published by Hospice Palliative Care Ontario which reflects Ontario's unique legislation in this area (did you know "A Living Will" is not a term in Ontario Law?) are recommended resources as part of your Advance Care Planning conversations in addition to the listing found on page 22.

WHO IS/ARE MY SUBSTITUTE DECISION MAKER(S)?
(DEFAULT OR NAMED IN A POAPC DOCUMENT)

DO THEY KNOW MY WISHES AND VALUES? HOW HAVE I MADE THEM AWARE OF MY WISHES AND VALUES?

MY PLAN TO RENEW THESE CONVERSATIONS IS:

RENEWING THESE CONVERSATIONS IS HELPFUL TO SUPPORT OUR FRIENDS AND FAMILY IN A STRESSFUL TIME. BESIDES, YOUR WISHES COULD CHANGE. IT IS SUGGESTED TO MAKE THESE CONVERSATIONS A HABIT!

*Ontario Law provides that you will always automatically have a Substitute Decision Maker for personal care even if you choose not to name your SDM in a Power of Attorney for Personal Care. A hierarchy of who in your life will rank the highest and meet the requirement to be your Substitute Decision Maker for health care is part of the Ontario Health Care Consent Act. Refer to: speakupontario.ca

MY BUCKET LIST

"YOU ONLY LIVE THAT AGE ONCE, ENJOY IT!" – WALTER JOHNSTON

TOP 5 THINGS I STILL WANT TO DO:

1. ______________________________

2 . ______________________________

3. ______________________________

4. ______________________________

5. ______________________________

WHAT ARE THINGS THAT MAKE MY LIFE MEANINGFUL?

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WHAT ARE THE SIMPLE PLEASURES I ENJOY THAT I HOPE TO KEEP DOING FOR AS LONG AS I CAN?

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My Sunset **YEARS**

IN MY SUNSET YEARS....I HOPE TO:

WHAT MODIFICATIONS MAY NEED TO BE DONE AROUND MY HOME THAT I'VE THOUGHT ABOUT:

WHAT COMPANIONSHIP PLANS DO I HAVE, HOPE FOR:

WHAT ARE SOME DIETARY CHANGES TO TAKE INTO CONSIDERATION:

ABOUT ME

WHAT DO I WANT TO BE REMEMBERED FOR?

WHAT DO I WANT PEOPLE TO KNOW ABOUT ME? (PROVIDE A BASIC PICTURE AND FEEL FREE TO ADD EXTRA PAGES)

MY VALUES: (GENEROUS, KIND, INCLUSIVE, VALUE CULTURE, ETC.)

MY ACCOMPLISHMENTS/TALENTS:

LIST VOLUNTEER POSITIONS HELD OR OTHER ACTIVITIES:

CAREER HIGHLIGHTS, JOBS AND POSITIONS HELD:

SPECIAL ABILITIES: (MUSICAL, ATHLETIC, ETC.)

MY MEMORABLE LIFE EVENTS: (TRAVELS, ALTRUISM, ETC.)

MY FAMILY:

HEALTH CARE

YOUR PHYSICIAN, NURSE PRACTIONER, NURSE, CASE COORDINATOR, ETC., CAN BE VALUABLE IN PROVIDING YOU WITH IMPORTANT INFORMATION TO SHARE WITH THOSE CLOSE TO YOU.

THINGS I'VE DISCUSSED AS PART OF MY VISITS TO MY HEALTH CARE PRACTITIONER:

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BASED ON MY FAMILY'S HEALTH HISTORY AND MY OWN HEALTH HISTORY, THESE ARE SOME OF THE HEALTH SCENARIOS THAT MAY ARISE AND MY WISHES:

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MY HEALTH CARE TEAM HAS SUGGESTED THE FOLLOWING WAYS OF ENHANCING MY HEALTH:

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ARRANGEMENTS I'VE MADE

THERE ARE MANY OPTIONS AND CONSIDERATIONS FROM THE FUNERAL SERVICE TO THE TYPE OF GATHERING YOU WOULD LIKE TO HAVE.

THINGS I KNOW I WANT AND THE REASONS OR GUIDING PRINCIPLES FOR MY CHOICES: (E.G. I WISH IT TO BE DIGNIFIED)

THINGS I HAVE ALREADY ORGANIZED:

THINGS I AM STILL THINKING ABOUT:

THINGS I HAVE THOUGHT ABOUT FOR THE PEOPLE WHO WILL BE ATTENDING:

WHO IS GOING TO HELP PLAN AND EXECUTE THE ARRANGEMENTS:

OTHER THOUGHTS:

RELATIONSHIPS I WISH WERE DIFFERENT OR I COULD REPAIR:

PEOPLE I'D LIKE TO CONNECT WITH AGAIN:

FINANCIAL, PROPERTY, ESTATE MATTERS I STILL HAVE TO DECIDE ON AND/OR PUT INTO PLACE: (E.G. I STILL NEED TO MAKE MY WILL!)

SPIRITUAL QUESTIONS OR WONDERINGS I STILL HAVE ABOUT DEATH AND DYING:

IMPORTANT STUFF I WAS HOPING TO DO THAT I HAVEN'T BEEN ABLE TO GET AROUND TO AND I'D LIKE TO SEE COMPLETED BEFORE I DIE:

DURING MY *Special Time*

(AKA IN THE FINAL DAYS, WEEKS OR MONTHS BEFORE I DIE)

When the subject of death and dying comes up, many people have reflected on what kind of funeral they'd like, the music they want played during the service and so on. We have the time after we are *gone* all thought through, but what about when we are *going*? How do we want to spend that special time that really only happens once!

WHERE I MIGHT LIKE TO BE:

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WHO WOULD I TAKE COMFORT IN HAVING NEAR ME? (DO YOU WANT A LOT OF PEOPLE, OR HAVE IT BE A MORE PERSONAL, QUIET TIME?)

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MUSIC, LITERATURE, READINGS OR SCRIPTURE I MAY FIND COMFORTING: (THE LAST SENSE TO GO IS OUR HEARING)

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ANYTHING I FEAR, OR DO NOT WISH FOR IN MY FINAL DAYS OF LIFE:

PERSONAL HYGIENE THAT WILL BE IMPORTANT FOR ME: (E.G. KEEP MY HAIR WELL KEPT, KEEP ME DIGNIFIED LOOKING)

SUPPORTS I'D LIKE: (E.G. SPIRITUAL, HOSPICE VOLUNTEER VISITOR)

ANYTHING ELSE THAT WILL KEEP THIS TIME MEANINGFUL FOR ME: (E.G. PETS, BIRDS, OTHER SENSORY OR SOCIAL EXPERIENCES)

Important
PAPERS AND PASSWORDS

WHERE THE IMPORTANT STUFF IS KEPT:

Personal records and documents you may wish to have in a special, secure spot, however being able to locate these documents easily will make things easier for loved ones/family/executors. These pages may be copied and kept in a secure place. Does someone know where this is and have you reviewed it with them periodically (we forget things!)?

Please note, Bruce Peninsula Hospice Inc. is not responsible for how private information entered in your Personal Conversation Guide is stored or shared. Always ensure that your private information is stored securely and only shared with people that you consider safe and trustworthy.

WILL, POWER(S) OF ATTORNEY (PERSONAL CARE OR PROPERTY), ORGAN/TISSUES DONATION CARD, SAFETY DEPOSIT BOX INFORMATION & KEY, REAL ESTATE TITLES, MARRIAGE CONTRACT, SEPARATION AGREEMENT, DEATH CERTIFICATE OF RELATIVE OR SPOUSE, ETC.:

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BIRTH CERTIFICATE, PASSPORT, SOCIAL INSURANCE CARD, HEALTH INSURANCE CARD, DRIVER'S LICENSE, VEHICLE REGISTRATION, MEDICAL AND DENTAL INFORMATION, ETC.:

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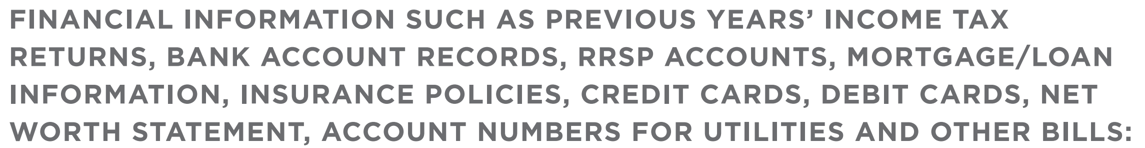

FINANCIAL INFORMATION SUCH AS PREVIOUS YEARS' INCOME TAX RETURNS, BANK ACCOUNT RECORDS, RRSP ACCOUNTS, MORTGAGE/LOAN INFORMATION, INSURANCE POLICIES, CREDIT CARDS, DEBIT CARDS, NET WORTH STATEMENT, ACCOUNT NUMBERS FOR UTILITIES AND OTHER BILLS:

WHO KNOWS WHERE THESE THINGS ARE?

ARE THERE ANY SPECIAL INSTRUCTIONS FOR PERSONAL OR CONFIDENTIAL PAPERS OR ELECTRONIC INFORMATION YOU MAY LIKE CARRIED OUT AND BY WHOM?

PASSWORD LISTING

Voice mail, cell phone, computer, and social media sites: (e.g. Facebook, online shopping accounts, online entertainment accounts, incentive cards.)

OBJECT OR WEBSITE	USERNAME & PASSWORD

This page may be copied and kept in a secure place.

RESOURCES

THIS CONVERSATION GUIDE IS "A STEPPING STONE"

The information provided is not a legal document and is not intended to be a substitute for professional legal, financial or health care advice. We encourage all readers to seek further supports and resources including independent legal, financial and health advisors.

Advocacy Centre for the Elderly (ACE) – acelaw.ca
Community based legal clinic for low income senior citizens, funded through Legal Aid Ontario. Discover information on a range of topics, including Powers of Attorney.

CLEO (Community Legal Education Ontario) – cleo.on.ca/en/publications/power
Find information regarding Power of Attorney for Personal Care and Power of Attorney for Property as well as mental capacity.

Government of Canada – seniors.gc.ca
Discover specific information for seniors including factsheets about social isolation, caregiving and planning for aging in place.

HCCA Ontario – ontario.ca/laws/statute/96h02

Hospice Northwest, Thunder Bay – hospicenorthwest.ca
Offers a comprehensive online guide: "Don't Duck the Conversation Personal Planning Guide", hospicenorthwest.ca/resources/dont-duck-the-conversation/

Hospice Palliative Care Ontario (HPCO) – hpco.ca
Ontario has unique laws for Health Care Consent and unique materials for Advance Care Planning – Hospice Palliative Care Ontario (HPCO) hosts the Ontario Speak Up Campaign and offers many additional resources including educational webinars, quick guides you can download, First Nations resources, a resource library and more.

Also discover a free online workbook to help start the conversation about Advance Care Planning for Ontario residents: speakupontario.ca

ServiceOntario Publications – publications.serviceontario.ca
Download a free booklet that contains instructions and forms for Continuing Power of Attorney for Personal Care and Power of Attorney for Property.

Disease specific organizations have helpful guides and materials about advance care planning including: cancer.ca, alzheimer.ca, heartandstroke.ca, ALS.ca etc.

Health Care providers including your Physician, Case Coordinator, Nurse, Social Worker or other professional health care providers.

ONTARIO DEFINITIONS

Advance Care Planning is the process of thinking about what is important to you and what makes your life meaningful. It is talking about future wishes, values and beliefs that would guide a person's Substitute Decision Maker when they would be called upon to make a treatment decision on your behalf.

Informed consent must be obtained from a person (when mentally capable) or the Substitute Decision Maker(s) (if mentally incapable). Health care providers are required to get informed consent prior to any care or treatment, as well as withdrawal or withholding of treatment.

They must explain the benefits, risks, side effects and alternatives to each treatment and what would happen if the patient did not agree to a particular treatment. Any questions about a person's health, care and/or treatment offered must be answered by the Health Care Provider. This process is informed consent.

To be a **Substitute Decision Maker,** the person(s) must be:

- willing to act as your Substitute Decision Maker
- mentally capable of making health decisions for you
- available — in person or by phone or by some other means — when a decision needs to be made
- not prohibited by a court order from acting as your substitute decision maker and
- at least 16 years of age.

If the person in your life that ranks highest in the list of Substitute Decision Makers in the Health Care Consent Act does not meet these requirements, then the health care professional will move down the hierarchy to the next person on the list. The hierarchy order functions from the top of the list to the bottom.

Source: Hospice Palliative Care Ontario 2017, HCC ACP in Ontario - Summary of Key Themes and Common Errors

THE RANKED LIST (HIERARCHY) OF SUBSTITUTE DECISION MAKERS IN THE HEALTH CARE CONSENT ACT

1. Guardian of the person. This is someone that is appointed by the court to be your Substitute Decision Maker.
2. Attorney named in a Power of Attorney for Personal Care. The person or persons YOU have chosen to be your Substitute Decision Maker if you prepared a Power of Attorney for Personal Care when you were mentally capable of doing so.
3. Representative appointed by the Ontario Consent and Capacity Board.
4. Spouse or partner.
5. Child or parent or Children's Aid Society or other person lawfully entitled to give or refuse consent to treatment in place of the incapable person.
6. A parent who only has a right of access.
7. Siblings.
8. Any other relative.
9. Public Guardian and Trustee of Ontario.

Source: Appendix C of Summary of Key Themes and Common Errors. Retrieved July 17, 2018 from: http://speakupontario.ca/wp-content/uploads/2018/04/HPCO_Summary-of-Key-Review-Themes-Mar_2018-Final-.pdf

Bruce Peninsula Hospice Inc.
369 Mary Street, Wiarton, ON N0H 2T0
info@bphospice.ca | 519-534-1260 ext. 5612
www.bphospice.ca

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