

A Guide for End-of-Life Planning & Support




Hospice
Wellington™

YOUR STORY MATTERS



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The purpose of this booklet is to help you and your family through end-of-life planning and support. We hope it provides guidance and answers some of the questions you may have.

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Hospice Wellington

Your Story Matters

Your story is our story at Hospice Wellington. We are recognized in Guelph and Wellington County for our leadership in nurturing an environment where anyone facing end-of-life or bereavement is comforted, loved and supported. We are a charitable organization that provides residential and community services at no cost to our clients. Working in collaboration with our clients, volunteers, staff, supporters and partners, we aspire to provide the best possible palliative care for individuals and families. We are accountable to you as your story unfolds—to provide you with the compassionate, respectful, holistic care and support you and your loved ones deserve. Through listening, we recognize that we all have a story that makes us who we are. No matter our role or job title, our experience, our strengths or struggles, we all walk through the doors of Hospice with our own stories of life.

Hospice Wellington provides services to support those individuals of Guelph and Wellington County who are living with a life-limiting illness or experiencing grief and bereavement. These programs extend to the families and caregivers supporting those diagnosed with a life-limiting illness. Programs are available in the community, as well as to those who have been supported by our residential hospice. Services include One-to-One Palliative, Caregiver and Bereavement Volunteer Support; Palliative Day Program for clients and respite for Caregivers; Group Support Programming for Bereavement and Caregivers; Art Therapy Groups and Workshops; Integrated Wellness Programs including a variety of complementary therapies, and a Lending Library.

Hospice Wellington has a 10-bed residence to provide palliative care for those who are at the end-of-life. We care for and support residents and their families. Our compassionate team has training and expertise in palliative care and is here 24 hours, 7 days a week, to care for you with the dignity and respect you deserve.

Our at-home setting feels warm and cozy and is a tranquil space for families. One family member whose mother was a resident at Hospice, says she is “forever grateful for the journal in every room, the quiet spaces for her teens, spare phone chargers, family time at the dinner table, books and music for support, the beautiful garden, fresh homemade apple crisp. All the little touches that make such a big difference.”

Accessing our residence services

If you would like to come to our residence, you must:

- Have a diagnosis of a life-limiting illness.
- Have a prognosis of less than 3 months.
- Have a care approach plan that is palliative not curative.
- Reside in or have relatives residing in the Waterloo-Wellington region.
- Have a valid OHIP card.
- Have a Residential Referral Form completed by a family physician, Home & Community case manager, home care nurse, discharge planner in hospital, or palliative care specialist.



To ensure the specialized hospice care we provide is directed to those most appropriate to our services and care, we work diligently with Partner Agencies/ Hospitals/Home & Community Case Managers and Community Agencies to prioritize admission to Hospice Wellington. We are extremely aware of the need to provide palliative care services to a growing and aging population with increased needs. We are made aware every day of the burden that caregivers feel during the time they are trying to care for a loved one at home. We know they are often overwhelmed and exhausted, which highlights the need for providing a full spectrum of services to include emotional and spiritual care.

Admission is prioritized by need. For more information, please read our Admission Guidelines. You can also call our residence at [519-822-6660](tel:519-822-6660) for further information, or to schedule a tour so we can take you through our facility and answer any questions you may have.

Palliative Care

The end-of-life deserves as much beauty, care and respect as the beginning. Hospice Wellington's hope is that those with a life-limiting condition and their families have access to palliative care services and supports so that they can make the most of every moment.



The World Health Organization defines palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

Palliative care:

- Provides relief from pain and other distressing symptoms.
- Affirms life and regards dying as a normal process.
- Intends neither to hasten nor postpone death.
- Integrates the psychological and spiritual aspects of patient care.
- Offers a support system to help the family cope during the patient's illness and in their own bereavement following a death.
- Uses a team approach to address the needs of patients and their families.
- Provides legacy work if requested.
- Enhances quality of life and may also positively influence the course of illness.

Coping with your diagnosis

Receiving the diagnosis that you have a life-limiting illness can be a shock. Here are some practical ways that may help you cope with the shock and allow you to make the best decisions for yourself.

1. Make sure you understand your diagnosis

Be well informed. Get as much information as possible from your doctors and other reliable sources. This can help you feel more in control of your situation.

2. Speaking with your doctor

Open communication is very important to ensure that you get the information you need and that your doctor knows how you are coping with the diagnosis. Symptoms of depression and anxiety are natural outcomes after receiving a diagnosis and it is important to let your doctor know how you are feeling. If you can, have someone attend appointments with you, to take notes and provide support.

3. Talk to others

Having a good support network is always helpful, even though speaking with your family and friends about your diagnosis may be a challenge. (see "Serious Illness Conversation.")

4. Asking for help

It may be hard for you to ask for help. You may find that friends and family shower you with offers of assistance. Give them a task. Ask them to do something specific (get groceries, make a meal etc.). It truly makes them feel more valuable.

5. Finding a dedicated support network

It may be helpful to find a dedicated support group (on-line or in your community). Talk to your health care team about this as they usually have a list of local support groups.

6. Use anger and grief as a “lever”

Responses of grief and anger are normal feelings to experience when receiving a diagnosis of a life-limiting illness, but these emotions don't need to be destructive. It may help you to keep a journal and write down how you are feeling in order to process them.

7. Don't let your diagnosis take over your life

Look for things that you enjoy doing (crafting, writing, or drawing). This could help you stay in touch with who you are outside of your health profile. Shift your mental and emotional focus to something pleasant and creative. Gentle exercise may also be useful and help you cope. Remember... one day at a time.

It is a work in progress to learn to live with your diagnosis. There is no right or wrong way of coping, but what is essential is that you stay in charge of your body and your life.



Serious Illness Conversations

How to tell your family and friends that you are dying.

It is one of the hardest things in life to be told that you are going to die. Another challenge and task is to tell your family and friends. There is no right or wrong way, only your way- what feels right for you

Only you can decide with whom you want to have this conversation.

Choose a quiet time and place. Give them the information openly and honestly that you are comfortable sharing.

1. Choosing the Right Approach

- Choose a setting that suits your needs (quiet, private and comfortable)
- Consider grieving with them rather than waiting for acceptance
- Tell them on your time but sooner rather than later
- Let them know ahead of time that you have something important to discuss
- Write a letter if you simply can't face having this conversation
- Ask them to keep the information private if that is a concern for you

2. Speaking Openly and Honestly

- Describe your situation as frankly and honestly as you can
- Start by telling them how much they mean to you
- Tell them how you are feeling
- Ask them to be understanding of your struggles

3. Keeping the conversation going

- Accept that everyone will react in different ways
- Encourage them to ask questions and express their feelings
- Offer them specific ways they can help if they ask
- Be clear that you aren't saying goodbye yet





Checklist of Things to Consider

You should organize your documents in a safe place – ideally all in one space and let your Power of Attorney(s) for Personal Care and Power of Attorney(s) for property as well as an Executor(s) know where that is. It is extremely important that they have access in order to carry out your wishes.

About you

☐ Do you have any Advance Care Plans? _____

Where are they kept? _____

Advance Care Planning is about deciding who will make health care decisions for you if you are not able to. It's about having conversations with your designated substitute decision maker about your wishes, values and beliefs to help them understand how you would like to be cared for.

You can visit www.speakupontario.ca for more information.

A substitute decision maker (SDM) is one or more persons you can choose and name, to act as your decision maker by preparing a document called a Power of Attorney for Personal Care.

☐ Who is your Substitute Decision Maker (SDM)?

Contact Information: _____

What are your wishes, values and beliefs for treatment related to advance care planning?

☐ **Do you have a POA for Property?** *(can be the same as for health or someone different)*

Who is this? _____

Contact Information: _____

☐ **Do you have a Will?** _____

Where is the original? _____

What Law Office is the Will at? _____

Who is the Executor? _____

Contact Information: _____

You can visit **www.attorneygeneral.jus.gov.on.ca** for more information.

☐ **Do you have a Do Not Resuscitate (DNR) Confirmation form filled out by a Doctor/Palliative Nurse/RN/RPN?**

This is an order written by your doctor that lets the rest of the health care team and your family know that in the event that your heart stops, and you stop breathing, you do not want the team to try to bring you back to life. This does not mean that you do not want care or treatments. Talk to your doctor or Nurse Practitioner about this. A DNR Confirmation form provides Emergency Responders (EMS) with direction not to resuscitate (If this form is not present, they are required by law to resuscitate).

We recommend you keep this confirmation form on the side of your fridge as EMS will look there.

❑ Do you have any Funeral arrangements made?

Which Funeral Home? _____

Contact Information: _____

Where is your copy kept? _____

- Have available clothing, jewelry, special items and pictures set aside (put in a clearly labelled bag to give to the funeral home – let someone know where this is kept) – you will need 2 pictures, one for the funeral home preparations and one you want for the public to see)
- Write out a list of important numbers for who to call when you die (eg. family members, doctor, nursing team etc.) and let someone know where this is kept (could be in a communication book that you set up)

You may already have arranged a pre-paid funeral – talk to your funeral home about options.

❑ Do you have Life Insurance? With whom (company)?

Who is your Beneficiary? _____

❑ Do you have a Pension Plan? With whom (company)?

Is there a defined benefit pension? Where?

❑ Do you have any other memberships that have Death Benefits?

Identification Documents

Where are these kept? – try to have them all in the same location.

- Driver's licence
- Passport
- Social Insurance Number (SIN)
- Marriage Certificate
- Birth Certificate

Financial Documents

- List all bank accounts – what bank do you deal with (tax free savings accounts etc.)

- Do you have RRSPs or RSPs? (where are they, Bank/ Work?) _____

- Home insurance – what company?

- Car Insurance – what company?

- Proof of ownerships – for vehicles, home, any assets

- Do you have any credit cards? List all of them

Personal Passwords

- Computer_____
- iPad/Tablet_____
- Cell phone_____

On-line Accounts

- Gas_____
- Internet_____
- Cable_____
- Water_____
- Home/Auto Insurance_____
- Banking_____
- Telephone Company_____
- Cell Phone Company_____



Communicating With Others

You may want to start a communication book. This book would be a tool for you to write down specific information for the nurses, doctors, family and caregivers.

- Write down important questions when you think of them – or ones your family might have for the doctors / nurses.
- Write information in this book that you want the caregivers/family to know (like “please make sure the hall light is out after 6pm”).
- How are you sleeping (sleeping patterns)?
- What is your food and drink intake?
- Are you having bowel movements/voiding – how much and how often?
- How is your overall behaviour/mood? (are you confused more than usual).
- If in bed or sitting more often – watch for skin breakdown – record any red or open areas to report (the nurse can address these).

This book can also be for the caregivers to write logs about their time with you. You can also keep a log of when pain medication was taken to track how much you are requiring, to communicate this with your doctor/nurse. These are important things to have written and communicated as the nurse may need to talk to the doctor to adjust medications/treatments/diet. It is also important to make sure your family/caregivers know so that they can ensure you are getting the proper care that you need.



Adapting your Home

ENVIRONMENTAL

- Surround yourself with familiar objects
- Put out pictures you love
- Have your favourite blanket and pillows
- Have a lamp for soft light
- Do you want a fan?
- Have your favorite music available
- Remove area rugs (avoid trips and falls)
- Have room/seating for visitors
- Perhaps an essential oil diffuser with aromas that comfort you and a salt lamp for soft light
- Ensure you have access to a phone (home line/cell phone to answer calls easily) and phone charger

PHYSICAL

- Do you need a bath chair or any assistive devices? (the health team care coordinator will assess this and get you what you need)
- Keep a garbage can close by
- Ensure there is easy access to a sink (for hand washing)
- Have gloves and masks available
- Hand sanitizer for visitors
- If using needles/sharps – have a container (Pharmacy can supply this)

SPIRITUAL

- Contact your faith community and/or spiritual community
- Do you have any rituals you want to have performed?

People vary greatly in their spiritual and/or religious beliefs and needs. During this time, a spiritual advisor can provide compassionate spiritual support to you and your family.

SOCIAL

- What are your cultural values, beliefs and practices that you want people to know about and follow? Make a list and post a note to make people coming into your house aware.

PSYCHOSOCIAL

- Do you have someone to talk to if you are feeling depressed, anxious, scared, or hopeless?



Funeral Information

The following information is needed by the funeral director.
This information is needed for the funeral director to obtain a permit for burial or cremation and a death certificate.

Name:

(Last Name) (Middle) (First name)

Maiden name: _____

Marital status: _____

(single, married, widowed, divorced, separated)

If previously married/divorced/widowed/separated, name of spouse:

Address:

(House/Apt. #/Street/Road) (City, Town) (Postal Code)

Date and Place of Birth:

Father's name: _____

(full first and last name)

Father's Place of Birth: _____

(province/country)

Mother's Maiden name: _____

(full first and last name)

Mother's Place of Birth: _____
(province/country)

Occupation: _____

Sex: _____

Social insurance number: _____

Date of Death: _____

Age at time of death: _____

Funeral Information

Even if you have a pre-paid funeral there may be things that were not covered in the plan.

What Funeral home are you using or wanting to use?

Are you wanting to be cremated or buried, do you want a 'green' environmentally friendly option?

Do you have a Plot?

Who owns the Plot? (*Interment rights holder*)

What Cemetery and Lot #?

Funeral Pre-Planning wishes

Would you like a death announcement/picture in the paper? *(Information about any other family members that have passed, that you would like included in the funeral notice)*

Do you want a visitation?

Where would you like this to take place?

Do you want pictures set up on the room or special items on display?

Do you want an open casket or closed?

Would you like any scripture/readings read at the funeral?
Who do you want to read them?

Do you want a eulogy?

Have you picked out your clothing/jewelry? Where is this kept so people know where to find it.

Whom would you like to officiate at the funeral?

Do you want any music played at the funeral? What songs?

Whom do you want to act as pall bearers? (need 6 people)

Would you like to have a gathering/reception after the funeral and burial? Where will this take place?

Some people do not want to have a funeral and just may want to have a Celebration of Life / Memorial service. Please write out below where you would like this to take place. Add any details you want.



What to Expect

This is to help your caregiver/family know what to expect in the last days of your life.

What to Expect

- Ensure that you get proper pain and symptom control, good emotional and spiritual supports and time to be with your loved one in ways that are most comfortable for you both.
- Someone who is dying may go through many physical changes. Each person is different, but there are some general trends. Talk to your doctor or nursing team about any symptoms you notice.

Allow Natural Death

- Someone who has been diagnosed with a life-limiting illness or terminal illness may die suddenly and unexpectedly (heart attack, stroke, etc.). Please discuss these possibilities with your loved one and doctor/nurses in advance so that they can all be on the same page if this occurs (talk about your Do Not Resuscitate wishes).

The Last Days or Few Weeks

Sleeping

- The person may sleep longer and may have trouble waking.
- Plan short conversations when they are awake.
- Ask visitors to stay for shorter periods.
- Re-position the person regularly to prevent bedsores (less necessary in last days).
- Vision may be less clear. They may prefer dimmer lights if their eyes are sensitive.
- The person may not react to your voice or touch. They may be sleeping very deeply or in a coma. Continue to talk in a calming, peaceful voice since they may be able to hear you.
- Remember they tire easily now, plan for rest periods between activities or visits.
- The person's eyes may remain open – even when they are sleeping. If possible, close them gently to prevent them from drying out. It can be difficult to keep their eyes closed (try over the counter lubricating eye drops).

Food & Fluid Intake

- They may eat and drink less.
- Loss of appetite and decrease in thirst are common. The body is beginning to shut down and does not need nourishment. Food and fluid may actually cause discomfort.

- Make sure their mouth, lips, nostrils, and tear ducts are moistened. Use proper cream, balm or drops (check with the nurses for advice) Do not use any petroleum gels if oxygen is in use.
- They may have trouble swallowing or forget how to swallow.

Elimination

- They may experience changes to their bowel and bladder function.
- Urine output and bowel function will decrease as food & fluid intake decreases.
- Common disfunctions may include constipation, incontinence and/or bladder retention leading to the need for a foley catheter. Urine and stool may also change colour.

Restlessness & Confusion

- They may become confused. At times, the person may become restless, seeing or hearing things that are not there.
- They may not recognize everyone or everything and may be confused about time.
- They may experience agitation or delirium as a result of natural chemical changes in the body and/or in relation to medications.

Breathing

- They may have shallow or irregular breathing.

- It is common for people near the end-of-life to not breathe for 10-30 seconds at a time (sleep apnea). This is not uncomfortable for the person. They might breathe like this for several days before death.
- They may make involuntary sounds (moaning or verbalizations). Check to ensure they are not in pain. Talk to the nurse about this.
- They may have “wet” sounding breathing (gurgling, congested sounding). This is not uncomfortable for the person. Turn the person on their side (if possible and safe to do so) and check with the nurse; they may be able to give medication to help.
- They may experience increased respirations.

Swallowing

- The person may have trouble swallowing.
- It is important to assess the person's swallowing and adjust texture and amount of intake accordingly. Improper assessment could lead to choking and/or aspiration.

Heartbeat

- The person may have an irregular heartbeat. It is normal for their pulse (heartbeat) to change rhythm since the body is slowing down. They may have a rapid (fast) pulse several weeks before death. This is not uncomfortable for them.
- Their pulse could also become weaker and irregular.

Skin

- The person may have cool arms and legs.
- Their blood circulation is slowing down. It does not usually mean they are feeling cold but rather their blood circulation is returning to the core of the body and is a natural part of dying.
- They may become restless. If they are too warm, remove a blanket.
- They may want lighter clothing.
- The skin may show different colours and temperature as the circulation slows.

Any questions about the management of these symptoms should be directed to your healthcare team.

When to call the nurse

Some symptoms may become worse at end-of-life and interfere with the comfort of your loved one. You should call the nurse if you have any uncertainty, or the treatment(s) being provided are not effective.

Nursing Agency: _____

Nursing on-call phone number: _____



Caregiver Supports and Strategies

This is a page addressed to those people who are caring for you. They too need to be aware of what they need to be healthy and strong while they support you.

- It is important to pay attention to nutrition and to eat well, even if you are feeling too tired or busy. Proper meals are important.
- Exercise regularly, and it is okay to start small (even if it's a short walk outside). Try doing what you enjoy most -- walking, jogging, swimming and cycling are all good forms of exercise.
- Keep up with your regular medical appointments and talk with your doctor/nurse practitioner about options such as time off work, respite and counselling.
- Find out if there is a local support group where you can talk with other caregivers who understand how you feel.
- Keep up with activities that are meaningful to you. These may include spending time outdoors, gardening, going for walks, reading, participating in hobbies and crafts, and spending time with family and friends.
- Consider trying other forms of self-care such as mindfulness, deep breathing and relaxation techniques.

- Ask family and friends for help, and don't be afraid to be specific, such as meals, housework, shopping, errands and outdoor work. Creating a list enables family and friends to pick specific tasks; this may help ease anxieties and fears.
- It is important to give yourself credit for all of the good things you are doing and for making use of what is available to you for help.
- Being caregiver is a very important role and at times you may need support. Hospice Wellington has resources to assist you. All of our services are offered at no cost to you.



When Death Occurs

After a death, it is normal to feel shocked and numb about what comes next

Who to call?

- Is there a list already made? Use this list to make calls.
- Call the nursing team (to come and pronounce) or the doctor if you can't reach the team.
- Make calls to family and people that need to know immediately.
- Call for a support person to come and help you make calls and be there for you.
- Once the nurse or doctor has pronounced, they will give you a form to send with the body to the funeral home.

Arrange for body transport

- The nursing team may do this, or you may need to call the funeral home.

Funeral home: _____

Phone Number: _____

For more information regarding what to do after the person has died, please refer to the funeral home directions.

Tips for Grief & Bereavement Support

Immediately following death, there will be funeral arrangement details and other demands that will keep you busy.

It is normal during this time to feel like you are in a fog or to feel exhausted. Accepting support is not a sign of weakness. It is a sign of solidarity with your community. Allow your community of friends and family to help you through this passage. Whether it is a second pair of eyes or ears as you settle estate matters, a fully stocked fridge with healthy meals, or a safe, friendly place for your children to be cared for while you are attending to your own grief, this is the time to allow the strength of others to support you.

Grief impacts us in every area of our lives: physically, mentally, emotionally and spiritually.

Ensuring you are getting the proper sleep and nutrition can help you manage the other stressors of grief. This is easier said than done when your life has been turned upside down. Don't be afraid to reach out to your physician or healthcare team for a check-up. Often when we're caring for others, we ignore our own health. Now, more than ever, it is important to care for yourself.

When you feel ready for support, Hospice Wellington will be there for you. Just pick up the phone and call us. We'll explain the bereavement supports available to you and walk beside you during your grief journey.

Bereavement services at Hospice include:

- One to one support
- Group Support
- Wellness supports including yoga, walking group, reiki, and mindfulness resources.

Call Hospice Wellington at 519-836-3921 x228 for support, or if you have any questions.

'Talking about sadness and grief can help let out some of the pain and sometimes that leaves more room in your heart to remember what you loved about someone'

-Nicholas Sparks





Helpful Resources

Speak Up Ontario

www.speakupontario.ca

Hospice Palliative Care Ontario

www.hpcoco.ca

A Caregiver's Guide: A Handbook About End-of-life Care
(Canadian Hospice Palliative Care Association)

https://hospicetoronto.ca/PDF/Acaregivershandbook_CHPCA.pdf

Bereaved Families of Ontario

<https://bereavedfamilies.net>

Canadian Virtual Hospice

www.virtualhospice.ca

Hospice Wellington Resources Page – (you will find links here
to many of the resources you may need)

<https://www.hospicewellington.org/resources>

“Conversations Worth Having”

<https://www.acpww.ca>

The Nightingale Centre For Grieving Children, Youth and
Families

<https://nightingalecentre.org/>

Resources Used In The Creation Of This Booklet

www.ariadnelabs.org/areas-of-work/serious-illness-care/

www.wikihow.com/Tell-a-Good-Friend-That-You-Are-Dying

<https://www.joincake.com/post-death-checklist-1>

www.hpcconnection.ca- 'When Someone is Dying in the Community' booklet

www.palliativecare.ca

www.hpcoc.ca

www.mayoclinic.org

"A Caregiver's Guide -A Handbook about End-of-life Care"
(The Order of St. Lazarus and Canadian Hospice Palliative Care Association)

Thank You

Thank you to the Hospice Wellington Residence and Community Teams and to community members for their help and input in the creation of this booklet.

Thank you to our generous donors who help provide the funding to offer these supportive services to our community.



Notes:

Notes:

Hospice Wellington

Contact Information

Community Services: (519) 836-3921
Residence Services: (519) 822-6660
Website: www.hospicewellington.org
Address: 795 Scottsdale Drive
Guelph, ON N1G 3R8



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