AFTER DIAGNOSIS:
PLANNING FOR YOUR END OF LIFE

IT'S YOUR LIFE. IT'S YOUR CHOICE.

DYING WITH DIGNITY CANADA

The health care system can be complicated and disjointed. Through this resource, **Dying With Dignity Canada** (DWDC) outlines valuable considerations for those diagnosed with a life-limiting condition.* The focus of this resource is on end-of-life care decisions and the importance of thinking about and discussing options and priorities early and often. Much of the information and perspectives shared in this resource were generously offered by DWDC's Clinicians Advisory Council — a knowledgeable and compassionate group of nurse practitioners and physicians. We are grateful for their input.

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*Life limiting conditions are serious illnesses that are expected to impact one s life expectancy. Some may impact life expectancy in the near term, such as terminal cancer, while others may be progressive and gradual, leading to decline over several years, such as dementia.

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FIRST STEPS AFTER DIAGNOSIS

If you've recently been diagnosed with a life-limiting condition, consider the following:

Think about your values

It is important to determine what is valuable to you at this point in your life. You may wish to consider the impact of medical treatments on quality of life and whether these might also affect the length of life remaining; this may mean contemplating what treatments you are willing to endure for the possibility of more time. Some people may want to try several medical treatments, and others may want to limit those interventions.

Values may change over the course of your illness. That is okay. You may have changes in perspective later, so it is important to check in with yourself often and not just when things "get bad."

You may want to consider your end-of-life process and how you want it to play out; this may include reflecting on what matters most to you in your final years, months, weeks, days, and hours.

Explore options for care and treatment

If you do not have a primary care provider (nurse practitioner or family physician), it is important to try and connect with one soon after diagnosis. They can help you explore available options to maintain your current quality of life and those that might be considered later, as your health status changes.

Some examples include disease-modifying treatments, palliative care to address symptoms and lessen suffering, home care, hospice/end-of-life care, and medical assistance in dying (MAID). If you are interested in any of these options, you should inquire about both eligibility and availability.

You may ask for a referral to palliative care immediately after diagnosis. Palliative care can be a beneficial support early on to address symptoms of the disease, as well as symptoms of the disease-modifying treatments and is not limited to the final weeks or months of life.

The health care system is often focused on "doing more." If you are no longer interested in diagnostic tests or disease-modifying treatments, this is something that should be communicated and may need to be expressed several times.

Reflect on and document your preferences

This could include writing a will and completing an **Advance Care Plan** with your **Substitute Decision-Maker** (**SDM**) or **Power of Attorney for Personal Care** (**POAPC**), as well as legacy projects, such as organizing items in your home or writing down important stories about your life.

Have conversations

Surround yourself with as much support and understanding as possible by talking to your trusted family and friends about what is happening, and your future wishes and priorities; this is the essence of Advance Care Planning. Keep the lines of communication open with your health care team.

QUESTIONS YOU MAY WISH TO ASK:

- What is my prognosis?
- What can I realistically expect at different stages of my illness? Will the illness progression be a steady decline, or will there be periods of recovery?
- What symptoms might I experience as the illness progresses?
- What are my options for symptom management? How available are these options and who can provide them?
- What care supports can I anticipate needing (e.g. toileting, bathing, dressing, wound care, meal preparation) down the road?
- What forms or paperwork should I complete now?
- Are there any additional supports I can access? Is there anyone else that should be involved in my care (e.g. home care)?
- Should I develop an end-of-life plan now?
- Who should I call if I have questions or experience changes?
- Are there websites, brochures, or other resources that I should be aware of and refer back to as things progress?

WHAT TO EXPECT AS DEATH APPROACHES

Death means different things to different people. For some, it is incredibly sad and lonely. For others, it is a beautiful experience that is welcomed after years of suffering and decline.

For some, there is uncertainty. Others experience curiosity and are comforted by what might come after death. A person's culture and personal or religious beliefs may impact their thoughts and feelings about death.

"It could be sad, or it could be welcomed. It may entail suffering or not. It may be peaceful and quiet. It may be frightening. Some consider it an adventure to see what comes next."

~ Clinicians Advisory Council Member

You can often predict death by considering the full experience of the past year. For example, have you had more visits to the emergency room or been hospitalized? Following these episodes, do you regain your prior level of functioning? Do you need more help with daily tasks such as bathing, using the toilet, feeding yourself, or getting dressed?

These could be signs that you are nearing the end of your life. How quickly these changes occur may indicate how close you are to dying. For example, if noticeable changes are happening week-to-week, it could mean that death could occur in a matter of weeks. If changes are happening day-to-day, death may occur in a few days. Being aware of these changes and what they mean can provide an opportunity to connect with loved ones one last time.

Active dying

Active dying often involves "less" of everything – less movement, less wakefulness, etc.

Signs of active dying can include:

- Sleep changes: Deeper sleep, less wakefulness
- Changes to input and output: Eating and drinking less, or nothing at all, less urination, and fewer bowel movements
- Breathing changes: Periods of apnea where you stop breathing and then start again
- Cool or mottled skin
- Weakness: Inability to leave your bed or needing help with repositioning

Just because you are dying does not mean you will develop pain. If pain has not been a difficult-to-treat symptom throughout your disease, it is unlikely to become a difficult-to-manage symptom during the active dying stage.

DECIDING WHERE YOU WANT YOUR DEATH TO TAKE PLACE

Where you die impacts the experience. The process of dying will be quite similar regardless of the location, but there are some key factors that will differ depending on the location. This can include who is providing care and options for administering medication for symptom management.

Home

Dying at home is often considered to be less clinical than in other settings. For some, it is more comfortable because you can be surrounded by what is familiar to you, including your own bed.

In a home setting, your family provides much of the care with support from nurses and personal support workers (PSWs). In some regions, families provide the bulk of the care, including toileting, bathing (including the genital area), medication administration, scheduling, note-keeping and communicating with the health care team. It may be important to investigate the cost of private-pay home care services to determine if it is a feasible option to supplement provincial/territorial services.

When professionals visit the home, be sure to ask them for advice; nurses, PSWs and others tend to have years of experience and important practical tips that you can implement with some support and education.

Be sure to also ask about other supports available, such as medication delivery from the pharmacy, community volunteers for respite services, transportation services, housekeeping and meal delivery or preparation. You may also ask about occupational therapists who can help make the home environment easier to navigate and more aligned with your needs through the use of assistive devices.

It is important to know who the most responsible practitioner (nurse practitioner or physician) is, as they will oversee prescribing medications, providing orders to the nursing team, and completing the Medical Certificate of Death.

QUESTIONS YOU MAY WISH TO ASK:

- Is remaining at home with support from home care feasible? If so, for how long?
- How will I know if staying at home is no longer feasible? If it's not, what are the other options?
- What services do you provide? How much care will my family be required to provide?
- What is the cost of the services? Are there funding options available through government or community organizations?
- How available are these services?
- When will the visits be, and for how long?
- Will the same home care person visit each time?

Hospital

Dying in hospital may be the right choice if dying at home is not an option. For example, if you have limited family support, or if you want your family to just be present with you and not provide care. At the hospital, care is provided by paid staff (physicians, nurses and allied health care providers, such as respiratory therapists). To make time spent in hospital more comfortable, you may consider bringing in comforts from home, such as bedding, your favourite foods, or photographs. Frequent visits from family and friends can also provide additional comfort.

QUESTIONS YOU MAY WISH TO ASK:

- Can pets visit? What do those options look like?
- Can the nursing team contact the physician to get additional questions answered on my behalf?
- Can I request a family meeting with all members of my health care team?

If MAID is something you want to consider, you should ensure – ideally prior to admission – that assessments and provisions can occur onsite.

Hospice

Hospice settings try to create a home-like environment. Care is usually provided by both family and hospice staff.

Hospice support is not always available immediately. For some, there is a wait to access these services.

QUESTIONS YOU MAY WISH TO ASK:

- What are the limits for admission? (Most hospice residences will only admit people if their death is anticipated within a certain number of weeks)
- Can people visit whenever they want?
- How many people can visit at a time?
- Can pets visit? What do those options look like?

If MAID is something you want to consider, you should ensure – ideally prior to admission – that assessments and provisions can occur onsite.

PALLIATIVE CARE

Research has shown that starting palliative care early leads to the best patient and family experience. It is not something that is only helpful in the final days or weeks; you can benefit from palliative care for many months, even from the time of diagnosis.

To determine if palliative care is appropriate, clinicians may ask themselves: Would I be surprised if this person died in the next 12 months? If the answer is "No," palliative care is likely appropriate.

Access to palliative care is often more straightforward for people with a cancer diagnosis; however, regardless of diagnosis, you can ask about and advocate for these supports.

QUESTIONS YOU MAY WISH TO ASK:

- How available is this service?
- How do I get involved with palliative care if I don't have a cancer diagnosis?
- Are palliative care providers available outside regular office hours, in case I have symptom concerns?

Palliative care may mark the end of disease-modifying treatment, but it doesn't mean that care will no longer be provided. Palliative care is not "giving up." It is a holistic type of care that focuses on improving quality of life and managing symptoms.

Many health care providers are able to provide palliative care, such as nurse practitioners, registered nurses, and family physicians. Specialists can also provide palliative care.

THE CAREGIVER EXPERIENCE

Some challenges that a caregiver may experience include:

Communication

Some caregivers may struggle to access members of your health care team to ask questions or receive information. Some may also feel as though members of your health care team are not communicating amongst themselves, leading to delays and frustration.

Denial

Witnessing your decline and recognizing that your life may be ending soon can be very difficult for caregivers.

Guilt

Some caregivers may struggle to ask for or seek out respite care, which can provide short-term relief. Taking breaks to return to caregiving refreshed is extremely important. For some, respite care may be lacking or unaffordable in their area.

Caregivers may feel relief when a loved one dies. This is a natural reaction and there is nothing to feel guilty about.

Anticipatory grief

If you are choosing an assisted death, caregivers may feel anticipatory grief leading up to the MAID date. This is common even for those who are supportive of MAID.

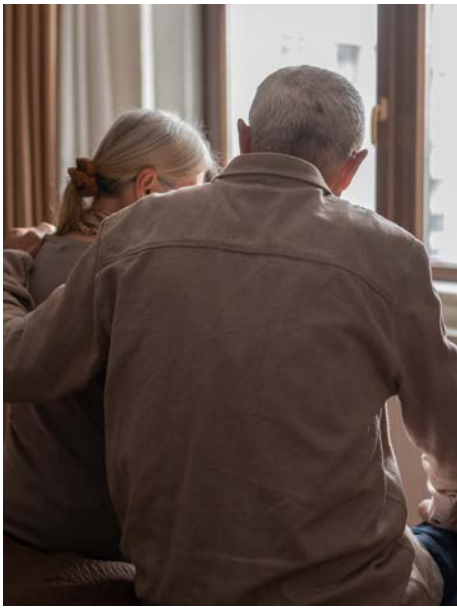
Anticipatory grief can also happen outside of a MAID death and caregivers may feel this intensely during their caregiving experience.

Burnout

Caregiving can be difficult and exhausting. Many caregivers will spend all their time and energy on your care without rest or adequate support; this is unsustainable. You may not recognize the extent of care your loved one is providing you, leading to additional complications.

"Some caregivers share that despite how difficult it is caring for a dying loved one at home, they would not have done things differently and felt very privileged to be able to provide this intimate, meaningful care. Other families are not capable, for a variety of reasons, of caring for someone until death at home."

~ Clinicians Advisory Council Member



Advice for caregivers

It is important for caregivers to look after themselves, even as they care for their person. Feeling emotions is an important part of the caregiver's experience; it is okay to not be okay.

Caregiving is a marathon, not a sprint. To be sustainable, it is important that the caregivers make time for themselves and take frequent breaks.

This does not mean just stepping away to run more errands; it should ideally include creating space to nap, workout, go for a walk, or meet a friend for lunch. Caregiving 24 hours a day is not realistic. There are limits to what someone can provide, and that is okay.

"Having open conversations about realistic expectations right from the beginning of the illness journey is important, so everyone is on the same page."

~ Clinicians Advisory Council Member

There may be tasks that family and friends can help with, but caregivers may just need someone to talk to. It is okay to ask someone to just listen quietly and sympathetically, rather than trying to provide solutions.

Depending on the situation, there may be social workers who can also provide some support. Seek out the support of caregiver or friendly visitor groups offered by local hospices, caregiver organizations, or disease-specific organizations, such as the Canadian Cancer Society, who may have other resources and supports. These organizations may also offer bereavement support, so building relationships with them early may be helpful for future needs that arise.

Continue to regularly ask about supports at several points in the journey, especially as new needs arise. This is something that can be done early on and throughout the process. When it comes to supports, it is important to decide what is helpful and what is not; it is completely okay to politely decline supports that are becoming a burden to organize and facilitate.

FINAL THOUGHTS

It is common for there to be a lack of communication among health care team members – even those who are supporting the same patient. If you have specific needs, don't hesitate to ask. This may mean that you are asking many different people or raising your question multiple times. Advocating for yourself (or having someone advocate for you) is important, especially if the health care team is not clearly understanding your beliefs, values, and wishes.

Talking about health status and thoughts about the end of life is important. If you start these discussions early and have them often, that will have a positive impact. These conversations may be uncomfortable, but they are vital. Health care providers can be just as uneasy when it comes to talking about death as those outside the medical space, and some may shy away from the topic. This can lead to families being quite shocked when a death happens.

"The "best" deaths that I have been privileged to be a part of are within families where nothing has been hidden, the realities of the situation have been faced head-on, and the best has been made of a situation that we would all change if we could – but can't. Caring for someone at the end of life, when they are aware they are dying and have said and done the things to feel as if their life is complete, is a beautiful gift that transcends the individual and leaves a lasting impression for everyone who has been a part of their life and death. Good dying leaves a positive legacy."

~ Clinicians Advisory Council Member

ADDITIONAL RESOURCES

- *The Waiting Room Revolution*
- *"Hope for the Best, Plan for the Rest"*
- *Early Identification & Prognostic Indicator Guide*
- *Bridge C-14*
- *MyGrief.ca*
- *MAID Family Support Society*
- *Canadian Virtual Hospice*

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