



Remaining at home: Things to consider

Many Canadians say they would like to die at home, probably because home feels comfortable and familiar. Yet, most of us aren't aware of what supporting a death at home might involve. The purpose of this article is to outline some of the potential challenges and rewards that come with a home death. That way, both patients and caregivers can have a better idea of what might be expected.

Is there a "best" place to die?

Deciding where to provide care can be a difficult decision and you may find that you change your mind as circumstances change. There really is no one "right" answer. What is ultimately most important is that the person feels comfortable and you have the support that you need. If you try to stay flexible in your planning, you might be able to avoid feelings of guilt or regret if things change in the future. People often hesitate to make a change in location when they feel it means breaking a promise, either to themselves or to a family member. Instead of promising a home death, you might decide:

- to stay at home for as long as possible;
- to regularly review how caregiving is going with the health care team.

One of the reasons people choose a home death is because they can have family nearby in familiar, comfortable surroundings. With the support of local health care services (such as a palliative care program with home care resources), this may be a rewarding and meaningful experience for the family. But, near the end of life, families may feel overwhelmed with caregiving responsibilities and find that they are spending very little time talking, sharing or sitting quietly with the person who is dying. If you find yourself in this situation, you may want to re-create the home environment in a health care setting.

You can sometimes create surroundings that reflect the way the person has lived – even in a hospital room. Photographs, music or other important family items can help to personalize what may otherwise be an institutional space. For some families, removing the responsibilities for primary caregiving can free up time and mental space for family members just to be together. For them, maintaining the spirit of being "home" is more important than actually being at home. For others, there is a sense of purpose and accomplishment that comes with caring for a family member at home.

Things to think about

If you are considering a home death for you or a member of your family, there are some basic elements that will help make that possible:

- The patient and the family support the idea of a home death.
- More than one family caregiver is available.
- Skilled medical support is available at any hour of the day.

After these basics, there are some practical considerations:

- Does the family have the resources to support a home death? For example, is there wheelchair access into the home? Is there a bedroom on the main floor? Can caregivers afford to take time off work, or are they eligible for caregiver benefits?
- Is the patient able to perform some tasks, such as transferring to a toilet or holding a spoon for eating, or does the caregiver need to help with all tasks?

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- If the patient is having physical symptoms, like pain or trouble breathing, has the caregiver been provided the needed resources and information to make the patient comfortable?
- Is there enough room in the home for medical equipment that would help in providing care?
- Is the family comfortable with health care providers coming into the home to help with caregiving? Home care workers, palliative care nurses or doctors may be some of the people who visit the home.

See also: [Caregiver and Survivor Benefits](#)

Open lines of communication

Ongoing communication is essential in caring for a family member at home. A shared understanding of each family member's roles and responsibilities will help to avoid feelings of resentment or anger. If possible, talk about how you are feeling throughout this experience, as you will likely experience many different emotions. Seeking the support of people you feel comfortable confiding in may help to reduce feelings of isolation and may also lead to offers of help.

Open, honest communication with the health care team is also helpful. Keep in mind that many health care providers will be watching for cues from you about how much information you are ready to receive. You may have to let your health care team know you are ready to have more detailed information.

Community supports

It is important to have the support of health care providers who are easy to reach and responsive to your concerns. Your health care team can be a great support in helping you to develop a home caregiving plan. The team can help you understand what resources you need now and what resources you may need in the future. They can also help connect you to other support networks in your community.

Some of the people on your support team may include:

- nurses or doctors working with local or regional palliative care programs. Even if in-home visits are not offered through the program in your area, program staff may still be available to offer telephone advice. These programs are often run through hospitals;
- family doctors or nurse practitioners who are willing to make home visits;
- home care nurses who can help you to manage symptoms at home by visiting regularly, assessing your health care concerns, and coordinating care with other members of your health care team;
- health care aides with home care programs who may help with bathing, light meal preparation and cleaning;
- respite staff offering short-term patient care for several hours or even several days;
- hospice volunteers who can visit, provide support, and help you to feel less isolated at home.

Home care programs may also provide access to equipment such as wheelchairs, walkers, bath seats, shower rails, and hospital beds to help family caregivers provide safe care.

Remember that you are an important part of your health care team. Sharing your observations, questions and concerns with your care providers helps them identify the appropriate resources.

See also: [What Is Palliative Care?](#)

Planning ahead

People with terminal illness will generally experience changes in their physical abilities as illness progresses. Over time, they may develop new or progressing symptoms. Preparing for these changes in advance with your health care team can help you to feel more comfortable when these changes occur.

Prepare for common symptoms

Talk to your health care team about what to do if your family member experiences symptoms such as pain, shortness of breath, confusion, restlessness or increased chest secretions. All of these symptoms can usually be managed at home, even if the person is unable to swallow medications.

Prepare for medication changes

Sometimes the health care team can anticipate when new challenges might arise and a new medication might be required. In that case, you may be provided with a prescription so that you are ready for the change.

There are other medication issues to consider. All of these can usually be anticipated and prepared for, often avoiding the need for hospitalization:

- Does the patient still need existing medications? Medications that are not needed to provide comfort (for example cholesterol medications) may be discontinued.
- Might any existing medications be harmful as the patient's condition declines? For example, medication to lower blood sugar may cause new risks if the patient is no longer able to take in food.
- Is there a plan in place to manage symptoms when pills or tablets become hard for the patient to swallow? Medication may then be administered under the tongue, with skin patches, by injections under the skin, or through other means.

See also: [Help with Medications](#)

Prepare for emergencies

Talk with your health care team about who you should call if you need urgent help at home during the day or on evenings and weekends. Possible options include your family health care provider, a palliative care tele-health network, your home care nursing office, or 911. Keep information about emergency contacts in a spot that is easy to find, such as on the fridge door.

Prepare for caregiving breaks

As a family caregiver, you may be required to help with bathing, toileting, lifting, and turning a person in bed. The physical work of providing care can be exhausting, particularly if you are living with your own health concerns. Plan to have friends and other family members ready to help or to give you a break when you need it. Scheduling regular breaks in advance can help to ensure that you have time to replenish your energy.

See also: [Caring for Yourself](#)

Prepare for physical changes

Over time, people living with terminal illness become weaker and less able to physically care for themselves. Using equipment such as walkers, bath seats, shower rails or commodes can help the person maintain a sense of independence even as they become weaker. It may be helpful to look around your home from the perspective of someone with a physical disability: *"Can we get a walker or*

wheelchair through the bedroom door? Will that rug be a tripping hazard?"

These are some physical changes that are often significant for patients and families.

- **Needing help with toileting**

Many people feel awkward thinking about helping a family member use a toilet. If the person is unable to move very well, you may need to bring a commode to the bedroom, or you may need to use a catheter. Most people report that dealing with such realities of life requires no loss of dignity if dealt with matter-of-factly.

- **Losing the ability to move around the home**

Eventually, the person with illness stops being able to move around the home and starts spending most of the day in bed. This can be emotionally distressing for all members of the family. In addition, the loss of mobility brings new demands on caregivers who need to ensure the person is clean and comfortable in bed, while at the same time completing other household tasks like cooking and laundry. By thinking ahead, you can have a plan in place to make sure you have enough people ready to take on the new tasks that come with caring for someone who is bedridden.

- **Losing interest in food and water**

One of the concerns families have in the final stages of terminal illness is that the person is no longer interested in eating or drinking. The patient can be comfortable without medically administered fluids, but this situation is often upsetting for family members who feel they are denying the patient something essential.

See also: [Lack of Appetite and Loss of Weight](#)

- **Loss of consciousness**

Another transition that can be very difficult for family members is when the patient is no longer able to take part in conversations or be aware of people who are visiting. Caregivers may feel less comfortable providing care or giving medication without feedback from the patient. Caregivers may also be observing changes in the patient (moaning or grimacing, for example) and not be sure how to react. Again, talking to the health care team in advance can give you the knowledge you need to react to these situations.

See also: [When Death Is Near](#)

Prepare important documents

- **Health care directives / advanced care directives / living wills**

These are documents that provide specific direction to health care providers in the event that a person is unable to communicate their wishes themselves. The person can also name someone to relay their wishes for medical care. Ideally, this proxy will have an excellent understanding of the person's values and wishes. The proxy will need to feel comfortable making health care decisions on the person's behalf when the person is unable to do so. Preparation of a health care directive also gives families an opportunity to discuss the values and wishes of the person who is ill so that they can offer guidance when difficult decisions need to be made.

See also: [Health Care Directives](#)

- **Letter of anticipated death**

In Canada, certain deaths are classified as reportable - meaning the death must be reported to the provincial or territorial medical examiner's office. The circumstances surrounding these reportable deaths are then investigated by the police or coroner's office. Depending on which province or territory you live in, a death at home may be classified as reportable. However, it is possible in many provinces to notify the medical examiner's office of an anticipated home death due to a terminal illness before the death occurs. Check with your health care team to find out what steps need to be taken in your area. Generally, your doctor needs to write a

letter of anticipated death and give copies to the medical examiner's office and funeral home. Then, when the death occurs, no investigation is required.

The promise to stay at home

If you have promised a family member that you will help them die at home, you may feel anguish at the thought of breaking that promise if things become too challenging or exhausting. If possible, try to remember what you were trying to achieve through the promise. What was the spirit or intent of the commitment? It may be possible to achieve the spirit of the commitment away from the home environment.

Families often experience mixed emotions about a death at home, especially when:

- the person is unconscious and no longer able to respond to family members;
- they realize that they may not be comfortable living in the home after a death.

Mixed emotions when the patient is unconscious

Sometimes family members find that much of their energy and inspiration for caring for someone at home comes from the meaningful two-way connection that exists at such an important time. They may feel drained of this energy when loss of consciousness means the loss of two-way feedback. Families may find that they are ready to stop being the primary caregivers at this point.

In other cases, family members find that the work of grief begins when the person becomes unconscious. They may feel overwhelmed and feel ready to move the person into a care facility.

Sometimes families in these situations continue to provide caregiving at home even though they would prefer to move the person into a hospital or another facility. Very often, they stay because they have promised a home death. If you're in this situation, ask yourself this question: Whose needs are being met by staying at home? If you are unable to see how anyone's needs are being met, then it may be time to move the person into another care setting, knowing that the spirit of the promise has already been fulfilled.

Mixed emotions about living in the home after a death

As the final hours approach, some families realize they are uncomfortable with the thought of someone dying where they live. The spaces occupied by the patient will bring back strong reminders of that person and families may find it hard to imagine living in these spaces after a death occurs. There are things you can do to return to the normal activities of daily living after a death in a home.

See also: [Rituals to Comfort Families](#)

Other factors may make staying at home difficult:

- The time and attention required by the patient may cause stress within the broader family. Spouses or children may feel that they are unfairly "forgotten" during this time.
- The patient may become delirious or aggressive and agitated. Managing someone who is restless is extremely challenging in a home environment. Family may also feel that they have already lost the person who is dying because the person's personality and communication style are not the same.
- Not knowing when death will arrive requires a kind of endurance on the part of the family. It's like being asked to run a race with an unknown finish line.
- Keeping the patient comfortable near the end of life requires ongoing vigilance, drug changes

and, sometimes, difficult clinical decisions.

- The possibility exists that death will occur after medication is given, since medication is delivered so regularly. If a family member has administered the medication, that person may be left with a memory that is quite traumatic. Although the patient has died after a lengthy disease process, family members tend to associate the death with their actions. For family members who are not familiar with the medications, this can feel as though the medications have contributed to the dying process, even though the death was an expected outcome after a lengthy illness. The support of the health care team is helpful in guiding families through these concerns.

If you find yourself having trouble deciding what to do, imagine the person with the illness could come in and see the situation. If you think that person would say *"This is too hard for you. I don't want to be such a burden on my family,"* then in a sense, you've been given permission to do what's best for the entire family, whatever that may be.

Conclusion

Perhaps one of the most important considerations when thinking about a death at home is ensuring that you have the support you need to provide quality care. You will need support from health care providers, friends and family, and perhaps your faith community and your place of work.

Whatever decision you make about the location for the death of someone close to you, remember that there are always other options available to you. You can't always anticipate what will happen and neither can your health care team. But, working together as a team, you can make sure the approach you've taken is still right for you.

For more information about providing care at home, see [Module 3](#) of the Caregiver Series on the [CaregiversCAN](#) site.

For additional resources and tools to support you in your grief or to learn more about supporting others, visit [MyGrief.ca](#).

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