Please note that this document was written in late April 2020. Some policies and practices may change. Please visit: https://bit.ly/grief-and-dying-in-the-age-of-COVID-19 for any updates to this document.

## Grief, Dying, and Death During a Pandemic



### Wellbeing Waterloo Region

This resource was written in April 2020 at the request of the region-wide COVID-19 pandemic response group in Waterloo Region. The authors include practitioners and scholars in the areas of:

- Social work
- Spiritual care
- Palliative care
  Counselling
- Death education
- Funeral service
- Bereavement

## Are you experiencing sadness or grief during these stressful times of COVID-19?

Is someone you care about dying, or has someone recently died? Are you looking for emotional or spiritual support as you grieve?

## This resource is for you

#### This resource includes:

- 1. When we feel grief
- 2. When someone you care about is dying
- 3. After someone you care about has died
- 4. Resources

#### Is it possible to feel grief about something other than death?

Grief is something you may feel if you have any kind of loss, not just death. The COVID-19 pandemic is a crisis. People feel

- sorrow
- anxiety
- stress
- the loss of a job
- the loss of what is normal
- the loss of meeting with people
- the loss of education and training
- the loss of control

• the loss of a belief in a just world and more. All of these kinds of things can be sources of grief. Grief can be tiring for any reason so be kind to yourself. You do not need to be alone in these feelings. Consider reaching out to a:

- friend
- neighbour
- a faith leader
- grief support organization
- or counsellor

#### I'm feeling sad that so many people are suffering and dying from COVID-19. How can I make sense of all this?

Sadness is a natural emotional response to this stressful time. You might also feel:

- heartache
- anger
- helplessness
- anxiety
- or a sense of loss

All of these are normal responses to human suffering.

When we feel grief

Is it possible to feel grief about something other than death?

These are very hard times that may remind you of your own helplessness, and you can experience grief as the world seems to be changing so quickly. You may want to think about ways you can nurture community even though you are not in control of the circumstances. In what ways can you make connections with others when your heart is feeling a sense of loss? As you try to make sense of COVID-19, it might help to start talking with a trusted friend, or write down your thoughts in a journal.

#### What is anticipatory grief?

Anticipatory grief can occur before the actual loss, and usually happens during a long-term illness where death can be anticipated or expected. During this time, people already begin to feel grief. Anticipatory grief can also arise because of the anticipation of other kinds of loss. During the COVID-19 pandemic, people have:

- lost their jobs
- people have lost in-person connection with each other
- and people have lost a sense of certainty about the future

Anticipatory grief can happen when we fear that there is more loss to come.

#### Does grief follow set stages?

No. Many people know about the "stages of grief". Research has shown that people's feelings are unique and change between thinking about the loss and trying to move back to normal. These changes in feelings can change minute by minute. This can happen over weeks and months. These feelings can change minute by minute, or over weeks and months. There are no stages and there is no timeline for grief. Grief remains a personal journey.



### When someone you care about is dying

Will someone be close to the person when they are dying?

## Will someone be close to the person when they are dying?

Hopefully yes. However, both physical distancing and personal protective equipment (masks and face shields) could make it more difficult, there might be more options. If death is very near, some places allow for 1 or 2 "essential partners in care" or "designated visitors" (wearing protective gear) who can be in the same room as the person who is dying. Even if you cannot be in the same room, you can use a cellphone, iPad, or telephone to talk, or you may be able to visit from the other side of a window. Nurses or other care givers can share written notes and can hold the person's hand. In many religious traditions, Praying with each other while in different places can give the person support.

#### Can someone hold the person's hand when they're dying?

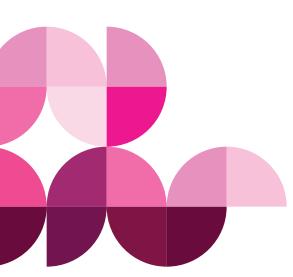
Hopefully yes. Nurses, hospice workers, and other care givers are trained to be kind at the end of life. If you have been chosen as an "essential partner in care" who can be in the room at the very end of life, hold the person's hand by sliding your hand under their hand. This is softer, and allows them to lift theirs away if they wish.

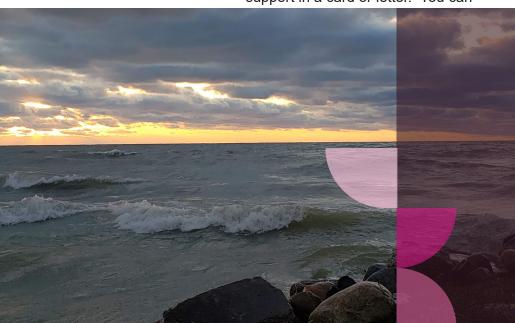
#### What does palliative care look like when so many of the regular palliative care practices are not possible?

Palliative care may be delivered in a different way because of physical distancing, but the idea behind the care remains unchanged – to relieve suffering and to provide as much comfort, care and support to the dying and their families as possible. Even if the patient does not have COVID-19, face-to-face talks with a palliative care doctor may be replaced with video calling or telephone support to lower the risk of infection. Palliative Care doctors are still giving pain medications as needed. Palliative Care Nurses and Personal Support Workers are taking the needed precautions (i.e. hand hygiene protocol, wearing personal protective equipment) so that they may safely tend to the medical and physical needs at the end of life.

## What are some ways I can show my love and support from a distance?

Call or video chat with the person who is ill. Send them words of support in a card or letter. You can







### When someone you care about is dying

What are some ways I can show my love and support from a distance?

mail or drop off the card at their door. Drop off a gift (e.g. artwork from their grandchildren, a CD of their favourite music, chocolates, a stuffed animal). Deliver a meal (or two) at their door or provide a gift card for a restaurant that offers home delivery. Hold a family meal by video. This way all family members can eat and chat together. Share something you've learned from that person (in a letter or over the phone) that you know will stay with you forever. Share some pictures with notes about why they are special to you.

#### Does COVID-19 change any of the rules or practices in Medical Assistance in Dying (MAID)?

We ask you to talk to the healthcare team. You can share your questions and thoughts about Medical Assistance in Dying (MAID). Access to MAID is different in each region - even more during the pandemic - so it is good to reach out to your healthcare team for information.

#### Someone I care about is dying and we can't say goodbye to each other. What do we do next?

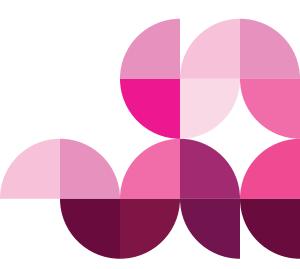
Send the person a message through the healthcare team at the hospital who can read your message aloud or play a video. Make sure the message says what needs to be said as it may be your only chance. Ask if there is a chance you can visit in person, but if this is not possible ask if you can be on webcam while they die. If the person can no longer read, speak, or hear, write a letter to them and then burn the letter – trust that your message has been heard in some way. Connect with family and friends by webcams or on the phone, and each share what that person meant to you. Share memories and stories, support each other, and send your loving thoughts and prayers to the dying person.

#### What if the person I care about is dying of something other than COVID-19? If we know for sure that they don't have COVID-19, can we be close to them?

Talk with the healthcare team, but know that physical distancing has limits on in-person visiting. This will not change even if a person does not have COVID-19. In a spirit of openness and respect, check with staff for other options.

#### I've always had an image of having my family and friends with me when I die. Because of physical distancing, what image will I need now?

Many palliative patients who are dying of something other than COVID-19 can still have a home death, surrounded by family care providers and healthcare professionals. If you live with family members, they will be able to be present at your home death. You and your family will be supported in your home by members of the community healthcare team (e.g. nurse, personal support worker, physician). However, other members of your family who do not live with you, may not be able to enter your home and be with you when you die. This is to protect your care providers and your healthcare team from being infected with the COVID-19 virus. If you are dying of a palliative disease (not COVID-19), but do not wish to die at home, you may choose to be admitted into a local residential hospice facility. Visiting rules may vary but staff of the residential hospice facility will be by your side, providing care and support until the very end.





### When someone you care about is dying

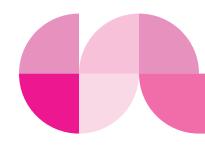
Will COVID make it difficult to follow my wishes?

I prepaid for my own funeral. If I die and a regular funeral can't happen because of physical distancing, what happens to all the money I gave to the funeral home?

If an executor or estate trustee would like to make any changes to a prepaid funeral, the money for those unused pre-paid items or services will be returned to the person's estate or named beneficiary along with interest. A planned funeral can be changed at any time and is flexible to the family's needs. Every time is unique, and people are advised to consult with the Funeral Director they have chosen, as well as this helpful resource from the Bereavement Authority of Ontario

I've been having Advance Care talks with my substitude decision maker. I have let people know my end of life plan. Will COVID make it hard to follow my wishes?

You have done very well in preparing your Substitute Decision Maker to make healthcare decisions on your behalf if you are incapable of making the decisions for yourself. The people you have told, know your wishes and will work with the healthcare team to make good decisions on your behalf.







Is there some other way I can feel like I'm connected with them?

I can't be present with the person I care about in the minutes following their death (because of physical distancing). Is there some other way I can feel like I'm with them?

Those who accompany the dying sometimes talk about the importance of spending as much time with the deceased as feels needed. During a pandemic, staying with the person who has died may not be possible. If death is near and you know you want to keep close to the person after their death, here are some options:

• a well-washed prayer shawl can be dropped off, letting the health care team know that it be placed on the person at the time of death

• a homemade washcloth can be given to the nurse who can wash the hand or forehead of the person



on behalf of the family

#### What are some important things to keep in mind for the time right after death?

As of mid-April 2020, there are new rules for the hours following someone's death even if the death is not related to COVID-19. Family members or next-of-kin have a limited amount of time to choose a Funeral Service Provider to move the body from the facility. There is still the option to move between Funeral Service Providers later if you change your mind. It is important to think about funerals before the time of death and discuss them. Even as these kinds of rules are put in place, the dignity of the person is important. These rules are to transfer the person from the healthcare facility to the funeral home without delay. This is to give them the care by the best-trained people.

#### In my faith tradition, we have specific practices for caring for the body of the deceased. Can we maintain these practices during a pandemic?

This depends on what these practices are, and how they can be adapted amidst taking care for the common good (which is a tenet of most faith traditions). This depends on what they are and how they can happen without risking the safety of others. For example, ritual washing is omitted during the COVID-19 pandemic. Placing items with the body can be discussed with your faith leader and funeral director. Placing items of spiritual or sentimental significance with the body prior to cremation or

burial is a timeless practice, and we encourage you to discuss these details with a faith leader in your tradition as well as the Funeral Director.



What happens at a funeral when people aren't allowed to hug?

## What happens at a funeral when people aren't allowed to hug?

Love and support can be felt through being present. Eye-to-eye contact can can be very good, as well as other gestures like blown kisses.

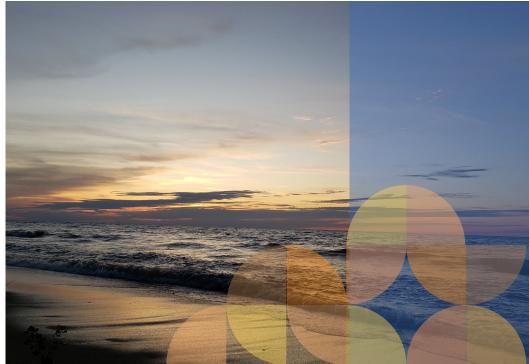
#### How do I show my love and support when I can't attend a visitation?

Write a letter or a card to the grieving family. Make a memorial donation. Send a gift certificate from a restaurant that is doing take-out/delivery. Drop a meal off on the front porch of the grieving family (let them know it is coming). Make a video card (i.e. record yourself and those you're isolating with sending your condolences and sharing memories of the person who died). Ask if it's possible to attend by video.

#### Some people choose to organize a home-based funeral. Is this still possible during COVID-19?

During the pandemic, the largest size of a funeral-related gathering is 10 (April 2020). This applies to gatherings in a funeral home, at a cemetery, at a crematorium, and in a private home. Aside from this limit on numbers, those planning a home-based funeral will need to do many of the same kinds of things as Funeral Directors in terms of finding creative ways to use technology, social media, and other methods of nurturing a sense of care and connection among the bereaved. In terms of caring for the body of the deceased, there are very specific guidelines that must be followed see the COVID-19 updates from the Bereavement Authority of Ontario.







How can our family grieve when a funeral or memorial service isn't possible?

#### The funeral has to be postponed for at least several months. Is there some kind of funeral-like ritual we can do now?

Arrange a time to honour the person who died. Find a time that works with a number of households who can join together by video – this is a way to give your own "at-home" funeral before the in-person funeral happens in the future. Choose songs, poems, and readings that reflect the person's life. Wear nice clothes, do your hair, have a program/ agenda – make it as real as possible. On an individual level, do something in honour of the person such as planting a tree, making a donation to their

favourite charity, doing a good deed for someone else, compiling a CD of their favourite songs, or creating an "altar" in your home featuring a candle, pictures, and special keepsakes that remind you of the person who has died. Light a candle each day in their memory.

#### How can our family grieve when a funeral or memorial service isn't possible?

Grief is tiring and now you have time to grieve without having to plan a formal funeral right away. Use the time to focus on yourself and your own grief. Grieving takes time and looks different for everyone. What works for one person may not work for other members of the same family:

- journal
- read
- look through photo albums
- go on walks
- find what works for you to process your grief
- practice self-care and connect with the person who has died in a new way

As painful and sad as it is to deal with the death of someone, keep talking to others who are also grieving. Talking can help and make you feel less alone. Remember that everyone grieves differently and that's okay – it has been said that grieving is a "journey not a destination". Know that not everyone needs professional help in grief but that these are unusual times. Ask yourself, "What do I need right now?" If you feel you need it, consider reaching out to a faith leader, spiritual caregiver, or counsellor, many of whom can talk by phone or through video.

After the person died, I started meeting with a counselor and that really helped. Now I'm supposed to do counseling over the phone or computer, but I find that very awkward. Are there any other options?

At this time phone and virtual support is safest both for you and for your counsellor. Give it a chance – at least 2 or 3 sessions – knowing that new things usually feel awkward until we get used to them. You'll be able to meet face-to-face again. This situation is just for now, not forever. Your counsellor will have ways to address your concerns about video or calls.



What are some other things to remember when I'm grieving?

## What are some other things to remember when I'm grieving?

Grief is unique to each and every person so the ways to grieve are very individual as well. For some, journaling can be helpful. Sometimes it can be helpful to read over previous entries in your journal. There are many ways to reflect on how the person who died would want to be remembered, and how they would want you to be part of their legacy. Do not "self-medicate" with drugs or alcohol. You will benefit more from getting sleep, eating well and staying active.

## How do I grieve when I can't attend a funeral or memorial service?

If a funeral is planned but you cannot attend due to the limit on

the number of visitors, ask the family or the Funeral Director for advice about how you can attend in some other way. You may be able to attend the graveside service while staying in your car, or say a prayer in your own home while the funeral is taking place, or watch a livestreamed broadcast of the funeral. Even if a funeral is postponed by months, you will still grieve in the meantime – it may just look and feel different from what you have known in the past. Consider:

- talking on the phone with a friend or family member
- accessing an online grief support resource
- or arranging for phone check-ins with a faith leader, spiritual caregiver, or counsellor





## RESOURCES

Advance Care Planning Information (1-800-349-3111) https://www.speakupontario.ca/

Bereaved Families of Ontario (Midwestern Region) (519-603-0196) https://bfomidwest.org/programs/living-with-loss/virtual-living-with-loss-group/

Cambridge Memorial Hospital (Spiritual Services) (519-621-2333) https://www.cmh.org/programs/spiritual-services

Canadian Mental Health Association (Waterloo Wellington) (264-2993) Here 24/7: 1-844-HERE-247 (437-3247) https://cmhaww.ca/

Canadian Virtual Hospice <u>http://www.virtualhospice.ca/en\_US/Main+Site+Navigation/Home.aspx</u>

Carizon Family and Community Services (519-743-6333) https://www.carizon.ca/

Christians Together Waterloo Region https://twitter.com/christians\_wr?lang=en

Delton Glebe Counselling Centre (519-884-3305) https://www.glebecounselling.ca/

Distress and Crisis Ontario (416-486-2242) http://www.dcontario.org/centres.html

Grand River Hospital and Regional Cancer Centre (Spiritual Care) (519-742-3611 Ext. 2142) <u>http://www.grhosp.on.ca/care/visitors/spiritual-care</u>

Hospice Waterloo Region (519) 743-4114) http://www.hospicewaterloo.ca

Interfaith Grand River https://www.facebook.com/IGR2001

KidsGrief.ca https://kidsgrief.ca/

K-W Counselling Services (519-884-0000) https://www.kwcounselling.com/

LivingMyCulture.ca http://livingmyculture.ca/culture/

Multifaith Information Manual (print resource) http://canadianmultifaithfederation.weebly.com/shop-manual.html

Muslim Social Services (519-772-4399 ext. 2707) http://muslimsocialserviceskw.org/

MyGrief.ca http://www.mygrief.ca/

Shalom Counselling Services of Waterloo (519-886-9690) https://shalomcounselling.org/

St. Mary's General Hospital and Regional Cardiac Centre (Spiritual Care) (519-744-3311) https://www.smgh.ca/care-services-support/spiritual-care/

Waterloo Wellington Local Health Integration Network (1-888-883-3313) http://www.waterloowellingtonlhin.on.ca/

When Someone Dies (brochure) http://www.hospicewaterloo.ca/wp-content/uploads/2016/01/ WhenSomeoneDies5thEd.pdf

When Someone is Dying (brochure) http://hpcconnection.ca/wp-content/uploads/2016/08/ whensomeoneisdying\_community\_18jan2018\_final.pdf