

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 coordinating psychosocial and spiritual supports in Waterloo Region. The authors include practitioners and scholars in the areas of social work, palliative care, counselling, bereavement, spiritual care, death education, and funeral service.

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 an experience that you may have at any kind of loss, not just death. Some have described the COVID-19 pandemic as a psychological crisis in addition to an epidemiological crisis. People feel sorrow, anxiety, stress, and many different kinds of loss – the loss of a job, the loss of normalcy, the loss of person-to-person connection, the loss of educational opportunities, 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 exhausting 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. These are very hard times that may remind you of your own vulnerability, 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 initiate a conversation 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 experience 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 a specific progression of stages?

No. Many people are familiar with the “stages of grief” but research has shown that people’s feelings are unique and fluctuate between concentrating on the loss and restoring meaning to life. These fluctuations in 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 we feel grief

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



When someone you care about is dying

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

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Hopefully yes. Although the combination of physical distancing and personal protective equipment (masks and face shields) could make it more difficult, there might be some creative options. If death is very near, some institutions allow for 1 or 2 “essential partners in care” or “designated visitors” (wearing appropriate 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 communicate, or you may be able to visit from the other side of a window. Nurses or other care providers can deliver hand-written messages and can hold the person’s hand. In many religious traditions, praying together even while in different locations can nurture a feeling of connection.

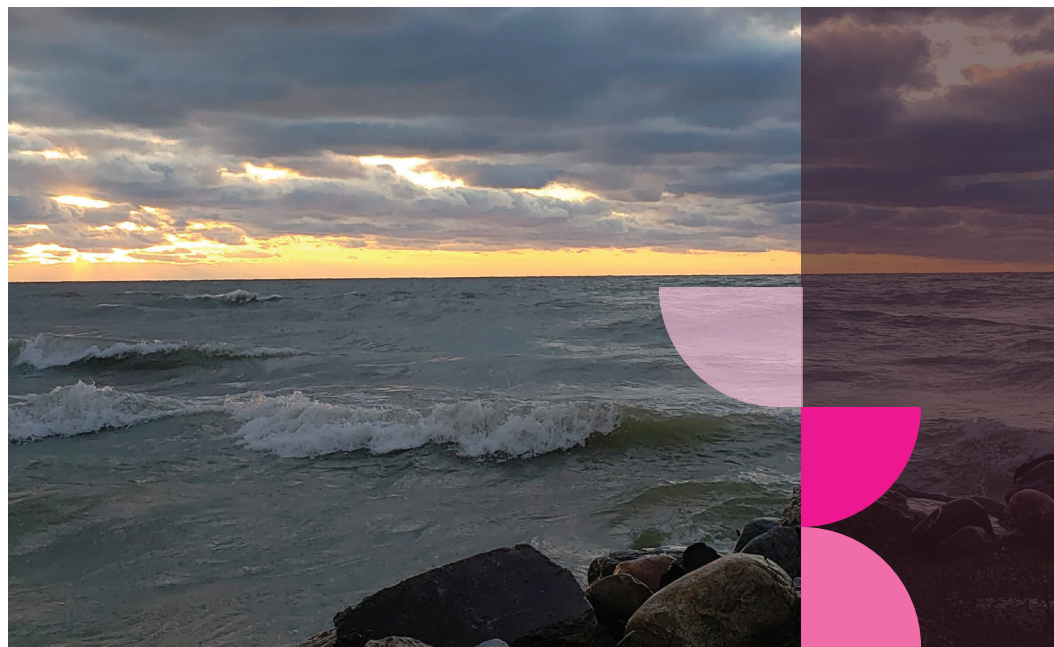
Can someone hold the person’s hand when they’re dying?

Hopefully yes. Nurses, hospice workers, and other care providers are trained to offer compassionate accompaniment at the end of life. If you have been designated as an “essential partner in care” who can be in the room at the very end of life, consider holding the person’s hand by sliding your hand under their hand. This is gentler, 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 philosophy 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 consultations with a palliative care physician may be replaced with video conferencing or telephone support to lower the risk of infection. Palliative Care Physicians are still providing pain and symptom management services and are prescribing or adjusting pain medications as needed. Palliative Care Nurses and Personal Support Workers are taking the necessary 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.





When someone you care about is dying

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

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Telephone or video chat with the person who is ill. Send them words of encouragement in a card or letter that you can mail or drop off at their doorstep. 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 doorstep or provide a gift card for a restaurant that offers home delivery. Initiate a family meal by video so 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 photographs with accompanying written explanations about why they are meaningful to you.

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

We encourage you to consult the healthcare team in your setting so you can share your questions and thoughts about Medical Assistance in Dying (MAID). Access to MAID varies depending on the jurisdiction – particularly during this pandemic – and so it is important 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 opportunity. Inquire about an exception to tightened visiting rules, and if this is not possible ask if you can be present via 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 mysterious way. Connect with family and friends via webcams or on the telephone, and each share what that person meant to you. Reminisce, share 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?


Consult with the healthcare team, but know that physical distancing requires significant limitations on in-person visiting, regardless of

who does and who does not have COVID-19. In a spirit of openness and respect, explore the visiting limitations in a particular setting, and work with staff on options.

I've always had an image of being surrounded by my family and friends when I die. Because of physical distancing, what kind of deathbed situation can I imagine now?

Many palliative patients who are dying of a condition that is not 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





When someone you care about is dying

Will COVID make it difficult to follow my wishes?

members of your extended family who do not live with you, unfortunately, 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 inadvertently being infected with the COVID-19 virus. If you are dying of a palliative disease (not COVID-19), but do not wish to die

reunion with those who have “gone before”, we are never alone.

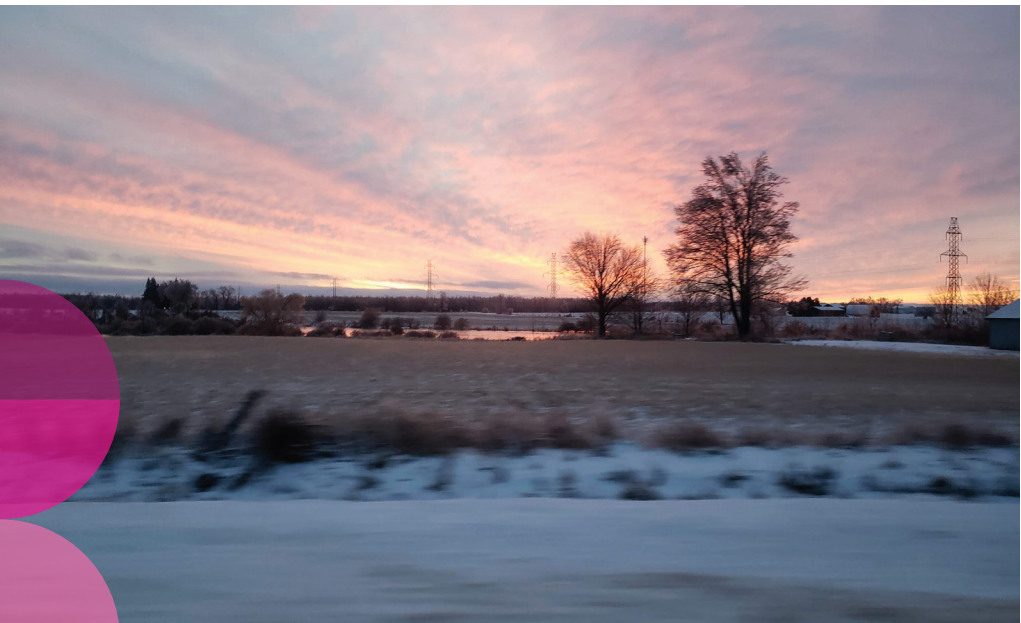
I prepaid for my own funeral. If I die and a regular funeral can't happen because of physical distancing, what happens to all the money I gave to the funeral home?

If an executor or estate trustee would like to make any changes to a prepaid funeral, the money

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 Planning conversations with my Substitute Decision Maker and my family so they know what kind of care I would want if I become incapable of making my own decisions. Will COVID make it difficult 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. Your thoughtfulness in having the conversation with the Substitute Decision Maker – including telling them about your wishes, your values, and your hopes – will be of great service and comfort to them as they work with the healthcare team in order to make decisions on your behalf.



at home, you may choose to be admitted into a local residential hospice facility. Visiting restrictions may vary but the dedicated and compassionate staff of the residential hospice facility will be by your side, providing care and support until the very end. Some faith traditions believe that with Divine presence, and a sense of

for those unused pre-paid items or services will be returned to the person's estate or named beneficiary along with accumulated interest. A prearranged funeral can be changed at any time and is flexible to the family's needs. Every situation is unique, and people are advised to consult



After someone you care about has died

Is there some other way I can feel 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 connected 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, this can be difficult or even impossible. If death is near and you anticipate wanting to maintain a connection with the person after death, consider one of the following options: A well-laundered prayer shawl can be dropped off, with instructions that it be placed on the deceased at the time of death. Or a special homemade washcloth (made by family members) can be given to the nurse or care provider who can gently wash the hand or forehead of the deceased as a caring gesture on behalf of family members who are not physically present (e.g. One Washcloth Project).

What are some important things to keep in mind for the time immediately following death?

As of mid-April 2020, there are new rules for the hours following

someone's death regardless if the death is related to COVID-19. For example, depending on the location of the death, family members or next-of-kin have between 1 and 3 hours to choose a Funeral Service Provider to transfer the body from the facility. There is still the option to transfer between Funeral Service Providers later if you change your mind. This emphasizes the importance of thinking about funeral arrangements prior to the time of death, and discussing them if possible. Know that even as these kinds of rules are put in place, the intent is to uphold as much dignity and respect as possible for the deceased, for the family of the deceased, and for specific cultural/religious beliefs of the family. These rules are meant to transfer the body of the deceased from the healthcare system to the funeral sector without delay, to place them into the care of those who are best-trained to offer this care.

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 entail, and how they can be adapted amidst taking care for the common good (which is a tenet of most faith traditions). For instance, though ritual washing is an ancient practice, it is usually omitted during the COVID-19 pandemic except symbolically (e.g. on the outside of a burial shroud). 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.





After someone you care about has died

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

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Love and support can be felt through being present, and does not always require physical touch. Eye-to-eye contact can be very powerful, as well as physical gestures at a distance such as “blown kisses” or the “Namaste greeting” in which an individual holds the palms of their hands together and upright in an almost universal posture of greeting and prayer.

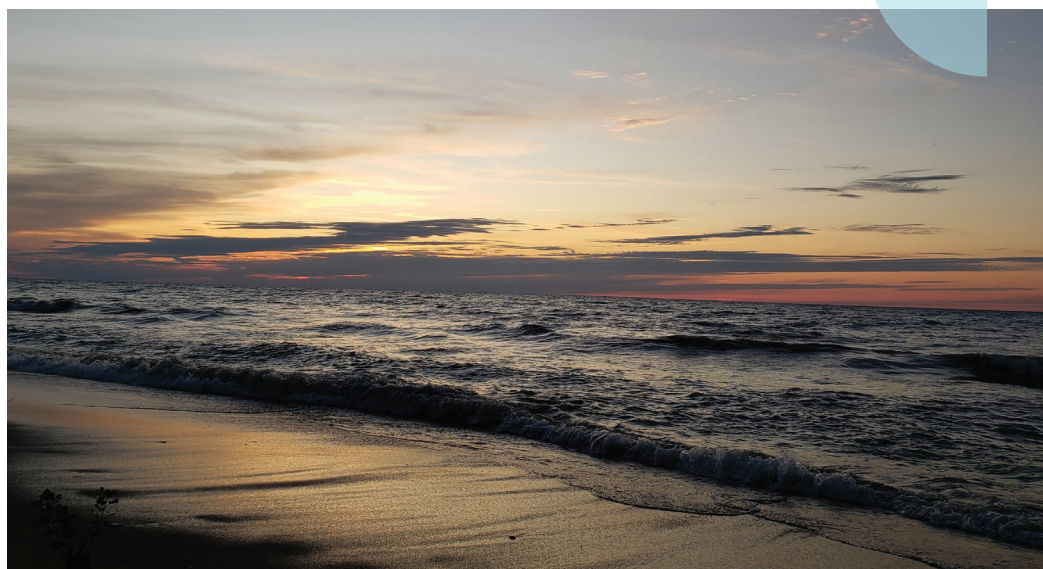
How do I show my love and support when I can't attend a visitation?

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 virtually, perhaps with a family member who can use their smartphone to facilitate a brief videoconference conversation with

a few family members during the visitation.

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

During the pandemic, the size of a funeral-related gathering is subject to a maximum number as specified by the Bereavement



Authority of Ontario (as of early April 2020, the maximum is 10 people). 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





After someone you care about has died

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

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.

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 videoconference – this is a way to initiate your own “at-home” funeral before the scheduled 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 realistic 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 exhausting 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 experience the death of someone, keep lines of communication open with 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 are available by phone or through video technology.

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?

Unfortunately, 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



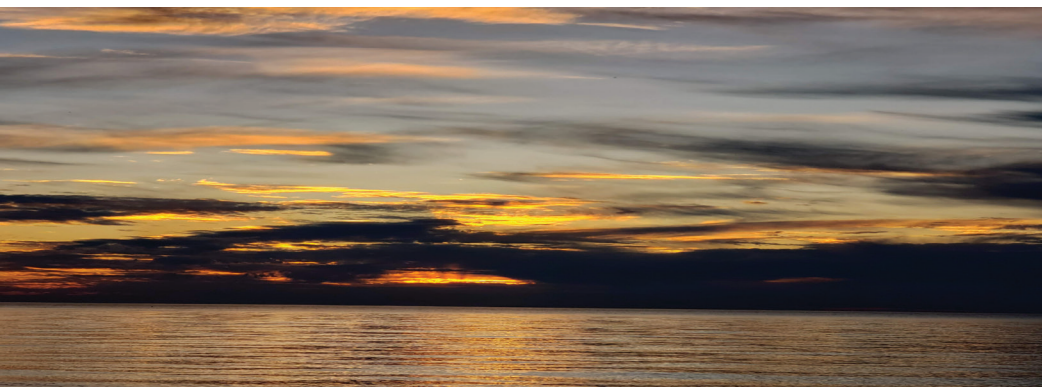


After someone you care about has died

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

things usually feel awkward until we get used to them. Eventually you'll be able to meet face-to-face again. This situation is just for now, not forever. Your counselor will have some strategies to address your concerns about the technology.

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. Be cautious about "self-medicating" with any substance or behaviour. You will



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.

Journaling is an ancient practice that can be framed as "beginning" with the naming of something you are grateful for (or something you are lamenting) and then "concluding" with a particular quality or blessing that you seek for the coming day. Sometimes it can be helpful to read over

benefit on your grief journey from maintaining good patterns of sleep, nutrition, and physical fitness.

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 limitation 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 live-streamed broadcast of the funeral. Even if a funeral is postponed by several months, you will still grieve in the meantime – it may just look and feel different from what you experienced in the past, or what you are expecting it to feel like now. When a larger-scale gathering cannot be held for now, consider smaller, interim rituals than can be undertaken. 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

<https://www.speakupontario.ca/>

Bereaved Families of Ontario (Midwestern Region)

<https://bfomidwest.org/programs/living-with-loss/virtual-living-with-loss-group/>

Cambridge Memorial Hospital (Spiritual Services)

<https://www.cmh.org/programs/spiritual-services>

Canadian Mental Health Association (Waterloo Wellington)

<https://cmhawww.ca/>

Canadian Virtual Hospice

http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx

Carizon Family and Community Services

<https://www.carizon.ca/>

Christians Together Waterloo Region

https://twitter.com/christians_wr?lang=en

Delton Glebe Counselling Centre

<https://www.glebecounselling.ca/>

Distress and Crisis Ontario

<http://www.dcontario.org/centres.html>

Grand River Hospital and Regional Cancer Centre (Spiritual Care)

<http://www.grhosp.on.ca/care/visitors/spiritual-care>

Hospice Waterloo Region

<http://www.hospicewaterloo.ca>

Interfaith Grand River

<https://www.facebook.com/IGR2001>

KidsGrief.ca

<https://kidsgrief.ca/>

K-W Counselling Services

<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

<http://muslimsocialserviceskw.org/>

MyGrief.ca

<http://www.mygrief.ca/>

Shalom Counselling Services of Waterloo

<https://shalomcounselling.org/>

St. Mary's General Hospital and Regional Cardiac Centre (Spiritual Care)

<https://www.smgh.ca/care-services-support/spiritual-care/>

Waterloo Wellington Local Health Integration Network

<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

