# On Death and Dying

# ON DEATH AND DYING

JACQUELINE LEWIS

University of Windsor Windsor, ON





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## LAND ACKNOWLEDGEMENT

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Jacqueline Lewis

#### Citation & Attribution

The suggested citation for this book in APA format is:

Lewis, J. (2022). On Death and Dying. eCampusOntario. <a href="https://ecampusontario.pressbooks.pub/deathanddying/">https://ecampusontario.pressbooks.pub/deathanddying/</a>

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## **ACKNOWLEDGEMENTS**

Jacqueline Lewis

#### **Project Funding**

This project was developed with funding from the Government of Ontario and <u>eCampusOntario Virtual Learning Strategy (VLS).</u>



#### **Project Team Members**

A number of people contributed to the completion of this eCampus Pressbook. I would like to thank them for their tireless efforts.

Jillian Holland-Penney, MA, worked for the duration of the project while completing her MA degree at the University of Windsor. After completion of her degree in January 2022, she moved into a full-time role for the last 3 months of the project. Her various contributions include serving as project manager, research and development of Pressbook content, co-editor of all materials, and co-author of most chapters. The successful completion of the project would not have been possible without her hard-work and dedication.

Nobuko Fujita, PhD (Office of Open Learning, University of Windsor), played an integral role in the development of the eCampusOntario funding application and bringing the project through to fruition. Throughout the project she provided technical and administrative support, including her expertise with the Pressbook platform, helping to implement my vision for this book.

Jacqueline Durocher and Brandon Bernardon both worked on the projects as research associates while completing their MA degrees at the University of Windsor. As part of their contributions to the project, they conducted research, developed audio-video resources, and co-authored chapters.

Dave Cormier, Patrick Carnevale, Madelyn Poulin and Mikayla Paesano (Office of Open Learning, University of Windsor), through their expertise with the Pressbook platform, helped to implement my vision for this book.

Beth A. Robertson, PhD, through her work as EDDI and copy-editor, played an integral role in providing feedback on ways to improve earlier versions of the book.

Shreyas Tambe (Office of Open Learning, University of Windsor) provided support for video postproduction.

Alicia Higgison provided essential administrative and accounting support for the project.

I also want to acknowledge the tireless efforts of my spouse Minde Lawson, who during the pandemic provided me with at home technical and IT services, and who assisted with the creation of audio/visual materials for this course

#### **Chapter Reviewers**

Several current University of Windsor students and recent graduates reviewed and provided feedback on chapters in this eCampus Pressbook. I would like to thank them for their invaluable contribution to the project.

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Yara El-Houssami is a current BA(H) student in Forensic Science and Criminology at the University of Windsor.







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- Videos developed for this project contain closed captioning and also offer downloadable transcripts.

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## OTHER RESOURCES

This course aims to create a class environment of mutual respect and psychological safety. It is therefore important that students understand, in advance of taking this course on death and dying, that throughout this course they will be challenged (via course materials and assignments) to critically engage with issues tied to death and dying, and issues and topics related to their own mortality, including end-of-life planning. Given the potentially challenging and sensitive focus of this course, it is important for each student to recognize that they may find some course content emotionally difficult or distressing. It is therefore recommended that students read the syllabus and carefully peruse the course text material and assignments, to determine if this course is right for them. To a limited degree, students may also, in consultation with the professor, opt to not fully participate in certain course sessions or not consume particular course content. For students who decide to take this course, the following support resources are available if needed:

#### Resource List

#### For University of Windsor Students:

| Name & Location   | Contact Information         | Additional Information  |
|---|-----------------------------|---|
| Student Counselling Centre  CAW Student Centre Room 293 | (519) 253-3000<br>ext. 4616 | <ul> <li>MonFri. 8:30am-4:30pm</li> <li>Free for university students</li> <li>http://www.uwindsor.ca/scc</li> </ul> |
| Student Health Services  CAW Student Centre Room 242    | (519) 973-7002              | <ul><li>MonThur. 9am-5pm</li><li>Fri. 9am-1pm, 2pm-5pm</li></ul>  |

## Windsor-Essex County (Off-Campus):

| Name & Location   | Contact Information   | Additional Information  |
|---|---|---|
| Community Crisis<br>Centre744 Ouellette Ave.<br>Windsor, ON N9A 1C3   | (519) 973-4435  | <ul> <li>8am-8pm</li> <li>Open 7 days a week.</li> <li>Walk-in service at community crisis centre</li> </ul>  |
| Windsor Regional<br>Hospital Emergency<br>Department  | 1030 Ouellette Ave.(519)<br>973-4411<br>1995 Lens Ave<br>(519) 254-5577 | <ul> <li>24-hour crisis line.</li> <li>24-hour walk-in service.</li> </ul>  |
| Windsor Essex<br>Community Health<br>Centre (weCHC) –<br>Teen Health<br>1361 Ouellette Ave.<br>Room Number: 101 | (519) 253-8481  | <ul> <li>Tues. &amp; Wed. 9am-8pm</li> <li>Mon. &amp; Thurs. 9am-6pm</li> <li>Fri. 9am-5pm</li> <li>By appointment only</li> <li>Services for ages 12-24</li> </ul> |
| Distress Centre of<br>Windsor – Essex<br>County<br>1466 Ouellette Ave,<br>Windsor, ON N8X 1K3                   | (519)256-5000<br>www.dcwindsor.com                                      | <ul> <li>12pm-Midnight</li> <li>7 days a week</li> <li>Free, anonymous, confidential emotional support, crisis intervention, and referrals by phone</li> </ul>      |
| Canadian Mental<br>Health<br>Association 1400<br>Windsor Ave. Windsor,<br>ON                                    | (519)255-7440<br>(519)326-1620(Leamington)                              | MonFri. 8:30am-4:30pm     http://www.windsoressex.cmha.ca/  |

#### XX | OTHER RESOURCES

| Name & Location  | Contact Information | Additional Information   |
|--|---------------------|--|
| WE Trans Support1435<br>Tecumseh Rd E,<br>Tecumseh, ON<br>N8W 1E4                                      | (226) 674-4745      | • info@wetranssupport.ca   |
| Amherstburg<br>Community<br>Services 320 Richmond<br>St.<br>Amherstburg, ON<br>N9V 1H4                 | (519)736-5471       | • MonFri. 9am – 4pm  |
| Community Support<br>Centre (Belle River)<br>962 Old Tecumseh Rd,<br>Belle River, ON<br>NOR 1A0        | (519)728-1435       | • MonFri. 8:30am-4:30pm  |
| Windsor Essex Community Health Centre (weCHC) – Leamington 33 Princess St #450, Leamington, ON N8H 5C5 | (519) 997-2828      | <ul> <li>Mon. &amp; Wed. 8am-5pm</li> <li>Tues. 8am-8pm</li> <li>Thurs. 8am-6pm</li> <li>Fri. 8am-4pm</li> </ul> |

## Online/Telephone Support:

| Name &<br>Location  | Contact Information   | Additional Information  |
|---|---|---|
| My Student<br>Support<br>Program (SSP)                    | 1-844-451-9700 Outside of North America:001-416-380-6578 https://www.uwindsor.ca/wellness/347/ my-student-support-program | <ul> <li>Free confidential counselling by licensed counsellors.</li> <li>24/7, via call or text.</li> <li>At any time, students have access to 35+ languages/cultures.</li> </ul> |
| Good2Talk   | 1-866-925-5454  | Free confidential help line for post-secondary students.  |
| Here 24/7:<br>Mental Health<br>and Crisis<br>Service Team | 1-844-437-3247  |   |
| Canadian Crisis<br>Hotline                                | 1-888-353-2273  |   |
| Crisis Services<br>Canada                                 | Toll Free (24/7):1-833-456-4566<br>Text Support: (4pm – 12am ET daily): 45645   |   |

| Name &<br>Location                      | Contact Information                           | Additional Information  |
|---|---|---|
| Better Help                             | www.betterhelp.com                            | <ul> <li>Online access to professional counsellors.</li> <li>On the web and available for iPhone and Android users.</li> </ul>  |
| The LifeLine<br>App                     | www.thelifelinecanada.ca                      | <ul> <li>Access to phone, online chat, text, &amp; email crisis support.</li> <li>E-counselling, self-management tools, access to crisis centres across Canada.</li> <li>For iPhone &amp; Android users.</li> </ul> |
| Big White Wall<br>Canada                | www.bigwhitewall.ca                           | Anonymous peer support<br>community accessible<br>anytime.  |
| Canada Suicide<br>Prevention<br>Service | 1-833-456-4566www.crisisservicescanada.ca/en/ | <ul> <li>Offers 24/7/365 bilingual support to people in Canada who have concerns about suicide.</li> <li>Phone line available 24/7.</li> </ul>  |

| Name &<br>Location             | Contact Information       | Additional Information   |
|--------------------------------|---------------------------|--|
| Distress and<br>Crisis Ontario | http://www.dcontario.org/ | <ul> <li>Across Ontario.</li> <li>Offer support and a variety of services to their communities.</li> <li>Usually 24 hours a day, seven days a week.</li> <li>The website also offers a chat function.</li> </ul> |

## Indigenous-Specific Resources:

| Name & Location  | Contact Information | Additional Information   |  |
|--|---------------------|--|--|
| Hope for Wellness Help Line                                  | 1(855)242-3310      | <ul> <li>Offers immediate mental health counselling and crisis intervention to all Indigenous peoples across Canada.</li> <li>Phone and chat counselling is available in English, French, Cree, Ojibway, and Inuktitut.</li> </ul> |  |
| Anishnawbe 24/7 – Mental Health<br>Crisis Management Service | (416)891-8606       | For Indigenous clients.  |  |
| Talk4healing   | 1(855)554-4325      | For Indigenous women.  |  |
| National Indian Residential School<br>Crisis Line            | 1(866)925-4419      | <ul> <li>Offers support to former residential school<br/>students and those affected.</li> <li>Available 24 hours.</li> </ul>  |  |

## **COURSE & E-BOOK INTRODUCTION**

Jacqueline Lewis

### On Death & Dying

This course provides a critical exploration of a variety topics related to the study of death and dying. Topics covered include: historical and cross-cultural perspectives; genocide; plagues and pandemics; palliative care and hospice care; medical assistance in dying (MAiD); grief and bereavement; memorials and commemoration; and death planning (e.g., obituary writing, advanced directives for care, appointment of power of attorney for personal care, funeral planning, etc.). Each chapter of this Pressbook requires students to read and watch course material and then complete an assignment. Chapter assignments are designed to encourage students to critically and personally engage with and reflect upon the chapter topic. There are a series of questions at the start of each chapter that are meant to facilitate student engagement with the chapter materials. The assignments and questions also provide a foundation for small group and classroom discussions on the topics covered.

<sup>①</sup> Given the potentially challenging and sensitive focus of this course, it is important for each student to recognize that they may find some course content emotionally difficult or distressing. It is therefore recommended that students read the syllabus and carefully peruse the course text material and assignments, to determine if this course is right for them.

### **Understanding Text Font Colours & Style**

| FONTS   | MEANING  |  |
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| © Bolded Red Font   | Content warnings   |  |
| Bolded Royal Blue Font                                    | Required reading and/or video course content.<br>Instructions for students             |  |
| Black underlined titles or hyperlinks inside shaded boxes | Required reading and/or video course content.  |  |
| Black underlined or <b>Bolded underlined</b> words        | Supplementary information (hyperlinks or definitions).<br>Not required course content. |  |

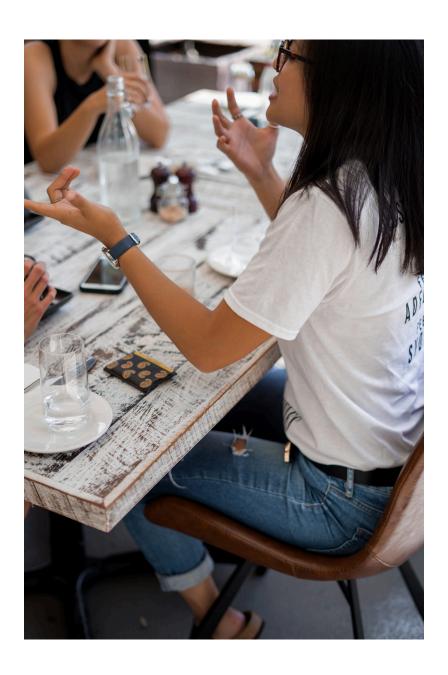
# Course Syllabus

On Death & Dying Syllabus

## **Grading Rubric**

On Death & Dying Assignment Rubric

# CHAPTER 1: LET'S TALK ABOUT DEATH & DYING



Jacqueline Lewis

## 1.0 INTRODUCTION

#### **Chapter Introduction**

When was the last time you thought about death? Perhaps it was tied to something in the daily news coverage or in a popular crime drama you were reading or watching. What about the last time you talked about death, what did you talk about and with whom? When was the last time you talked to people in your life about issues related to death and dying, including what both you and they want at the end of life? The purpose of this chapter's assigned material (chapter content, including embedded links and videos, assigned readings and viewings, and the chapter assignment) is to get you to think about death and dying on a more personal level, to understand the importance of talking about death, and to begin these crucial conversations with those you love. This material also introduces you to some of the topics we will be covering in this course and to the orientation of this course more generally – one that challenges you to think about and push past the discomfort we associate with death and dying, to participate in the process of bringing conversations about death back into life, and to embrace death positivity more generally.

#### **Chapter Objectives/Learning Outcomes**

After completing the chapter materials, you should have an understanding of:

- 1. The approach we will be taking in this course to the subject matter of death and dying.
- 2. The social reluctance to engage in discussions of death.
- 3. The importance of engaging in conversations about death with family and loved ones.
- 4. Ideas of how to start "the conversation".

## Questions to Think About When Completing Chapter Materials

- 1. How have you approached/dealt with/responded to conversations about death in your life?
- 2. How can death positivity bring about healthy social change?
- 3. What are your wishes for end-of-life care (e.g., where do you wish to be; with whom; who will be your primary care giver; are there treatments you do or do not want, etc.)?

## 1.1 DEATH & DAILY LIFE

The topic of death pervades our daily life via the media we access. We hear about it in daily news reports (e.g., in memoriam of a famous person, as a result of an accident or violence, tied to regional and national conflicts, or from genocide, etc.). Television includes numerous shows that focus on death (e.g., police/crime dramas, shows on the work of coroners or pathologists, murder mysteries), or at least include death in most episodes (e.g., medical dramas). There are also a large variety of books and book series involving death and dying that have made the New York Times "What to



Chat bubbles.

Read" series. Some examples about death and dead bodies are series by authors such as Patricia Cornwall and James Patterson. On social media we find death announcements, online obituaries, Facebook memorials, condolences, and annual death anniversary posts. Despite our daily exposure to death through the media, we rarely voluntarily engage with death-related topics on a more personal level (The Lancet, 2022). We typically do not think or talk about death, ours or our loved ones, and when such death-related topics come up, we feel discomfort and often shy away from them and/or discourage the discussion through our words and actions (e.g., "Mum we don't need to talk about that now. You are going to be around for a long time").

#### Click the links to learn more about why we avoid talking about death:

Body or Soul: Why We Don't Talk About Death and Dying
To Die Well, We Must Talk About Death Before the End of Life

## 1.2 TALKING ABOUT DEATH



Speak Up Ontario Logo. ©Speak Up Ontario (2021). All rights reserved. Image used with permission. When was the last time you sat down to have a conversation about death with loved ones? If you cannot remember the last time you had a conversation about death or any of the issues tied to death and dying, you are not alone. Part of the reason for this is that there are social norms and cultural beliefs that discourage us from talking about death, including beliefs that talking about death can bring bad luck, illness and or actual death.

This is ironic considering that if there is one sure thing in life, it is that we all will die. Birth and death are the two biggest rites of passage we all will experience in our lives. Both often are associated with pain and discomfort and the cycle of life – the start of it and the end of it. However, while we talk about, plan for, and celebrate birth, dying and death are not similarly honoured. The question is why? As with participating in all life-oriented celebrations, being present and participating in end-of-life (EOL) care can be an act of honouring the life of a loved one and an opportunity for real human connection (McGroarty, 2019).

Click the link to learn more about the importance of talking about EOL wishes with parents when they are still healthy:

'How Will I Move on Without You?': What I Learned When I Talked to My Parents About Death

#### **Death Avoidance**

Often when people learn that someone they know is dying or has a terminal illness, they avoid talking about it with them. They neglect to initiate, be receptive to, or engage in a dialogue about important EOL issues. Such topics of conversation can pertain to the dying person's:

- Feeling about their diagnosis.
- Hopes and fears.
- Treatment preferences type of treatment they want/don't want (including nutrition and hydration).
- Definition of quality of life.
- Wishes for specific circumstances around death who will be with them, where will they be, will it involve medical aid in dying (MAiD See Chapter on End of Life), etc.

- Advanced care planning (ACP) and estate planning (i.e., advanced directives for personal care, will and estate plans, powers of attorney for personal care and for financial matters and property).
- Wishes for what they want to happen to their body after death (e.g., organ donation, body donation to science, traditional burial, green burial, embalming or not, cremation, aquamation, a mushroom shroud, etc.).
- Preference for how they and their life will be remembered (e.g., a cemetery marker, a park bench, a tree
  planting, etc.).
- Preferred type of memorial (e.g., traditional funeral, celebration of life, memorial), how it will look and who will be there.

(Kassalainen et al., 2021; Life File, n.d.; Monuments & Memorialization, n.d.).



Two men talking

#### The Importance of Talking About Death & Dying

Although these may seem like scary topics of conversation, they are important ones. And why not have them? When it comes to conversations about dying and death, we often provide rationalizations such as a desire to not upset the person who is dying. But people who are dying often want to talk, yet remain silent due to similar concerns for their loved ones (Facing End Life, n.d.). People who provide care for the dying indicate

#### 10 | 1.2 TALKING ABOUT DEATH

that engaging in discussions of death and dying with loved ones is the biggest act of love you can give each other, helping both the person being cared for and the care giver (The Conversation Project, 2014a). In fact, research shows that when dying people and their families discuss wishes for EOL care, the outcomes for all discussion participants are improved (The Conversation Project, 2014a; Sorrell, 2018).

Having these conversations provides us the opportunity to really connect with the people in our lives and to realize some of the richness of life that is only made possible by acknowledging the inevitability of death (O'Brien, n.d; Booth, 2019). Ideally, these important conversations should happen long before we get old or sick or start the dying process (IHI, n.d.; Sorrell, 2018), but we often wait until we have no choice. When these discussions must occur in the midst of a crisis, they are much more difficult and heart wrenching. It also often means that we end up having to guess a loved ones wishes (Kaasalainen, et al., 2021).

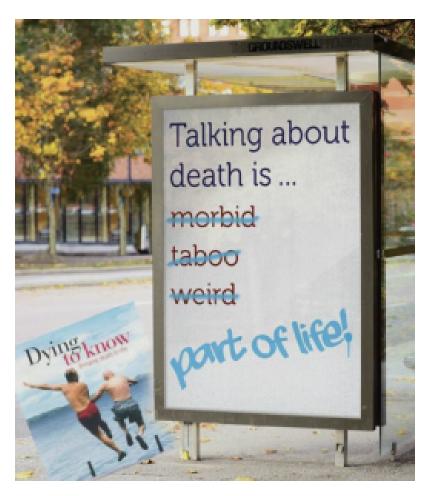
#### VIDEO:Learning How to Think About Death Changed How I live

In the following video, John Lehland, journalist and author, explains how talking to an elderly friend changed his perspective on aging and death and the importance of acknowledging his own mortality.



One or more interactive elements has been excluded from this version of the text. You can view them online here: <a href="https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=708#oembed-1">https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=708#oembed-1</a>

# 1.3 DEATH POSITIVITY & LISTENING TO THE DYING



Talking about death is a part of life! ©The Groundswell Project Australia (2020). All rights reserved. Image used with permission.

#### **Death Positivity**

We often approach the topic of death and dying with feelings of apprehension, trepidation, fear, or sadness. There is some basis for this fear, as the path toward death for the dying person is often a lonely one and typically involves pain, physical, and mental suffering (Moore & Williamson, 2003). For the friends and family of the dying person, there is the fear of the pain, sadness, and grief that we as humans experience with the loss

of a loved one (Moore & Williamson, 2003). There is also the fear of the unknown, as we cannot know what happens to a person after death.

But does death have to be approached in this way? What if we worked toward transforming this understanding? What if we created physical and emotional spaces that facilitated discussions of death, while offering comfort, support, and solace to the dying and the bereaved? This is where the concept of death positivity comes in. Being death positive means being open to honest conversations about death and dying (Kelly, 2017) and is the foundation of a social movement that challenges us to reimagine all things tied to death and dying, including the development of Compassionate Communities (CCs).

#### Listening to the Dying

A good way to start a course on death and dying is by listening to the voices of people who are nearing the end of life, to hear their experiences, their struggles, and the wisdom they share. Many heart wrenching stories are impacted by the death negativity that pervades our society. However, in the following video interview with Audrey Parker, a 57-year-old Canadian woman with terminal Stage 4 breast cancer, you will hear a somewhat different perspective. She talks about her choice for Medical Assistance in Dying (MAiD) and offers advice about how to make each of our life's journeys the best they can be. Click the link under Audrey Parker's photograph to watch her video interview on CTV News (Keep in mind that Audrey Parker's medically assisted death occurred prior to the 2021 changes to Canada's Medical Assistance in Dying legislation – See Chapter on End-of-Life Care).



Remembering Audrey Parker. ©Dying With Dignity Canada (2021). All rights reserved. Image used with permission.

VIDEO: Why A N.S. Woman is Opting for Assisted Death Earlier Than She Planned

# 1.4 THE DEATH POSITIVE MOVEMENT

# Compassionate Communities Initiative

#### VIDEO: Imagine Aging Project: Exploring Death Friendliness

The following video explores the meaning of death friendliness and the concept of age-friendly communities.



One or more interactive elements has been excluded from this version of the text. You can view them online here: <a href="https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=714#oembed-1">https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=714#oembed-1</a>

According to the World Health Organization (2021), the world's population is aging faster than it has in the past. This means that people are living for longer; living for longer periods with chronic illnesses and with increasingly complex needs; and dying at older ages (Rawlings et al., 2018; Richards et al., 2020). As a result, a civil society effort referred to as the Compassionate Communities (CC) initiative/model has emerged to deal with such changes. The CC model "aims to de-professionalize, de-medicalize end-of-life care, return it to the community, and build up social capital that can then be mobilized when citizens come to the end of their life" (HPCO, 2019, para. 6). In a CC, members of the community play an active role in caring for each other. CCs can therefore be viewed as circles of care or social support networks available in the community to aid people as they age, develop illnesses, approach the end of life, and experience bereavement (Rawlings et al., 2021).

Click the link to learn more about the Ontario Compassionate Communities Provincial Strategy:

<u>Compassionate Communities</u>

#### VIDEO: ANew Vision for Death and Dying

The following video is based on the work of the Lancet Commission on the Value of Death. The members of the commission propose a new social vision of death and dying, one that combines greater community engagement with health care and social services for the dying and support for the bereaved.





One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=714#oembed-2

# The Death Positive Movement

CCs are part of a broader 21st century death positive movement. The movement began in 2011 with Caitlin Doughty's founding of a funeral reform collective known as The Order of the Good Death (Caitlin Doughty, n.d.). The aim of the movement is to "promote open, honest engagement with" and discussions about death and dying (Kelly, 2017). The movement is broad in scope, reimagining everything tied to death and dying (McGroarty, 2019). For example, we find death positivity in CCs and other initiatives that emphasize dignity, respect, caring and compassion throughout our lives, including at the end of life. There are also death doulas, functioning similarly to birth doulas, who provide continuous care and support to the dying and their families (before, during and after death).

End of life rituals tied to funerals/memorials and ways to deal with dead bodies are evolving rapidly. We see this in the green funeral industry, the introduction of acquamation, and the movement back toward the use of natural burial shrouds, homemade coffins, and family completed burials (See Chapter on Dealing with Bodies). And there are the innovative death conversation initiatives including the Conversation Project, Death Cafés, and Death over Dinner, that work to get people to come together and engage in discussions about anything tied to death and dying over food and drink. Focusing on the positive, rather than the negative, can help us rethink death. Various parts of the death positivity movement aim to enhance life, a sense of community, caring and connection and ultimately to make sure that at the end of it all, we die well. The three short videos below explore the Death Café, Death over Dinner, and the Conversation Project initiatives.

#### VIDEO: DeathCafes: Discussing Death, and Especially Life

The following video takes us inside of a Death Café, where we learn about what it is, what occurs there, what motivates people to go, and the experiences of people who have attended.



One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=714#oembed-3

#### VIDEO: Death Over Dinner: What is Death Over Dinner?

The following video explains the Death over Dinner initiative, how it works and the rationale behind it.



One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=714#oembed-4

#### VIDEO: ABC World News with Diane Sawyer: The Conversation Project

In the following video Diane Sawyer goes inside a family gathering to witness "an act of love" — that is, having "the conversation" with their father about his end of life wishes.



One or more interactive elements has been excluded from this version of the text. You can view them online here: <a href="https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=714#oembed-5">https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=714#oembed-5</a>

# 1.5 CHAPTER SUMMARY

# **Key Summary Points**

- 1. There is a social tendency to shy away from death on a personal level, to avoid conversations about our own wishes and those of our loved ones at the end of life. Such conversations, however, bring closeness, connection, reduce stress, and enhance the comfort of our loved ones at the end of their lives.
- 2. Being death positive means being open to honest conversations about death and dying.
- 3. Death positivity is a social movement that challenges us to reimagine all things tied to death and dying, including the development of compassionate communities. Some examples of initiatives designed to get us talking about death are Death Café's, Death over Dinner, and the Conversation Project.

## **Additional Resources**

Talks at Google. (June 14, 2018). *Inviting the wisdom of death into life — Frank Ostaseski* [Video]. YouTube. <a href="https://youtu.be/wBraurRo\_bg">https://youtu.be/wBraurRo\_bg</a>

# 1,6 REQUIRED COURSE MATERIALS

In addition to the videos and reading links embedded into the chapter, you are required to complete the following course material:

# **Required Course Viewings**

TEDx Talks. (May 9, 2017). *Let's talk about death – Isabel Merrin* [Video]. YouTube. <a href="https://youtu.be/R2HcxtBCK-o">https://youtu.be/R2HcxtBCK-o</a>

The Conversation Project. (June 18, 2014). *The Conversation Project: An overview* [Video]. YouTube. <a href="https://youtu.be/owH-os9I19I">https://youtu.be/owH-os9I19I</a>

# **Required Course Readings**

Ariturk, D. (April 1, 2019). *Death is a social construct*. Duke University Research Blog. <a href="https://researchblog.duke.edu/2019/04/01/death-is-a-social-construct/">https://researchblog.duke.edu/2019/04/01/death-is-a-social-construct/</a>

Kendal, S. (January 25, 2021). *It's an important time to talk about death*. Now Toronto. https://nowtoronto.com/news/theres-never-been-a-more-important-time-to-talk-about-death

Troyer, J. (April 10, 2014). Death isn't taboo, we're just not encouraged to talk about it.

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# 1.7 CHAPTER ASSIGNMENT

# Let's Talk About Death & Dying Assignment

This assignment challenges you to begin the process of sitting down and engaging in death-related conversations. There are several options to select from for this assignment. The options allow you to choose based on your comfort level going into the assignment, and how much you are ready to push that comfort level. There are two parts to the assignment (for all options), one part requires you to do something and the other to write about your experience. It is important to complete all chapter materials (chapter content, including all embedded links to readings and videos, and the required course materials) prior to starting the assignment.

## Assignment Formatting & Style for Written Report

- Assignment formatting requirements: Arial 12-point font; 1 inch/2.54 centimeter margins; single spaced; APA in-text citation style, reference section and cover page.
- Use proper essay/paragraph style.
- Clearly indicate which Option you have chosen for your assignment.
- Proofread your submission to make sure it is clear, well written and intelligible.

## Options for Assignment #1

#### Option 1

Attend a Death Café (in person or virtual). <u>Find a local or virtual death café</u> or do a Google search to find an in-person event in your local area, that is going to occur prior to the due date for the assignment.

## Steps to completing the Option 1 assignment

- Watch the video on Death Cafés in Chapter 1.4 and read and watch the material from Chapter 1, including the Required Course Materials.
- Sign-up for the death café you have chosen.
- Attend the death café.
- Note certain details of the death café you attend, including date, time, location, a photo/picture or ad

for the event you attend.

• In 750-1000 words, write about your experiences attending and participating in the death café. Examples could include: a brief synopsis of what it was like to attend a death café; a brief synopsis of what you talked about/contributed to the conversation; what surprised you the most about your death café experience; how you felt at the start of the café; how you felt at the end of the event, etc.

#### The following must be submitted as part of Option 1 assignments

- 1. A proper APA style cover page.
- 2. The details on the death café attended (date, time, location, photo of event ad).
- 3. A written report.

### Option 2

Plan a "Death over Dinner" event where you engage in conversations about death and end of life preferences with friends and/or family.

Steps to completing the Option 2 assignmentWatch the video on Death over Dinner in Chapter 1.4 and read and watch the material from Chapter 1, including the Required Course Materials.

- Go to the <u>Death over Dinner</u> website and click "Get Started" to plan your dinner event. Once you have finalized the choices for your event (Note: you can redo this process until you are happy with the result. Each time you redo it, the website will send you a new plan).
- Plan your guest list (first names, last initial, relationship to you).
- Create your invitation. Revise the suggested outline for invitation wording in the email sent from the website so it is appropriate and accurate (including that you are doing this for a course assignment).
- Plan your menu (e.g., appetizer, main course, dessert, beverages), keeping in mind recommendations from the website.
- In 500-600 words, write about the experience of making your plan to host a Death over Dinner event.

## The following must be submitted as part of Option 2 assignments

- 1. A proper APA style cover page.
- 2. A copy of your death over dinner plan sent to you from the Death over Dinner website.
- 3. A brief explanation of your choices for your dinner plan (the choices you made on the website).
- 4. Your guest list, with a brief explanation of your guest choices and the number you plan to invite.
- 5. Your invitation that you will send out to guests.
- 6. Your dinner menu, with a brief explanation of your meal choices.

7. Your written report (in addition to the written components of 3-6 above).

Variation on Option 2: you have the option to actually host the Death over Dinner that you plan. If you decide to host a Death over Dinner event for this assignment, you will need to do so prior to the deadline. After you host your dinner, you are then required to write "your story"/your experience of planning, participating in and hosting a death over dinner event. "Your story" must be 350-600 words in length and would replace the written report detailed above for Option 2 (non-variation version). The Death over Dignity website asks people who host dinners to write "your story" pieces to post on their website. Your written submission should follow that format. Whether or not you submit "your story" to the website is up to you.

#### Option 3

Plan a conversation about death and end of life preferences with family and loved ones.

#### Steps to completing Option 3 assignment

- Watch the video on "The Conversation Project" in Chapter 1.4, and read and watch the material from Chapter 1, including the content within Required Course Materials.
- Read the Conversation Project's Starter Guide.
- Fill in the Starter Guide. Be sure to do this on your computer and to save your responses, as you are required to submit this document as part of your assignment.
- In 500-600 words, write about the experience of completing the Starter Guide.

## The following must be submitted as part of Option 3 assignments

- 1. A proper APA style cover page.
- 2. A completed/filled in copy of your Conversation Starter Guide.
- 3. A copy of your 500-600 word report on what the experience was like thinking about and filling in your guide.

Variation on Option 3: Once you have filled in your Conversation Starter Guide, you have the option to actually have "the conversation" with loved ones. If you do this prior to the deadline for the assignment, then instead of the written report for Option 3 (non-variation version) you are required to write about your experience of thinking about and filling in your starter guide, as well as your experience of preparing for and having "the conversation" with loved ones. This written report can be up to 1000 words in length.

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# CHAPTER 2: HISTORICAL BELIEFS & DEATH-RELATED PRACTICES



Jacqueline Lewis, Jillian Holland-Penney & Jackie Durocher

# 2.0 INTRODUCTION

# **Chapter Introduction**

There is much variability in human custom, ritual and belief surround death. By looking historically, we can see some of the diversity in human after-death related practices. These include how we have dealt with the dead and how we responded to those losses. This chapter explores some of this diversity. Its primary focus is on non-Indigenous North American customs and rituals, from the late 18th century through the early 20th century, and the key factors that influenced these changes. What is evident, is an increasing fear of death as our personal involvement with our dead declined, due to advancements in the field of medicine and the professionalization of mortuary practices.

# **Chapter Objectives/Learning Outcomes**

After completing the chapter materials, you should have an understanding of:

- 1. The diverse nature of death-related beliefs and practices in human history and how different cultures throughout history have celebrated death and mourned their loved ones.
- 2. The significance of burial rituals that are symbolic of cultural traditions and sentiments often tied to dying and the afterlife.
- 3. Changes in death-related practices from the late 1700s to the early 1900s in non-Indigenous North American society.
- 4. The importance of the belief in the cycle of life for some Indigenous community's deathrelated beliefs and practices.
- 5. The key factors leading to changing death-related attitudes and practices in the late 1900s.

# Questions to Think About When Completing Chapter Materials

- 1. What role can bringing death back into life and public spaces, such as the way death has been depicted in art, provide an opportunity for stimulating changes in attitudes related to death and dying in contemporary society?
- 2. How have your own views on death and dying changed as you read about the way death has been understood among different groups at different points in human history?
- 3. How did moving death out of the home and away from the family likely impact the grieving process and perspectives on death?
- 4. How did colonization negatively impact traditional Indigenous death-related beliefs and practices?
- 5. Identify 3 things covered in the chapter materials that you did not know before. How did this knowledge impact you and your views of death related practices today?

# 2.1 DEATH RELATED CUSTOMS & RITUALS IN HISTORY

There are an abundance of death-related beliefs and practices (e.g., customs and rituals) that we as humans have used to deal with our dead (McRae, 2018; San Filippo, 2006). Through end-of-life (EOL) rites, the living honour the dead and/or address fears of the dead (e.g., the threat the dead pose to the living) (Powell, 2019; San Filippo, 2006). For example, the practice of closing or covering the eyes or the face of the dead and moving bodies feet first, were meant to protect the living (Rodgers, 2017; Powell, 2019). The former practice is believed to have started as a way to close a "window from the living world to the spirt world" (Powell, 2019, para. 2). The latter practice was tied to the belief that if a body was moved headfirst, it could look back and beckon the living to follow them (Rodgers, 2017). The fear of calling a loved one to follow is also part of the reason why widowed Victorian women wore black. The belief was that dressed in black, they would appear as a shadow and were therefore at less risk of being beckoned by the spirits of their dead husbands to join them (Currie, 2017).

#### Click the following link to read about Victorian mourning culture:

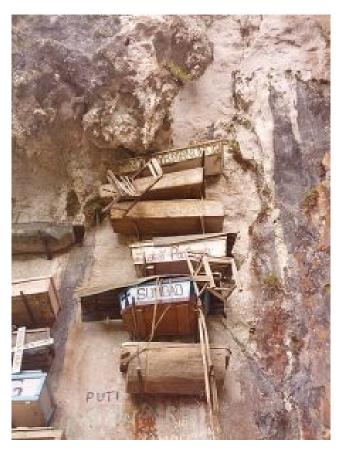
Why I Wore Black After He Died: Lessons from Victorian Mourning Culture

When exploring death related practices historically, it is also important to look at the disposal of dead bodies. Archeological research details the numerous ways bodies have been dealt with. Dead bodies were left in caves, in trees or on mountaintops, burned on pyres or other forms of ritual cremation, placed in catacombs, buried in the ground or under mounds of earth. For example, early Italian farmers about 7000 years ago placed their dead in caves, after they defleshed and then broke apart the skeletal remains (Shaw, 2015). Anglo-Saxons (from the 5th-10th century) buried their dead in organized graveyards, using small burial mounds as markers for each. However, much larger barrows/burial mounds were also built by the Anglo-Saxons to honour their high-status dead, possibly kings (see top left and top right image below) (Davidson, 1950; Carver, 1986).



Examples of burial rituals

According to ancient Hindu custom, the Hindu funeral/cremation ceremony involves placing the dead on a pyre of logs and then setting it alight (see bottom left image above). This tradition is still the dominant practice today (Mikles, 2021). In other parts of the world (e.g., Rome, Paris, Lima), at different periods of time, the bodies or bones of the dead were placed in catacombs. The Roman catacombs, dating back to the first century, "were constructed as underground tombs, first by Jewish communities and then by Christian communities" (see bottom right image above) (Sood, 2012). And among the Igorot people of the Philippines, there is an ancient practice dating back 2000 years (and still practiced today), involving the suspending of coffins on the side of a cliff, in order to allow the dead closer proximity to ancestral spirits who predeceased them (see image below) (Dilger & Hizon, 2018).



Igorot hanging coffins on cliff side in the Philippines.

# Click the following links to read about historical perspectives on death and dying:

Death, Burial & the Afterlife in the Ancient Celtic Religion What Ancient Cultures Teach Us About Grief Mourning and Continuity of Life

# 2.2 DEATH IN NORTH AMERICA, LATE-18TH TO LATE-19TH CENTURY

"It is important to recognize that the experience of dying and death, like all experiences in life, from pregnancy and birth onward, are affected by gender, race, class, ethnicity, geography, marginalized status, ability, sexual orientation and marital status, and, perhaps more than any, by... [Indigenous] status. Nonetheless, it is important to document the major changes that have taken place to enable us to place present-day conditions within evolving trends" (Arnup, 2013, p. 6).



Casket laid out in home parlour with family mourning, mid-1800s.

In Western cultures such as early U.S. and Canada (not including Indigenous peoples), customs and rituals surrounding death directly evolved from those in Europe and England, resulting in a set of death-related beliefs and practices meant to show proper respect for the dead (Mourning After, n.d.). Death was viewed as

inevitable and an integrated part of the community (Kinch, 2017; O'Connell, 2014). People died at home. Family members, typically the women, cared for their loved one's body (i.e., bathed and dressed) (Chavez, 2019; Frontline PBS, 2015). Neighbours or the local carpenters, would build a very simple wooden casket/ box (O'Connell, 2014). The body would then be laid out and displayed at home, in the parlour if the house had one, or even on the dining table (Currie, 2017). Burials took place close to home, either at a family or church cemetery (O'Connell, 2014; Juarez, 2018).

Not only did these rituals and practices result in more exposure to death, but the process of attending to the dead allowed communities to come together to support one another in grief, strengthening interpersonal and social bonds (Wojcik & Dobler, 2017). Ultimately, these rites of passage and celebrations that dealt intimately with death, allowed people in the 18th and 19th century to avoid a fear-based understanding of the end of life (Wojcik & Dobler, 2017).



An example of a 19th century back yard family cemetery. ©Scwordie. All rights reserved. Image used with permission.



Church Cemetery, Nottingham from Beecham's Photo-Folio, Nottingham and Environs. ca. 1900.

#### VIDEO: The Fascinating History of Cemeteries

The following video by Keith Eggener uses animations to highlight historical traditions associated with dealing with bodies and demonstrates how the cemeteries we know today came to exist (Watch to 4:57 mark).



One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=736#oembed-1

# 2.3 DEATH IN NORTH AMERICA, LATE-19TH TO EARLY-20TH CENTURY

#### VIDEO: A Very Short History of Death

In this video Chris Woolf of PRI's The World, explains how prior to the 20<sup>th</sup> century, the visibility of death tied to a variety of social factors (e.g., food insecurity, poor hygiene, lack of knowledge of infectious diseases, high childhood mortality) contributed to a much lower life expectancy.



One or more interactive elements has been excluded from this version of the text. You can view them online here: <a href="https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=738#oembed-1">https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=738#oembed-1</a>

There were important societal level changes beginning in the late 1800s through the early 1900s that moved death away from the daily lives of non-Indigenous North Americans, influencing how we view death and deal with the dead (Lundgren & Houseman, 2010). The four key changes were: an increase in life expectancy (Lundgren & Houseman; 2010; Roser et al., 2015); enhancements in medical knowledge, skills and technology (e.g., better understandings of viruses such as polio, vaccine developments and improvements, and the development of antibiotics), including the development of the hospital (DenHoed, 2016; Lundgren & Houseman, 2010); the emergence and professionalization of the funeral industry (Lundgren & Houseman, 2010); and the move from urban church yard cemeteries to rural park-like settings (Lundgren & Houseman, 2010; Ted-Ed, 2018).

In the early 1800s, life expectancy in North America was around 35 years of age (Roser et al., 2019). As public health improvements (e.g., understandings of and practices in sanitation; better nutrition, protection of drinking water; access to medicines such as vaccines, etc.) evolved, and medicine and medical advancements became focused on preventing death (Barkin & Gentles, 1990; Lundgren & Houseman, 2010), life expectancy increased to 50 years by 1900 and has steadily increased since then (except during the Spanish Flu pandemic – see Chapter on Plagues & Pandemics) (Barkin & Gentles, 1990; Roser et al., 2019; Whitmore et al., 2016).

By the end of the 19th century, cemeteries began to be moved outside of urban areas to allow for more space for the dead (Ted-Ed, 2018). The funeral industry also began the process of professionalization –

moving from the undertaker who built caskets, dug graves, and transported bodies to graves, to the mortician who offered full funeral package services outside of the home, including the increasingly popular practice of preserving bodies through embalmment (Walsh, 2017). With the assistance of medicine and the funeral industry, death was literally cleansed from people's lives. Most of the dying and death related practices that had taken place after the death of a loved one moved behind closed doors (Frontline PBS, 2015). Even today, if we are at the bedside of a loved one at moment of death, shortly thereafter they are taken away. The next time we might see their body, if at all, is the funeral service and only if there is an open casket. These key societal changes, including increased life expectancy, death prevention medicine, distancing from cemeteries and funeral practices, has led to physical and social distancing from death. Such distancing help account for a rising fear of death and the death avoidance practices common today (See Chapter on Talking About Death).

#### Click the following link to read about the popularizing of embalming bodies at end of life:

When You Die, You'll Probably Be Embalmed. Thank Abraham Lincoln For That

#### VIDEO: North American Funerals (History of Funerals in the U.S.)

This video explains the history of funeral practices in the U.S., starting with home-based funerals and moving toward those taken care of by the emerging funeral professionals.



One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=738#oembed-2

# 2.4 INDIGENOUS DEATH-RELATED BELIEFS & PRACTICES

A variety of factors make it challenging to provide a brief overview of traditional death-related beliefs and practices among Indigenous peoples in Canada. These factors include: the diversity among Indigenous peoples; the use of oral traditions to share histories and pass on knowledge; and the impact of colonization on traditional cultural and spiritual beliefs and ways of knowing.

# Diversity

Indigenous peoples have inhabited what is known as North America and Canada for tens of thousands of years, long before colonization (Stolen Lives, 2015). Today, within the geographic boundaries of Canada, there are three main Indigenous groups, as defined by the *Indian Act* (1985) and the Constitution of Canada (1982), First Nations, Inuit, and Métis (OECD, 2020; Canada, 2022a; Canada, 2022b). These three groups include more than 50 distinct Indigenous nations, comprising over 630 groups or bands, and over 60 languages (Hunter Crouse, 2020; IWGIA, 2021; OECD, 2020). There is much cultural and spiritual diversity across Indigenous peoples (Anderson & Woticky, 2018; Hunter Crouse, 2020) with traditional "beliefs, values and practices, [vary[ing] widely...over thousands of years" (Kinsella et al., n.d, p. 247). This includes death-related beliefs and practices (Anderson & Woticky, 2018; Muzyka, 2020; NCTR, 2020).

# **Oral Traditions & Knowledge Sharing**

Traditional Indigenous knowledges, and cultural and spiritual practices are passed down orally from one generation to the next within each community via storytelling, dances, performances, songs, and art (AHS, 2016; United Nations, 2019; Indigenous Foundations, 2009). Oral traditions are the foundation of Indigenous societies, "connecting speaker with listener in communal experience and uniting past and present in memory" (Indigenous Foundations, 2009, para. 2). Despite the diversity among Indigenous peoples, there is a common traditional spirituality "rooted in their connection to nature, the earth, and one another" (Kinsella et al., n.d., p. 247) and in the recognition of death as part of the circle of life (Anderson & Woticky, 2018).

VIDEO: The Value of Ceremonies for Family Members

In the following video, Richard Cardinal talks about how the ceremonies at the end of life help complete the circle of life and promote healing for the bereaved.



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Medicine Wheel.

2015).

The cycle of life reflects the belief that "birth and death are inextricably linked as a transition of the spirit through this world" (Anderson & Woticky, 2018, p. 51). For example, according to Longboat (2002:5), the Anishinaabe (Ojibway) perspective on life and death is that "in order to understand death, one must first embrace the cycle of life... with birth, life, death, and the afterlife...[being] four stages of the human spirit." Representations of the cycle of life, such as the medicine wheel, provides a way of interpreting life and death beyond the physical and into the spirit realm (Anderson & Woticky, 2018; Hampton, et al., 2010), where spirits are believed to live on (Anderson & Woticky, 2018; Duggleby, 2015; TribalTradeCo, 2020). The focus of many traditional Indigenous end-of-life rituals is on healing the spirit and preparing it for its journey to the spirit world (Anderson & Woticky, 2018; Duggleby, et al.,

#### VIDEO: What is the Medicine Wheel?

In the following video, Mallory Graham from TribalTradeCo.com explains the medicine wheel and why it is so important to Indigenous cultures (Watch to 3:30 minute mark).



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## Colonization

Ever since the arrival of settlers from European nations and the colonization of North America, Indigenous

peoples' ways of life, their cultural and spiritual views and practices and their lives have been increasingly threatened through forced conversion to Christianity; genocide and cultural genocide that occurred in the Residential School system; the banning of traditional practices, and more (See Chapter on Genocide) (TRC, 2015). Efforts to force Christianity on Indigenous peoples to supplant their traditional spiritual beliefs and cultural practices, negatively impacted oral transmission of knowledge, while significantly altering spiritual belief systems (Hunter Crouse, 2020; Kinsella, et al., n.d; Muzyka, 2020). For some Indigenous peoples, forced Christianity has overwritten and almost completely replaced traditional cultural practices. For others, it has resulted in a combining of spiritual practices, "a fusion" of traditional Indigenous beliefs and Christianity (Murray, 2015). In other communities, there is a growing revitalization and embrace of traditional Indigenous beliefs and practices (Kinsella, et al., n.d.).

#### Traditional Practices

In the following short videos, members of First Nations, Inuit and Métis communities talk about some of their traditional death-related beliefs and practices, including ceremonies they perform for the dead. This brief exploration of the present-day use of traditional Indigenous death-related beliefs and practices, provides a bridge to the next chapter on Cultural and Religious Beliefs and Death-Related Practices.

#### VIDEO: Grief and Celebration

In the following video Jim Tuttauk talks about grief after loss, as well as how a person's death impacts and is mourned by the entire community.



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#### VIDEO: Moving to the Spirit World

In the following video Elaine Lavallee talks about traditional death-related ceremonies that help loved ones move on to the spirit world.



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#### **VIDEO:** The Comfort of Ceremonies

In the following video Curtis Delorme talks about the comfort and clarity he experiences from participating in traditional after-death ceremonies.



One or more interactive elements has been excluded from this version of the text. You can view them online here: <a href="https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=741#oembed-5">https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=741#oembed-5</a>

# **Optional Material**

Click the following link to learn more about the diversity of Indigenous death-related customs and beliefs (Optional reading):

Indigenous Perspective on Death and Dying

#### VIDEO: Indigenous Religions of Canada

To learn more about the diversity of Indigenous customs and beliefs, as well as the impact of colonization, watch the following video (Optional viewing).



One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=741#oembed-6

# 2.5 CHAPTER SUMMARY

# **Key Summary Points**

- 1. Understanding death-related practices of the past, and how many of them revolved around the acceptance of death and dying, provides an opportunity to think beyond death-based fears and anxieties that many people have today. It ultimately teaches us that how we view and deal with death is malleable and subject to change.
- 2. There are numerous death related customs and rituals that have been practiced by humans throughout our history.
- 3. There are 4 key factors that led to the distancing of death in North American non-Indigenous society, beginning in the late 1800s: increasing life expectancy; the enhancement of medical knowledge, skill and technology focusing on avoiding death; the movement of the cemetery outside of the city; and the professionalization of the death industry.
- 4. There is much cultural diversity among Indigenous peoples in Canada, making it challenging to provide a quick synopsis of Indigenous death-related beliefs and practices. One common motif is the circle of life, which represents death as just one part of the life cycle and a transition point to the spirit world. Colonization, including forced conversion to Christianity and the Residential School system (IRS), resulted in the decimation of traditional Indigenous beliefs and practices that are now being relearned and reclaimed through oral knowledge transfer from community Elders.

## Additional Resources

Alberta Health Services (AHS). (n.d.). Indigenous peoples and communities in Alberta.

https://www.google.com/

url?sa=t&rct=j&q=&esrc=s&source=web&cd=&ved=2ahUKEwjjwvnEi8v2AhVNWs0KHWbwCHUQF

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- O'Connell, M. (May 7, 2014). 'Corporatization' of funeral industry drives quest for alternatives. CBC. https://www.cbc.ca/news/canada/corporatization-of-funeral-industry-drives-quest-for-alternatives-1.2626007

# 2.6 REQUIRED COURSE MATERIALS

In addition to the videos and reading links embedded into the chapter, you are required to complete the following course material:

# Required Course Readings

- Büster, L. & Dayes, J. (August 11, 2017). What we can learn from death rites of the past will help us treat the dead and grieving better today. *TheConversation.com*. <a href="https://theconversation.com/what-we-can-learn-from-death-rites-of-the-past-will-help-us-treat-the-dead-and-grieving-better-today-74718">https://theconversation.com/what-we-can-learn-from-death-rites-of-the-past-will-help-us-treat-the-dead-and-grieving-better-today-74718</a>
- Dugdale, L. (February 8, 2012). The art of dying well. *Hastings Center Report*, 40(6), 22-23. <a href="https://doi.org/10.1002/j.1552-146X.2010.tb00073.x">https://doi.org/10.1002/j.1552-146X.2010.tb00073.x</a>
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# 2.7 CHAPTER ASSIGNMENT

# Historical Beliefs & Death Related Practices Assignment

This chapter's assignment is about cemeteries, grave markers, and death statistics. It involves visiting one or more cemeteries, taking photographs, conducting some web-based research, and writing a short essay. It is important to complete all Chapter materials (chapter content, including all embedded links to readings and videos, and the required course materials) prior to starting the assignment.

## Assignment Formatting & Style for Written Report

- Assignment formatting requirements: Arial 12-point font; 1 inch/2.54 centimeter margins; single spaced; APA in-text citation style, reference section and cover page.
- Use proper essay/paragraph style.
- Paraphrase as opposed to relying on direct quotes.
- Proofread your submission to make sure it is clear, well written, and intelligible.

## Steps to Completing the Assignment

- a. Visit one or more cemeteries (the larger and older, the less likely you will have to go to more than one) and find 6 grave makers/headstones that meet the criteria in I & II below. Some cemeteries provide burial services for particular religious or cultural groups, either through separate cemeteries or sections of cemeteries. As different groups may tend to use different forms of grave markers, due to the small sample size for this assignment, it is better to stay with the same group for all 6 grave markers/headstone that you are required to identify. Calling the cemetery in advance will help you identify appropriate cemeteries and locations within cemeteries for this assignment. Stopping in at the cemetery office can also make it easier to find the locations for the type of headstone/grave markers required for the assignment.
  - I. Find and photograph 3 grave markers/headstones within a 10-year period for people who died between 1910 and 1932.
  - II. Find and photograph 3 grave makers/headstones within a 10-year period for people who died between 2000 and 2022.
- b. Go online and search Canadian statistics for the 2 decades from which you drew your sample markers/stones to find out: the 10 leading causes of death and life-expectancy for those 2 periods of time.

- c. Write a short essay (500-750 words) where you address/reflect upon:
  - I. The differences in appearance of the grave markers (e.g., what they look like, what they are made of, what is written on them, etc.), between your two selected decades.
  - II. The differences in the cause of death and life-expectancy across your two selected decades.
  - III. What you learned collecting the data for the assignment (the photographed grave markers and the collected statistics), as well as your experience completing the assignment, including spending time in a cemetery.
- d. Organize the photos, statistical data collected, and short essay into a document for submission. For each photo, indicate where and when it was taken. Clearly indicate which cemetery or cemeteries you went to and include their address(es).
- e. For the statistical data and any course materials referred to in your assignment, include proper APA intext citations and a proper APA reference section.

As explained in this chapter's materials, cemeteries are interesting historic sites, and many are places where you recommended that you do not visit a cemetery on your own. Instead ask a friend, family member, or classmate to join you.

## Assignment Submissions Must Include

- 1. A proper APA style cover page.
- 2. A short essay as detailed above.
- 3. Photographs of the 6 grave markers you selected.
- 4. A proper APA reference section that contains all the material cited in the assignment.

# 2.8 REFERENCES & MEDIA ATTRIBUTIONS

#### References

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# CHAPTER 3: CULTURAL & RELIGIOUS BELIEFS & DEATH-RELATED PRACTICES



Jacqueline Lewis, Jillian Holland-Penney & Brandon Bernardon

# 3.0 INTRODUCTION

# **Chapter Introduction**

What do we do when someone we know or love dies? How are we supposed to feel and act? How do we respectfully honour the deceased and support the bereaved? Answers to these questions are usually dictated by culture and religion. Death-related beliefs and practices are part of every culture, but how we deal with death is diverse. Although post-death events typically involve honouring the dead and supporting the bereaved (i.e., an individual, a family, or a community), these events can take a variety of forms (e.g., funerals, wakes, celebrations of life, etc.). Some are celebratory in nature, some are highly emotive, while others are solemn and reserved. This chapter provides an overview of some cultural and religious death-related rituals, ceremonies, and practices.

# **Chapter Objectives/Learning Outcomes**

After completing the chapter materials, you should have an understanding of:

- 1. Cultural rituals and ceremonies, and the role they play in death, grief, and mourning.
- 2. The death-related practice of professional mourning.
- 3. Cross-cultural and religious variations in funeral and death-related rituals, ceremonies, and practices.

# Questions to Think About When Completing Chapter Materials

- 1. What death-related tradition(s) do you have in your family? What would happen if someone in your family chose not to follow the practices dictated by your culture and/or religion?
- 2. Which death-related practice(s) do you find most interesting? What makes them interesting?

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- 3. What is role of death rituals and ceremonies for the bereaved and the community?
- 4. What are some similarities among the funeral rites and rituals of different cultures and/or and religions?

# 3.1 CULTURE, RITUALS & DEATH



Egyptian pyramids safeguarded the entombed bodies (History.com Editors, 2019).

# Culture

Culture is comprised of the beliefs, values, customs, language, symbols, and artifacts that are shared by a collective of people (UofM, 2010), which includes religious beliefs and practices (Edara, 2017). These shared aspects of culture shape how we, as cultural beings, behave and think – even if we are unaware or unconscious of such influences (Bowman, 2000). Shared elements of culture enable us to have both a common understanding of the world around us, as well as a sense of purpose and collective identity (Bowman, 2000). The various aspects of culture are passed down from generation to generation, and subject to cultural shifts over time (e.g., regarding the acceptability of styles of dress, ways of speaking, sexual behaviour, substance use, etc.) (Bowman, 2000; Texas A&M, n.d., UNESCO, n.d.).

Despite wide cultural variation, in terms of behavioural **norms** or standards, there are some commonalities between cultures (Gire, 2014). These commonalties are often tied to life course or transition events, such as birth, marriage and death. For example, most cultures throughout human history have had ceremonies and

rituals surrounding the death of a member of the community (Mitima-Verloop, 2019; O'Rourke, 2011; UofM, 2010), with funerals being "one of the most ancient known tangible signs of human social ritual" (O'Rourke et al., 2011, p. 743). The meaning attributed to death, and the practice and purpose of established death rituals or ceremonies that are used to mark this rite of passage, however, vary from culture to culture (Anderson & De Souza, 2021; Gire, 2014; Lowe, Rumbold & Aoun, 2021; Mitima-Verloop, 2019).

# Rituals & Ceremonies

Cultural rituals, ceremonies, and practices are shared social activities that help structure and make meaning out of the lives of social groups (Irwin, 2015; UNESCO, n.d.). According to Anderson and De Souza (2021:34), "a ritual is the undertaking of specific activities or behaviours that express symbolic... meaning, whereby specific thoughts and feelings are experienced individually, or as a group." Rituals reflect cultural norms and values. Whether performed alone or with others, they are an important part of a culture because they reaffirm individual and group identity (UNESCO, n.d.) and help us recognize and make sense of life transition events (Caswell, November 28, 2018).



People celebrating the el Día de los Muertos (the Day of the Dead).

There are a myriad of cultural rituals, ceremonies, and practices, including those tied to death. For example, the el Día de los Muertos (the Day of the Dead) is a traditional Mexican holiday, dating back to the Aztecs and Toltecs (PBS, October 31, 2019). It is celebrated each year between October 31 and November 2, a time when it is believed the dead can leave the spirit world to reunite and celebrate with their loved ones (History.com Editors, October 30, 2018). The Day of the Dead is "a joyous, ritualistically elaborate celebration of life"

(Weiss, November 2, 2010, para. 2), with traditional rituals and celebratory activities like parades, donning of skeletal face painting, erecting of decorative alters for loved ones, feasting, etc., serving to remind participants that life is cyclical, and that death is not "the end of one's existence, but simply another chapter of life" (PBS, October 31, 2019, para 1).

Click the link below to learn more about the Day of the Dead:

Day of the Dead (Dia de los Muertos)

# 3.2 DEATH RITUALS & CEREMONIES

## **Death Rituals**

"Death ceremonies are **rites of passage** for both the deceased and for the living" (Irwin, 2015, p. 121). Ritualistic practices around death involve activities and behaviour that are performed or engaged in to mark the significance of the loss to the bereaved and the community. Death rituals commence the moment a person is declared dead, although definitions of death vary historically and cross-culturally (Palgi & Abramovitch, 1984). Depending upon cultural practices, many of which are tied to religious beliefs, such rituals can involve: preparing of the body (e.g., it may be washed by family or community members or professional funeral staff; it may be dressed, kept naked, or wrapped in a burial shroud; it may be embalmed; etc.); watching over the body (e.g., pre-burial vigils); a funeral and body disposal (e.g., burial, cremation, etc.); prayer; a mourning period; ritual providing of food (i.e., feasting); and celebratory events (Cohen, 2002). Death rituals provide bereaved individuals and the community with time to process their loss and acclimate to the dramatic changes associated with that loss, including alterations in status or identity, such as moving from the status of married to widowed after the death of a spouse.

# **Grief & Mourning Rituals**

Grief and mourning rituals typically begin shortly after death. As detailed in the next chapter section, depending on culture and religion, grief rituals can take a variety of forms before, during, and after a funeral ritual and body disposal.

According to Irwin (2015), mourning and grief rituals serve several important purposes. They provide the bereaved an opportunity to acknowledge and share their experiences of loss, as well as their memories of the relationships they had with the deceased (Irwin, 2015). They facilitate the offering of support and comfort to the bereaved,



A weeping woman sitting on a chair at a funeral.

and they serve as a means through which to express loss (Irwin, 2015). As part of death rituals, we often see the open unrestrained expression of grief through the release of emotion (Wojcik & Dobler, November 1, 2017).

Throughout history and cross-culturally there are numerous examples of ritualized public outpourings of emotion, many of which take oral and physical forms, as part of the process of meaning-making and coping with death (Gamliel, 2014a & 2014b; Mitima-Verloop et al., 2021). For example, loud vocal expressions of grief such as "death wailing", "keening", "lamenting", and "chanting" can begin shortly after death and last until after the burial. Or they can occur at rituals that take place prior to funerals and body disposal and during the gatherings that often occur after these events. Such public rituals of sorrow are a "powerful way to give voice to the impact of the...loss on the wider community" (Wojcik & Dobler, 2017, para. 12) and can have a cathartic, grief releasing effect for participants and observers (McLaughlin, March 18, 2018; Sautter, 2017). An example of a traditional ritual emotional outpouring that is still practiced today, is the Haka chant dance of the Māori of New Zealand. The Haka is used for a variety of purposes, but it is "an integral part of the Māori mourning process.... Show[ing] love and compassion...and uplift[ing] the spirts of bereaved families (Māori Funeral Rituals, n.d.).

## Click the link below to see the Haka being performed by friends and family, at the end of a funeral for a teenager from the Māori community.

### <u>Teenager Breaks Down in Tears During Memorial Māori Haka</u>

Wailing, keening, lamenting performances, as traditional parts of expressing grief, are evident in various cultures historically and, to a lesser extent, today. A few examples include the keen, or lament for the dead that is at the core of traditional Irish wakes, and the ancient wailing practice of Yemenite-Jewish women (Mclaughlin, March 18, 2018; McLaughlin, 2019). These rituals are/were typically carried out by women, who are/were paid for their mourning services (Gamliel, 2014b; McGarry, August 19, 2021; Mendoza, February 15, 2018). Although there is much historical and cultural variation in the roles and styles of professional mourners, these individuals played an integral role in both pre-funeral events and funeral services (Natan-Yulzary, 2021).

### VIDEO: Professional Mourners of Sardinia

The following video illustrates one form of professional mourning and the role it can play in a culture.



One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=761#oembed-1

Today, professional mourners are still used in various parts of the world. You can rent a mourner in Essex UK, China, and even in the United States at the Golden Gate Funeral Home in Texas (Mendoza, February 15, 2018). Professional mourners are hired to provide the oral expression of emotion at a pre-funeral event

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and/or at a funeral (May, n.d.) and/or increase the number of people in attendance at a funeral (Mendoza, February 15, 2018). In cultures where public expression of emotions by the bereaved are viewed as inappropriate, such as in Taiwan, professional mourners may be hired to express emotions for the family (Dicken, 2021). Paid mourning services are, however, not always sombre and emotional, they can also provide entertainment through music, dance, etc., for funeral attendees as they celebrate the life of the deceased (Keyl, 1992).

Click the link to learn more about the role of professional mourners:

Paid for Their Tears: The Peculiar Profession of Professional Mourners

# 3.3 DEATH & DYING: CURRENT CUSTOMS & RITUALS

Cultures and religions around the world use a wide variety of different rituals, ceremonies and practices relating to dying and death. Despite diversity in form and style, there are some cross-cultural similarities in rituals and ceremonies, with many involving the sharing of food, expectations regarding appropriate attire, spending time with loved ones, and the use of song, prayer, and celebrations. The remainder of this chapter explores a sampling of some death and dying beliefs and practices around the globe.

### VIDEO:Death & Dying: Cultural and Religious Perspectives

In the following video Rochelle Wong from Vanderbilt University's School of Medicine discusses death and dying across cultures.



One or more interactive elements has been excluded from this version of the text. You can view them online here: <a href="https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=770#oembed-1">https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=770#oembed-1</a>

# Click the links to learn more about funeral rituals associated with some religions of the world: Buddhist Funeral Service Rituals



Buddhism Monk Temple.

### Christian Funeral Service Rituals



Berlin Cathedral Sculpture.

## Hindu Funeral Customs and Rituals



Manikarnika Cremation Ghat.

### Islamic Funeral Customs and Service Rituals



Mosque in Abu Dhabi.

Jewish Funeral Service Rituals



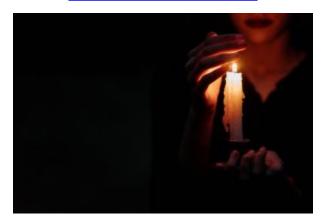
Star of David Symbol.

Sikh Funeral Service Rituals



Amritsar Golden Temple.

## Wiccan Funeral Service Rituals



Candles play a vital role in many Wiccan services as they represent light and the crossing over of the deceased soul (FuneralWise, n.d.-g).

# 3.4 CHAPTER SUMMARY

# **Key Summary Points**

- 1. Cultural membership shapes how we perceive and respond to death.
- 2. Vocal and physical expressions of emotion play an important role in end-of-life rituals and ceremonies, which includes the work of professional mourners.
- 3. There is much historical, cross-cultural, and religious variation in death-related rituals, including funerals.

# Additional Resources

National Funeral Directors Association (NFDA). (n.d.). *Religious funeral customs*. https://nfda.org/religious-funeral-customs

# 3.5 REQUIRED COURSE MATERIALS

In addition to the videos and reading links embedded into the chapter, you are required to complete the following course material:

# Required Course Readings

Anderson, D. & De Souza, J. (January 12, 2021). The importance and meaning of prayer rituals at the end of life. *British Journal of Nursing*, 30(1), 34-39. https://doi.org/10.12968/bjon.2021.30.1.34

Australian Museum. (March 4, 2021). *Death: The last taboo*. <a href="https://australian.museum/about/history/exhibitions/death-the-last-taboo/">https://australian.museum/about/history/exhibitions/death-the-last-taboo/</a>

Casswell, G. (November 28, 2018). Why we need end-of-life rituals. *TheConversation.com*. <a href="https://theconversation.com/why-we-need-end-of-life-rituals-107249">https://theconversation.com/why-we-need-end-of-life-rituals-107249</a>

Cook, C. & Solomon, S. (June 18, 2015). For believers, fear of atheists is fuelled by fear of death. *TheConversation.com*. <a href="https://theconversation.com/for-believers-fear-of-atheists-is-fueled-by-fear-of-death-41724">https://theconversation.com/for-believers-fear-of-atheists-is-fueled-by-fear-of-death-41724</a>

Graham, R. (May 29, 2021). 'You are going to die': Nun finds comfort in knowing end is near. *Arkansas Democrat Gazette*. https://www.arkansasonline.com/news/2021/may/29/you-are-doing-to-die-nun-finds-comfort-in-knowing/

# 3.6 CHAPTER ASSIGNMENT

# Cultural & Religious Beliefs & Death-Related Practices Assignment

This chapter's assignment requires you to identify and engage with cultural representations of death and dying. You have the choice between finding **EITHER** two pieces of art **OR** two pieces of writing/poetry/ literature, that are responses to or representations/expressions of death and/or dying. These can be forms of art or poetic literature from any culture or tied to any religion. It is important to complete all chapter materials (chapter content, including all embedded links to readings and videos, and the required course materials) prior to starting the assignment.

# Assignment Formatting & Style for Written Report

- Assignment formatting requirements: Arial 12-point font; 1 inch/2.54 centimeter margins; single spaced; APA in-text citation style, reference section and cover page.
- Use proper essay/paragraph style.
- Paraphrase as opposed to relying on direct quotes.
- Proofread your submission to make sure it is clear, well written, and intelligible.

# Steps to Completing the Assignment

- a. Identify 2 cultural representations of death and/or dying that resonate with you.
- b. If you have chosen works of art, find photos of each. If you have chosen written work, find the full text of the written work. Be sure to gather the information from the source where you found the images or text to allow you to provide in-text and reference section citations for your assignment.
- c. Do an internet search to find information on the person who created the pieces of art/poetic works <u>and</u> explanations of these works, ideally by the person who created them.
- d. Write a 700-1000 word reflection paper (give or take 100 words), splitting the space evenly between the two pieces. In your paper, reflect on:
  - I. Why you selected the pieces you did.
  - II. How/why they resonate with you.
  - III. What they mean to you/how you interpret their meaning.
  - IV. How your responses to the works (as per II and III) fit with or diverge from other explanations/

interpretations of the works (see C above).

- e. Organize the images of the 2 pieces of art or the text of the 2 poetic works and your reflection paper into a document for submission. For each piece of art/poetic work, be sure to provide: its title, the artist/ creator/author, when it was created/written, where it is available to be seen/read (e.g., is it in a gallery, where? Is it in a book, which one[s]?); and a citation for where you found it.
- f. Develop an APA style reference section for all material included and cited in your reflection paper, including the pieces you have chosen and where you found them.

# Assignment Submissions Must Include

- 1. A proper APA style cover page.
- 2. Either pictures/images of the 2 pieces of art or the full-text of the piece of written work you chose for the assignment.
- 3. A reflection paper.
- 4. A proper APA reference section.

# 3.7 REFERENCES & MEDIA ATTRIBUTIONS

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# CHAPTER 4: DEALING WITH BODIES AFTER DEATH



Jacqueline Lewis, Jillian Holland-Penney & Jackie Durocher

# 4.0 INTRODUCTION

# **Chapter Introduction**

When death occurs, the first thing that has to be decided upon is the means of body disposal. In Canada, when we consider typical ways to deal with dead bodies, we usually are thinking about burial and cremation. The reason for this is that these methods have been around for a long period of human history (See Chapter on Historical Beliefs and Death-Related Practices). The actual practices have changed substantially over time, however, with burial and cremation practices today differing from ancient or older rituals. Currently, there is a revival of more traditional versions of some of these methods of body disposal, reflected in what is referred to as the green burial or funeral industry. There are also some newer technological advances that provide alternative means of body disposal, some of which address concerns for environment and reducing our environmental footprint at the end of our lives. This chapter explores the options available for body disposal at the end of life, drawing attention to some of the problems associated with conventional and/or current body disposal practices.

# **Chapter Objectives/Learning Outcomes**

After completing the chapter materials, you should have an understanding of:

- 1. The differences between conventional practices for dealing with bodies and their precursors in human history.
- Conventional options for dealing with bodies and the problems associated with these practices.
- 3. Alternative options for dealing with bodies and the benefits of some of these practices.
- 4. The green burial movement.

# Questions to Think About When Completing Chapter Materials

- 1. What are some of the pros and cons associated with conventional methods of dealing with dead bodies?
- 2. What are the challenges the world is facing due to the way we deal with bodies at the end of life?
- 3. Why are certain environmentally sustainable and cost-effective options for dealing with bodies not as widely known and used, while more damaging and costly options are common practice?
- 4. Think about what you might want done with your body following death. What is the basis of your choice? How is it impacted by your culture and religion (See Chapter on Cultural and Religious Beliefs and Death Related Practices)?

# 4.1 TRADITIONAL DISPOSAL METHODS: EMBALMING, BURIAL & CREMATION

# **Embalming**

Embalming is a method/tool of body perseveration dating back to ancient Egypt, where the practice of mummification was used to ensure the preservation of the body, a requirement for the afterlife (Gannal, 2015; mummification, n.d.). Mummification is a multi-step process involving: organ removal, the drying out of the body; the wrapping of the body; the application of resin and oils; and eventually sealing the mummy in a sarcophagus (Gannel, 2015; Mummification, n.d.). There is evidence that mummification was used in many civilizations for thousands of years (e.g., Incan, Aztec, Africa, ancient Europe, Indigenous



Image of open casket body that is made to look like it is sleeping.

people of Australia, etc.) (Mummy History, August 21, 2018). In some cultures, evidence points to mummification as a process reserved for royalty or the privileged class, but in others it was more widely available. For example, in Sicily in the 18th and 19th centuries mummifying was also available to the middle class (Giuffra et al., 2006).

### **VIDEO:** The Mummification Process

In this video, the Getty Museum's Romano-Egyptian mummy Herakleides, is used to explain the Egyptian mummification process.



One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=789#oembed-1

The modern concept of embalming began in the mid-1800s during the U.S. Civil War as a means to preserve bodies for the transport home for burial (See Chapter on Historical Beliefs and Death-Related Practices). The popularization of embalming and the beautification of the corpse, led to increasing demand for the service and the emergence of the modern funeral industry (Doughty, 2017; FCASMC, n.d.). Current embalming practices involve replacing the body's blood with chemicals that help prevent body decomposition (Doughty, 2017; Chavez, 2019). The body is then further protected from decay that occurs after burial by the layers of metal and wood that surround caskets (Doughty, 2017) and entombment in a vault (see Burial below). Today, traditional embalming services cost around \$800 (Prices, n.d.), however, the U.S. company Summun, is offering modern mummification services. The process takes around 90 days and costs approximately \$67,000 USD (Morton, March 28, 2014).

## **Burial**

As noted in the chapter on History of Death and Death-Related Practices, burial is an ancient form of body disposal, however, what we view as traditional burial practices today actually began with the reintroduction of embalming type processes and the professionalization of the funeral industry in the mid-1800s in North America (Walsh, 2017). Burial as a method of body disposal typically requires the purchase of a burial plot (Doughty, 2017), a wood or metal casket, and an outer burial container. Burial containers come in two forms, burial vaults and grave liners. Both function to prevent soil sinkage, which would normally occur as the casket and body decompose, helping to maintain cemetery landscapes. The former also tightly seals the casket to prevent exposure and decay (Doughty, 2017; FCASMC, n.d.). The number of services and associated fees required for a burial today are costly (Understanding Funeral Costs, n.d.), with a typical burial in Canada costing on average around \$10,000 (Average Funeral Costs, n.d.).



An example of a concrete burial vault.

## Cremation

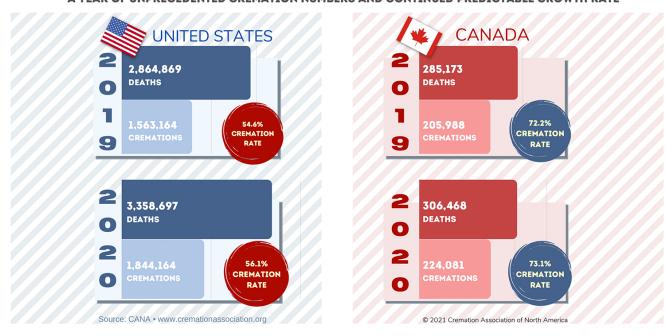


A willow coffin decorated with flowers is moved into a cremator.

The burning of the dead is another example of an ancient means of body disposal (See Chapter on Historical Beliefs and Death-Related Practices), and was the preferred custom in some cultures like ancient Greek and Roman societies (Naillon, n.d.; Robinson, 2021). Although the practice waned after the 1st century **CE**, due to the rise of Christianity and its prohibition on cremation, today cremation is one of the most common forms of body disposal. In Canada, the first crematorium opened in 1901 at Mount Royal Cemetery in Outremont Québec. Since then, the practice has continued to grow in

popularity among residents of Canada and has become the preferred method of body disposal (Cummings, February 16, 2020). According to a 2021 statistics report, 73% of the body disposals in Canada in 2020 were via cremation (CANA, 2021a) (See infographic below). That number was more than double the cremation rate two decades earlier (CANA, 2021b).

A YEAR OF UNPRECEDENTED CREMATION NUMBERS AND CONTINUED PREDICTABLE GROWTH RATE



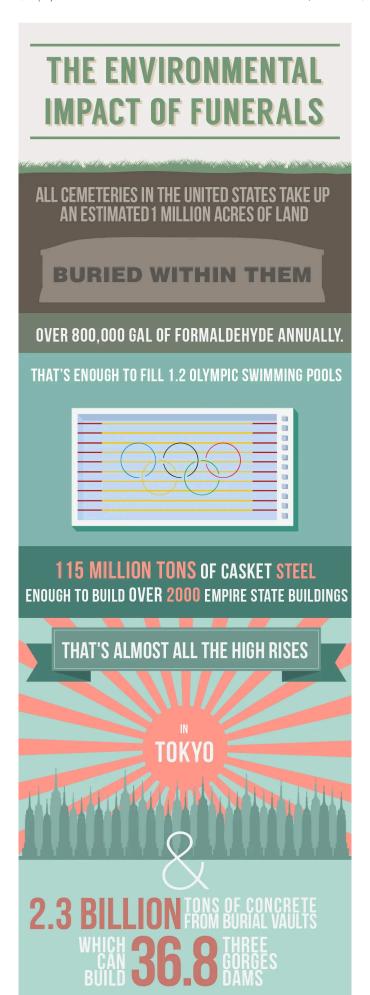
CANA 2019-2020 Cremation statistics for Canada and the US. ©CANA (2021). All rights reserved. Image used with permission.

Flame-based cremation involves the use of high heat to reduce human remains to bone and ash and the pulverization of the bone into tiny pieces, which are then placed into a container commonly referred to as an urn (CANA, n.d. -a; Ontario Cremation Services, n.d.). Prior to incineration, the body is placed into a casket or container made of wood or other flammable material (e.g., cardboard). The cultural shift to this form of body disposal has been attributed in part to the lower costs of this procedure — between \$2000 and \$5000, considerably less than burial (Cummings, February 16, 2020). Cremation also provides families with more time and greater flexibility to determine both the type of memorial service they want and what to do with their loved one's remains (Canadian Funerals, n.d.). Options for cremated remains are quite diverse. Urn contents can be scattered as part of a memorial process, or urns can be kept in one's home, buried or placed in a mausoleum or a columbarium (Ontario, 2014). Other newer options for ashes include turning them into a diamond, jewellery or glass art or even fireworks or part of a reef.

# 4.2 ENVIRONMENTAL IMPACT OF EMBALMING, BURIAL & CREMATION

Click the link below to view the infographic on the web:

The Environmental Impact of Funerals
Accessible text describing the infographic



Environmental impact of funerals infographic.

# 4.3 BURIAL CAPACITY & SPACE LIMITS

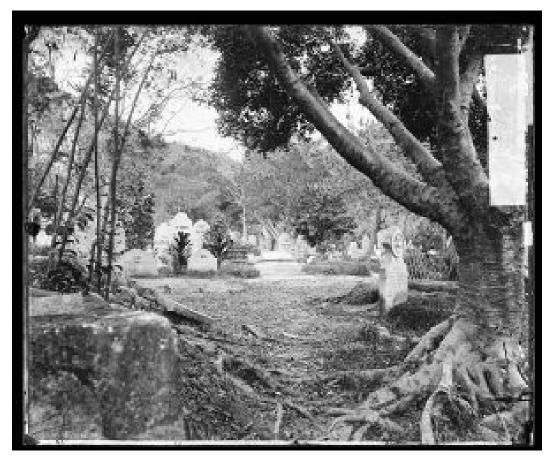
In addition to the environmental impact, another big problem associated with conventional body disposal methods is that we are running out of room to bury our dead in existing cemeteries (e.g., in graves for caskets or urns, in mausoleums, columbariums, etc.) and geographically, as not all land is usable for cemeteries/burials (Perfect Memorials, n.d.; Walls et al., November 5, 2014). This situation is particularly problematic for members of religions whose beliefs dictate that bodies must be buried in their entirety (e.g., Muslim and Orthodox Jewish) (Uzielli & O'Brien, 2016). Finding a way to deal with this situation



Image of crowded cemetery with limited room between plots.

becomes even more dire when we consider the space requirements that may be needed for the large aging population (O'Reilly, 2019; Simões & Perobelli, April 1, 2021).

Issues with cemetery capacity are not a new phenomenon. For example, in Paris in late 1700s cemeteries were literally overflowing with corpses (Geiling, March 28, 2014). The chosen solution was to dig up the remains of the dead and move the bones to the tunnels under the city, that had existed since the 13th century (Vitek, October 27, 2021). This process continued, on and off into the mid-1800s, with the tunnels used as a direct burial location at some points in time (Geiling, March 28, 2014). In total, it is estimated that the bones of around six million Parisian's are housed in the Catacombs of Paris (Vitek, October 27, 2021).



Happy Valley Cemetery in Hong Kong.

Today, cemetery capacity issues in various parts of the world are making the news. For example, in 2019 Happy Valley Christian cemetery, one of Hong Kong's oldest cemeteries, dating back to 1845 (see image above), made the headlines because it had reached its space capacity, with hundreds of thousands of human remains waiting for a spot (O'Reilly, 2019). In 2015, BBC News did a story entitled "The word is running out of burial space." It reported on how cemeteries in the UK are largely full and some have ceased providing burial services (McManus, March 13, 2015). As a result of the 6 million COVID-19 related deaths worldwide (as of March 2022), the issue has become even more dire in various parts of the world. In Sao Paulo Brazil, for instance, efforts to empty old graves have had to be sped up to make room for soaring death tolls (Simões & Perobelli, April 1, 2021).

### VIDEO: Hong Kong is Running Out of Space

This video explores the issues Hong Kong is facing in terms of space to put their dead and some potential future solutions.

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=797#oembed-1

One solution being explored to address limited space for the dead and inground burials is to build up. Multistory columbariums are already in use in some cities (i.e., Japan, Hong Kong – see image below of the Tsand Tsui Columbarium in Hong Kong) (Adelstein, March 18, 2019; Daifuku, n.d.). Other ideas include vertical cemeteries that can house caskets in high rise structures. There are proposals to build such structures in Oslo Norway, Paris France, Mubai India, and Santos Brazil (Hariyono, 2015). These structures would house not only the dead, but could also provide a variety of services including onsite faculties for funerals, prayer, and visiting with deceased loved ones (Hariyono, 2015; Philjake, October 28, 2018).



The multi-story Tsang Tsui columbarium in Hong Kong.

# 4.4 GRAVE RECYCLING





St. Louis Cemetery No. 1, New Orleans LA.

Mount Olivet Cemetery in New Orleans LA.

Grave recycling is another means by which to help with the problem of limited burial

space in cemeteries (Walls et al., 2014). The term applies to several different practices. It refers to the deepening of graves, where bodies are exhumed, graves are made deeper, then bodies are placed back inside, with other bodies placed on top (de Sousa, January 21, 2015; Walls et al., 2014). Grave recycling also refers to the process of exhuming bodies from graves and burying new ones in that cemetery plot. The exhumed remains are then: placed in a mass grave or a common <u>ossuary</u>; boxed and placed in a different part of the cemetery; or cremated and returned to family (Ferraz, July 18, 2018).

The reuse of graves has been going on for thousands of years across many cultures, particularly in Europe (de Sousa, January 21, 2015; Walls et al., 2014). "It is a system that has worked efficiently...all over the world" (de Sousa, January 21, 2015, para. 5). In 19th Century Europe, for instance, families only leased their plot spaces and were allowed to renew those leases after eight to fifteen years if they wished to keep their loved one in that resting space (Uzielli & O'Brien, 2016). In the late 1800s in Portugal, most dead were buried in churchyards until the plot was needed for a new body, at which time the old body would be dug up and placed in a common ossuary. A version of the practice was re-introduced in Portugal in 1962 (Ferraz, July 18, 2018).

As we grapple with issues of burial space, grave recycling is making a comeback in Europe. Although some places still permit perpetual burial plot purchases, there is a trend toward term limited grave/cemetery space rental in most European countries (Hoffner, December 2, 2016). Temporary leases are available for varying periods of time in countries like Germany, Greece, Italy, Portugal, Sweden, Switzerland, and the Netherlands. Depending on the country, leases can last anywhere from 3 to 50 years (Ferraz, July 18, 2018). In Greece, burial plot rentals are usually 3 years in length and prices for extensions are extremely expensive (Hadjimatheou, November 26, 2015). In the UK, some cemeteries are initiating grave recycling practices. For example, the City of London Cemetery has begun reusing burial plots that are at least 75 years of age (de Sousa, January 21, 2015).

Another form of grave recycling occurs in some family tombs, such as those found in New Orleans, Louisiana (see photos at top of page) (Hillinger, 1990). These above ground burial sites typically have 2 shelves, one above the other, that are large enough to hold a casket. Despite their size they can actually house the remains of many family members. The newest casket is always placed on the top shelf and left for a minimum of a year and a day. After that time, when the space is needed for another family member, the casket is removed, the remains placed on the lower shelf, and the casket destroyed (Cemeteries in NO, n.d.). In some tombs, there is space to gather up decomposed remains under the tomb. As space is needed, skeletal remains, ashes, etc. are pushed to the back of the tomb where they fall through a gap into to the space beneath (Atun-Shei Films, January 20, 2019; Hillinger, 1990). Watch the video below to learn more about New Orleans' crypts.

### Click the links below to learn more about burial plot recycling:

Losing the Plot: Death is Permanent, But Your Grave Isn't How Long are Graves Kept

### VIDEO: How to Fit 85 bodies in a New Orleans Above-Ground Tomb

The following video provides images and information on the New Orleans Above-Ground Tombs. (**Begin watching at 1:04 minute mark**).



One or more interactive elements has been excluded from this version of the text. You can view them online here: <a href="https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=801#oembed-1">https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=801#oembed-1</a>

# 4.5 ENVIRONMENTALLY SUSTAINABLE SOLUTIONS

### **Green Burials**

Natural, woodland, ecological, or green burials are environmentally friendly alternatives to the traditional methods of body disposal (i.e., burial and cremation) (Shelvock et al., 2021). This method is closely associated with traditional burials, but involves eco-friendly materials and adoption of more ancient practices (e.g., the use of burial shrouds). Bodies are not embalmed. They are buried in biodegradable containers/ caskets (e.g., bamboo, cardboard, paper, wool, willow, etc.) and/or burial shrouds, typically with no permanent markers such as had headstone (Robinson, 2021). One interesting variation is the use of a shroud or burial suit embedded with mushroom spores. The mushrooms help decompose the body, cleansing it of toxins that would otherwise end up in the earth (See Mushroom Burial Suit video below) (TED, 2011).

### VIDEO: Jae Rhim Lee: My Mushroom Burial Suit

The following video outlines what Infinity mushrooms are and how they can be used to provide the most environmentally friendly burial method of dealing with bodies after death.



One or more interactive elements has been excluded from this version of the text. You can view them online here: <a href="https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=803#oembed-1">https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=803#oembed-1</a>

Green burials are done in such a way as to minimize any negative impact on the land or burial site (Haker, 2012). The idea is to return the "body directly to the earth...[as] humans have been doing since time immemorial" (Rehagen, October 27, 2016, para. 9) and allow the body to decompose naturally and nourish the earth. Such burial practices benefit the living by preserving green spaces (i.e., forests and open fields) and protecting them from future development (Freehill & Pantuso, 2019; Ottawa Citizen, February 2021). They are also a more cost-effective alternative to traditional burial (Duffy, 2021). There are a variety of other green burial type options including placing the body or ashes into a pod that will be used to grow a tree (see video below), with pod burial sites eventually becoming forests (Freehill & Pantuso, 2019).

### VIDEO: Ecological Burial Pod turns Bodies into Trees

The following video explains how burial pod works.



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### VIDEO: Die As You Lived: What is a Green Burial?

In the following video Megan Spencer, co-founder of Green Burial Ottawa Valley, explains what it means to have a green burial and why more people are choosing to die as they lived.



One or more interactive elements has been excluded from this version of the text. You can view them online here: <a href="https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=803#oembed-3">https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=803#oembed-3</a>

# Aquamation

While green burial practices are re-imagining traditional body disposal practices, aquamation is a funerary innovation (Robinson, 2021). Aquamation, also referred to as water, bio-, green, or flameless cremation, or resomation, uses the process of alkaline hydrolysis to mimic natural decomposition (Robinson, 2021). The body is placed in a sealed chamber that is filled with water and alkaline chemicals. Then heat, gentle water flow, pressure and/or agitation is applied. At the end, bone fragments are pulverized as with regular cremation. The process results in about one-third more cremated remains, that can be returned to the family (CANA, n.d.-b). Alkaline hydrolysis is a much greener process than traditional fire-based cremation. There is no release of chemical compounds or carbon emissions during the process, it requires far less energy, and allows for the safe disposal of mercury from dental fillings (Shelvock et al., 2021).

### VIDEO: Bodies Dissolve in Water

The following video outlines the process of high and low temperature alkaline hydrolysis or aquamation as a method of body disposal.



One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=803#oembed-4

### Click the following links to learn more about green deaths:

The Green Death: How Environmentally Friendly Options Are Changing The Way We Bury Our Dead Return to Nature

# 4.6 THE IMPACT OF THE COVID-19 PANDEMIC ON DEATH-RELATED PRACTICES

The COVID-19 pandemic transformed the way we deal with dead bodies and the end of life (Mikles, January 26, 2022). These changes were tied to the sheer volume of deaths and resulting number of bodies that had to be processed, as well as safety concerns tied to bodies of people who died of COVID-19 (Lale, January 6, 2021). Large numbers of dead meant that normal religious requirements for burying the dead, such as the Jewish practice of burial within 24 hours, were difficult to follow. Delays in access and COVID-19 safety protocols made the organizing and performing of religious rituals on or for the dead by family and religious



Image of audio-visual equipment set up at a wake to stream funeral proceedings for audiences to watch online.

officials (e.g., washing and shrouding the body, sitting vigil with the body until burial), more challenging, difficult, and sometime impossible (MacNeil et al., 2021). Safety guidelines for the funeral industry, such as those detailed by the World Health Organization (September 4, 2020), further altered normal practices. For example, WHOs guidelines included recommendations to avoid embalming bodies and prohibiting family and loved ones from touching or kissing the body.

Local, regional and national public health restrictions, capacity limits, and social distancing requirements further impacted traditional death-related practices (MacNeil et al, 2021). At various points during virus surges and shutdowns, funeral homes were either unable to allow people inside or only a few at a time (Kohn & Gould, 2020). Traditional rituals and ceremonies were virtually eliminated (e.g., Christian practice of visitations prior to a funeral and Jewish Shiva customs of visitations after the funeral) (Watts, August 16, 2021). This served as an impetus for the evolution of virtual forms of visitation and funeral attendance, as well as the popularization of alternative means to sharing condolences, memories and other information via social media (Kohn & Gould, 2020; Conway, 2020) (See Chapter on Loss, Grief & Bereavement). These changes may well become a normal part of funerals after COVID to accommodate loved ones who are not able to travel to attend end-of-life events, who prefer online services (Stewart, January 16, 2022), and/or to reduce funeral related costs. Funeral homes are now offering live-streaming as part of funeral packages or as an

alternative to the traditional funeral for the budget conscious (Virtual Funerals, n.d.; Funeral Companion, n.d.).

### Click the links to learn more about funerals and COVID-19:

Small Funerals, Online Memorials and Grieving from Afar: The Coronavirus Is Changing How We Care for the Dead

Coronavirus Is Changing Funerals And How We Deal With The Dead

# 4.7 CHAPTER SUMMARY

# **Key Summary Points**

- 1. Current conventional methods of dealing with bodies after death are based on ancient practices.
- 2. Certain conventional methods associated with dealing with bodies after death are costly, contribute to the lack of space for the dead, and are not environmentally sustainable.
- 3. Alternative options for dealing with bodies provide an opportunity to move beyond our conventional understandings of burials and cremation.
- 4. There are a variety of "greener" ways to deal with bodies at the end of life. Some are variations on ancient practices and some are recent innovations.

# Additional Resources

### Additional Viewings

Channel 10. (June 13, 2011). *Grave recycling*. [Video]. YouTube. <a href="https://www.youtube.com/watch?v=wfvhUvSYIfg">https://www.youtube.com/watch?v=wfvhUvSYIfg</a>

NBC News. (November 19, 2020). Funerals in the COVID-19 area face immense and emotional hurdles | NBC News NOW. [Video]. YouTube. <a href="https://www.youtube.com/watch?v=0QoEpDjT21c">https://www.youtube.com/watch?v=0QoEpDjT21c</a>

### Additional Readings

Canada. (n.d.). Funerals. http://www.ic.gc.ca/eic/site/oca-bc.nsf/eng/ca03069.html

Hariyono, W. (September 14, 2015). Vertical cemetery. *Procedia Engineering*, 118, 201-214. <a href="https://doi.org/10.1016/j.proeng.2015.08.419">https://doi.org/10.1016/j.proeng.2015.08.419</a>

How long are graves kept. (n.d.). St. John's Dixie Cemetery & Crematorium. <a href="https://stjohnsdixie.com/cemetery/how-long-are-graves-kept/">https://stjohnsdixie.com/cemetery/how-long-are-graves-kept/</a>

Mayer, A. (May 16, 2018). *Back to the land*. CBC. <a href="https://newsinteractives.cbc.ca/longform/death-burial-green-recycling">https://newsinteractives.cbc.ca/longform/death-burial-green-recycling</a>

McGee, A. (May 7, 2021). Donating a body to science for medical research in Canada. Canadian Funerals. https://canadianfunerals.com/donating-a-body-to-science-for-medical-research-incanada/#.Yj4snpopAkg

Ontario. (n.d.). Arrange a funeral, burial, cremation, alkaline hydrolysis or scattering. https://www.ontario.ca/page/arrange-funeral-burial-cremation-alkaline-hydrolysis-or-scattering Philjacke. (October 28, 2018). Vertical cemetery: Graves in high rise towers. The Tower Info. <a href="https://thetowerinfo.com/vertical-cemetery-high-rise/">https://thetowerinfo.com/vertical-cemetery-high-rise/</a>

Understanding funeral costs in Ontario. (n.d.). Passages. https://www.passagescb.ca/understanding-funeralcosts

# 4.8 REQUIRED COURSE MATERIALS

In addition to the videos and reading links embedded into the chapter, you are required to complete the following course material:

# **Required Course Viewings**

Doughty, C. (April 3, 2017). A burial practice that nourishes the planet [Video]. TEDMED. <a href="https://www.ted.com/talks/caitlin\_doughty\_a\_burial\_practice\_that\_nourishes\_the\_planet">https://www.ted.com/talks/caitlin\_doughty\_a\_burial\_practice\_that\_nourishes\_the\_planet</a>

# **Required Course Readings**

Chavez, S. (August 22, 2019). The story of death Is the story of women. yes!. https://www.yesmagazine.org/issue/death/2019/08/22/dying-feminist-funeral-women-caitlin-doughty

# 4.9 CHAPTER ASSIGNMENT

# Dealing with Bodies After Death Assignment

In this chapter you learned about different options for disposal of bodies at end of life. The chapter's assignment involves reflecting on and planning how you want your body dealt with and how you want to be honoured/remembered/celebrated after death. It is important to complete all chapter materials (chapter content, including all embedded links to readings and videos, and the required course materials) prior to starting the assignment.

Click on the link below for some guidance on things to reflect upon when completing this assignment: *How to Plan a Funeral or Memorial Service* 

Keep in mind that what you are planning is for you and should therefore be about you and your wishes. You are free to step outside the box and make plans that fit with who you are, your values, beliefs, sensibilities, etc.

# Assignment Formatting & Style for Written Report

- Assignment formatting requirements: Arial 12-point font; 1 inch/2.54 centimeter margins; single spaced; APA in-text citation style, reference section and cover page.
- Use proper essay/paragraph style for C (the reflection part of the assignment). A heading with bullet points or essay format can be used for parts A and B.
- Paraphrase as opposed to relying on direct quotes.
- Proofread your submission to make sure it is clear, well written, and intelligible.

# Steps to Completing the Assignment

- a. For body disposal, identify:
  - i. Any organs or body parts you wish to donate or if you wish to donate your entire body to science (this requires identifying which Canadian medical schools the donation will go to. There are 20 that accept anatomical donations).
  - ii. Type of body disposal method you wish for yourself at the end of life (e.g., burial, entombment, cremation, aquamation, green burial, etc.).
  - iii. Type of vessel to be used for your remains (e.g., traditional casket, simple coffin, wicker or plain wood coffin, cardboard box, urn, traditional shroud, eco-friendly/biodegradable/mushroom

shroud, etc.).

- iv. Where your remains will go (e.g., traditional cemetery burial plot, mausoleum, urn, natural setting, ash scattering, etc.). If you are choosing cremation or aquamation, be clear if you want part of your remains to be placed in several locations (e.g., spread some ashes, have some in an urn, that then can be buried or put it in a mausoleum, etc.). Ideally, indicate actual location(s) preference(s).
- v. If choosing a traditional cemetery plot, indicate: if you want a grave liner or burial vault, the type of grave marker you want, and what you want written on the marker (type of marker often determines what can be included on it).
- b. Plan the event that will occur after your death to honour you and your life. Reflect on the following:
  - i. Will it occur prior to or after body disposal? If prior to and a casket is involved, will your body be present? Will the casket be open at any point? If so, who will be permitted to view the open casket?
  - ii. What will the event look like (e.g., traditional funeral, small intimate gathering, celebration of life, a wake, religious, secular, etc.)? Will there be flowers, pictures of you, music? If so, be clear about your choices.
  - iii. What will it involve (e.g., religious service, eulogy(ies), celebratory toasts, a wake, sitting Shiva, etc.)? Will there be food and drinks? If so, what will be served?
  - iv. Where will it occur (e.g., a religious institution, a funeral home, a local/community gathering location, your home, home of family or friend, graveside, at location of ash dispersal, indoors, outdoors, etc.)
  - v. When will it occur (e.g., shortly after death, several weeks or months after your death so that loved ones have had some time to grieve and can celebrate your life, etc.)?
  - vi. Who will be there (e.g., will it be public, family only, family and close friends only, etc.)?
  - vii. Do you want a permanent marker/memorial of your life? What would it be (e.g., a grave marker; name added to a memorial garden; a tree planted in your name; a bench erected in a public space with plaque with your name; a scholarship set up in your name, etc.)?
  - viii. What percentage of the money spent on your death should go towards body disposal and what percentage to the after death event, celebration, or memorial? In other words, do you want the financial focus to be on body disposal, end of life honouring event, or a memorial in your honour as per VII above?
  - ix. Do you want people to send flowers, make donations in your honour to commemorate your life, or something else? If donations, where do you want them to go?
- c. In addition to A and B above, write a 350-500 word reflection piece about your experience completing this assignment. Reflect on why you made the choices you did and the experience of completing the assignment.
- d. Cite course materials, via in-text citations and a reference section, to credit the sources you used to inform your choices.

# Assignment Submissions must Include

- 1. A proper APA style cover page.
- 2. Plan for body disposal.
- 3. Plan for after death event(s).
- 4. A reflection paper.

# 4.10 REFERENCES & MEDIA ATTRIBUTIONS

## References

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  <u>StatisticsReport2021-short.pdf</u>
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we bury our dead. Ottawa Citizen. https://ottawacitizen.com/news/local-news/the-green-death-howenvironmentally-friendly-options-are-changing-the-way-we-bury-our-dead

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Freehill, M. & Pantuso, P. (August 14, 2019). Return to nature. Yes

Magazine. https://www.yesmagazine.org/issue/death/2019/08/15/green-burial-nature-community-land

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# CHAPTER 5: PLAGUES, PANDEMICS & MASS DEATH EVENTS



Jacqueline Lewis & Jillian Holland-Penney

# 5.0 INTRODUCTION

# **Chapter Introduction**

Living through an infectious disease pandemic such as COVID-19 is a shocking experience. Life changes over night and is tilted on its side. Fears for the health and well-being of our loved ones and ourselves are heightened. Our survival instinct kicks in. Daily life and daily challenges are radically altered. Social connections shift and human connection is curtailed. What would it have been like to live through a pandemic in the early 1900s or perhaps the 1300s? It is important to contextualize our recent experiences within the history of human pandemics. This chapter aims to shed light on that history, demonstrating the commonalities of pandemics and plagues, and human reactions to them, from the past and the present.

# **Chapter Objectives/Learning Outcomes**

After completing the chapter materials, you should have an understanding of:

- 1. Definitions of plagues and pandemics.
- 2. Some of the causes and consequences of plagues and pandemics.
- 3. The history of pandemics, including notable ones like the Black Death, Spanish Flu, HIV/AIDs, and COVID-19.
- 4. Certain rhetoric commonly used during pandemics/plagues (i.e., pandemic deniers, antimaskers, anti-vaccination).

# Questions to Think About When Completing Chapter Materials

1. What are some comparisons that can be made between previous pandemics and the COVID-19 pandemic?

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- 2. In discussing the societal impact of pandemics, what are some of the changes you had to make in response to the COVID-19 pandemic? Which changes will you continue? How did these changes impact you?
- 3. One of the changes a pandemic can bring is shifting worldviews. How has your worldview been altered due to the COVID-19 pandemic? If it hasn't changed, explain why you think that might be.
- 4. How do you think knowledge of past pandemics can help us understand contemporary ones?

# 5.1 WHAT IS A PANDEMIC?



Global Pandemic.

A pandemic is an **epidemic** occurring worldwide, crossing international boundaries and usually affecting a large number of people (Health Canada, 2018). The World Health Organization (WHO) declares a pandemic when the growth rate of an infectious disease skyrockets, and each day cases grow more than the day prior (Columbia Public Health, 2021). Plagues are a type of infectious disease pandemic, but the term is often used in describing older pandemics like the Black Death. "The word 'plague' is a **polyseme**, used interchangeably to describe a particular, virulent contagious febrile disease caused by Yersinia pestis, as a general term for any epidemic disease causing a high rate of mortality, or more widely, as a metaphor for any sudden outbreak of a disastrous evil or affliction" (Huremović, 2019, p. 8). The following section provides a more in-depth analysis of facts pertaining to, as well as the history of plagues/infectious disease pandemics (here after referred to as pandemics).

Click the link below to learn the differences between

epidemics, endemics, and pandemics:

Epidemic, Endemic, Pandemic: What are the Differences?

# 5.2 HISTORY OF PANDEMICS

# General Facts & Information on Pandemics

- As human civilizations grew, constructing cities and creating trade routes to connect those cities, the more likely pandemics became (History.com Editors, 2021). This is also true today, as increasing global connections and interactions (i.e., globalization) represent a driving force behind pandemics (LePan & Schell, 2020).
- Healthcare advancements and improvements in understanding the factors that lead to pandemics have been progressively more effective in reducing the loss of life (LePan & Schell, 2020).
- Most of the infectious diseases that lead to pandemics are caused by zoonotic pathogens that have been transmitted to humans due to increased contact with animals through: breeding, eating, hunting, global trade activities (Piret & Boivin, January 2021), deforestation and its impact on biodiversity (Morand & Lajaunie, 2021). As long as these practices persist, pandemics will continue to occur, and their likelihood will increase. In fact, it is estimated



White ceramic sculpture with black mask

- that "the probability of novel disease outbreaks will likely grow three-fold in the next few decades" (Penn, 2021, para. 8).
- Pandemics and plagues of the past have been powerful change makers throughout history, shaping:
  politics; revolutions; war; entrenched racial- and economic-based discrimination; the redistribution of
  income and reduction of inequality; and societal world views (Chotiner, 2020; De Witte, 2020;
  Patterson et al., 2021).

### Click the links below to learn more about the history of pandemics:

<u>Visualizing the History of Pandemics</u> <u>Pandemics That Changed History</u>

As detailed in the *Visualizing the History of Pandemics* infographic above, there have been numerous pandemics in the history of human civilization. In the remainder of this chapter the focus will be on four

notable pandemics due to either their large death rate and/or their occurrence in recent history. The pandemics explored include:

- The Black Death in the 14th century
- The Spanish Flu from 1918-1919
- HIV/AIDS that first appeared in the early 1980s
- COVID-19 that emerged in 2020

# 5.3 THE BLACK PLAGUE



Plague Doctor.

The most fatal pandemic in recorded human history was the Black Plague, which began in 14th century Europe, lasting from 1346-1353 (Columbia Public Health, 2021). The plague bacteria, *Yersinia pestis* – a type of zoonotic bacterium – is transmitted to humans through bites of infected fleas (Mayo Clinic Staff, 2021; WHO, 2000). Plague is divided into three main types – bubonic, septicemic, and pneumonic – depending on which part of the body is affected (Mayo Clinic Staff, 2021). The Black Death is believed to have been a Bubonic plague (although some scientists disagree – see <u>Duncan & Scott, 2005</u>). It originated in central Asia from fleas that lived on black rats and was transmitted to humans via infected rodent flea bites. The theory is that the plague later spread through the human population via human fleas and head lice (Brooke, 2020, WHO, 2000). The inclusion of the term "Black" in the name of the pandemic is tied to one of its telltale visible physical symptoms, large swollen lumps in the groin and armpits

referred to as buboes that turned the skin black prior to bursting (Shipman, 2014). The plague resulted in the deaths of an estimated 75-200 million people, approximately 30-50% of Europe's population (Boundless, n.d.; Shipman, 2014). The aftermath of the plague created a series of religious, social, and economic upheavals, which had profound effects on the course of European history (Boundless, n.d.; Shipman, 2014).

### Click the link below to learn more about the Black Death:

<u>How Medieval Writers Struggled to Make Sense of the Black Death</u>

### **VIDEO:** The Black Death

The following video covers the history of the "Black Death," which spread rapidly across Medieval Europe and killed millions of people.



One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=828#oembed-1

# 5.4 THE SPANISH FLU



Emergency hospital during influenza epidemic, Camp Funston, Kansas (1918). Original image from National Museum of Health and Medicine.

The Spanish Flu, which lasted from 1918 through 1919 (Cambridge University, 2018), was caused by the H1N1 virus, a strain of avian flu (CDC, n.d.). In an 18-month period, over one-third of the world's population was infected and 3% of the world's population (an estimated 50 million worldwide) died (CDC, n.d.). In many countries, including Canada, more people died of the Spanish Flu than during WWI (CDC, n.d.). Since the pandemic began during the last year of WWI, wartime media censorship led to inaccurate reporting of flu-related rates of infection and death. In early 1918, the only country reporting on widespread flu rates was Spain. As a result, the flu that caused the 1918 pandemic became known as the Spanish Flu (Eghigian, 2020; History Channel, n.d.; Little, 2020b). The origins and initial geographical starting point of the Spanish Flu remain a mystery (Cambridge University, 2018).

Click the link below to learn more about the impact of the Spanish Flu in Canada:

<u>Stories of the 1918 Flu Pandemic</u> (Read contents under Introduction tab and the tab on Indigenous Communities and the 1918 Flu Pandemic).

## VIDEO: Warning from History

The following video by the University of Cambridge explores what we have learned about the Spanish Flu, the urgent threat posed by influenza today, and how scientists are preparing for future pandemics.



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Minnesota AIDS Project at the Twin Cities Pride Parade.

One of the more recent and devastating pandemics/epidemics is HIV/AIDS. HIV infection has led to the death of over 36 million people since the late 20th century (Columbia Public Health, 2021; WHO, n.d.-a) with over 37 million people living with HIV at the end of 2020 (WHO, n.d.-a). The origin of HIV/AIDs infection in humans is linked to a chimpanzee version of the virus (Simian Immunodeficiency Virus – SIV). It is believed that the virus was transmitted via blood contact to humans as far back as the late 1800s, likely through hunting chimpanzees. Since that time, it spread across Africa and to other parts of the world (CDC, n.d.).

The first human illnesses associated with HIV that made the headlines began to appear in 1981 in the gay male population of New York and San Francisco (Basic Facts, n.d.). The societal prejudice against the gay community at the time, led to stigmatization, discrimination, and a backlash against the gay community and the gay rights movement (Florcencio, 2018; Lewis, 1994). There was a general apathy on the part of governments towards people infected with the virus, which impacted research funding (Florcencio, 2018;

Krieger, 1988). As a result, most efforts to help people living and dying with the virus were community-based (Lewis & Fraser, 1996).

In the late 1990s medication was developed that now allows people with the disease to experience a normal life span with regular treatment (Columbia Public Health, 2021). Although the medication doesn't cure HIV/AIDS, and has many side effects, it does prevent the virus from multiplying and destroying a person's immune system (simpleshowfoundation, 2014; WHO, n.d.-c). However, access to this life-saving medication remains a problem for people living in certain areas of the world, such as sub-Sahara Africa (simpleshowfoundation, 2014; WHO, n.d.-c).

### Click the link below to learn more about HIV/AIDS:

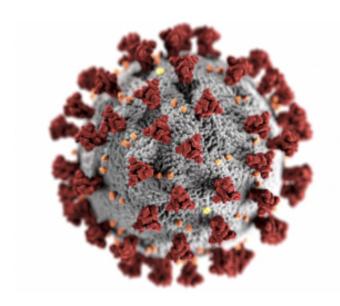
Why the HIV Epidemic is Not Over

### VIDEO: HIV/AIDS Video from Columbia Public Health

In the following video Wafaa El-Sadr (Chair of Global Health for the Dr. Mathilde Krim-amfAR, Director of ICAP and University Professor of Epidemiology and Medicine) talks about the importance of dealing with both the disease itself, as well as the societal implications of HIV/AIDS.



One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=834#oembed-1



SARS-CoV-2 virus, the virus that causes COVID-19.

COVID-19 was declared a pandemic by the World Health Organization on March 11, 2020 (Statistics Canada, 2021). Since that time there has been a degree of conflation between coronaviruses and the COVID-19 virus. While Coronaviruses (CoVs) refer to the family of viruses that cause respiratory and intestinal illnesses in humans and animals (What is coronavirus, 2020), Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2) is the virus responsible for the outbreak of COVID-19 (UK Research and Innovation, March 2020). The COVID-19 virus leads to acute respiratory distress syndrome (ARDS), which results in dangerously low levels of oxygen in the

blood (Washington Post, 2020). As of March 2022, over 6 million people have died from COVID-19 worldwide (Click WHO Coronavirus (COVID-19) Dashboard to see the most recent numbers) (John Hopkins University & Medicine, 2022). As new strains emerge (e.g., Delta, Omicron), the world continues to be impacted by the virus, as well as the restrictions that follow it.

### Click the links below to learn more about the impact of the COVID-19 pandemic:

<u>COVID-19 in Canada: A One-year Update on Social and Economic Impacts</u> (Read Pages 10-14 & 16-27).

How to Heal the 'Mass Trauma' Of COVID-19

### VIDEO: How COVID-19's Death Toll and Social Impact Compares to Past U.S. Pandemics

In news coverage by PBS News Hour, the following video describes the death toll from the COVID pandemic and how it has surpassed the number of lives lost to the 1918 Spanish Flu.



One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=837#oembed-1

# 5.7 HUMAN RESPONSES TO PANDEMICS



People waiting, wearing masks in San Francisco during the Spanish Flu in 1918.

# Pandemic Denial & Anti-Masking Sentiments

Throughout history and within contemporary society, disease and pandemics have typically been accompanied by extreme accusations, denial, misinformation, and mistrust (Navarro, 2020; Newey, 2020), which only exacerbate the death toll (Little, 2020b). Examples of pandemic denial were evident during the Spanish flu. During the flu's first wave in the spring and early summer of 1918, some European and U.S. newspapers claimed that the flu wasn't a serious threat (Little, 2020b). In the late summer, during the deadly second wave, the Interior Minister of Italy denied reports of the flu spreading (Martini et al., 2019). Antimasking claims were also evident during the Spanish flu pandemic (Carstairs, 2020; McMullan et al., 2020; Navarro, 2020). Although there was wide-spread support for wearing masks, support waned quickly and masking compliance levels fell, due to issues of comfort, doubts regarding efficacy, and impact on businesses/commerce (Carstairs, 2020; Little, 2020a; Navarro, 2020). This rings true during the COVID-19 pandemic as well. Less than half of the people in the U.S. follow health recommendations to wear a mask when out in public (Key, 2021; Miller, 2020).

#### Click the link below to learn more about the history of anti-masking sentiments:

Masking Resistance During A Pandemic Isn't New – In 1918 Many Americans Were "Slackers"

# Misinformation & Scapegoating

The stigmatizing and scapegoating of convenient targets is common during pandemics (Cole, 2020). Pandemic misinformation, conspiracy theories and the impact of low-science literacy levels, are integral in creating and reinforcing "us versus them" mindsets that lead to stigmatizing, scapegoating, and targeting of certain populations during pandemics (Miller, 2020; Poos, 2020). During the Black Death, Jewish people were blamed for spreading the plague by poisoning wells and streams. This led to the mass murder of the Jewish population by Christian mobs, across hundreds of communities (Cole, 2020; Poos, 2020). In 19th century U.S, immigrants were blamed for a variety of infections, including polio and cholera (Cole, 2020). Despite the Spanish Flu being accelerated by the movement of soldiers during WWI, German submarines and "enemy agents" were blamed for the spread of the flu by allied nations (e.g., the UK, U.S.) (Newey, 2020). With AIDS, the 2SLGBTQi community was targeted, followed by people who inject drugs (PWID), Haitians, and people with Hemophilia (Altman, 1983). With COVID-19, hate, violence and blame has been levelled against people of Asian descent, resulting from its label as "the China virus" (Lu, 2021; Poos, 2020; Vazquez, 2020).

## The Anti-Vaccination Movement

Another common feature of both past and present pandemics is **disinformation**, including: the denial of the safety and importance of vaccinations. The deep-rooted beliefs that underlie vaccine opposition have remained somewhat consistent since the introduction of smallpox vaccine in 1796, the very first vaccine created (Haelle, 2020; Youngdahl, 2016), although the exact concerns vary according to the cultural anxieties of the time (Haelle, 2021; Poos, 2020). Anti-Vaccination leagues, founded in the mid- to late-1800s in the U.K. and U.S, spurred anti-vaccination sentiments and distrust of medicine. This resulted in the questioning of the safety and efficacy of, and the motives behind, the smallpox vaccine and every vaccine developed since then (e.g., Diphtheria, Tetanus, Polo [DTP]; Measles, Mumps and Rubella [MMR]) (Haelle, 2021; McNamara, 2021; Youngdahl, 2016).

Vaccine hesitancy has had negative public health impacts. In terms of smallpox, anti-vaccination sentiments led to a significant decline in immunization rates, and the re-emergence of smallpox just a couple of decades later (McNamara, 2021). Over the past few decades, hesitancy has led to "outbreaks of communicable infections such as measles" (Geoghegan et al., 2020, p. 1). With COVID-19, we find rates of hospitalization and death increase in regions where vaccine hesitancy and resistance to other health preventive measures, like

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masking and social distancing, are prevalent (Hanna et al., 2021). We also see attacks against people associated with the virus, vaccines, and public health measures. This ranges from violence against people of Asian descent (Lu, 2021; Poos, 2020; Vazquez, 2020), to the picketing of hospitals, as well as harassment and assault of medical and hospital personnel (Larkin, 2021; Miller, 2021; Ungerleider & Warren, 2022).

# 5.8 CHAPTER SUMMARY

# **Key Summary Points**

- 1. There are a number of pandemics that have occurred throughout history. Some of the most devastating ones include the Black Death, Spanish Flu, and HIV/AIDS.
- Negative human responses are common across pandemics including: resistance to public health measures (e.g., anti-masking, anti-vaccination, anti-isolation); stereotyping and scapegoating; and misinformation campaigns.
- 3. Pandemics have an array of social costs and implications, which include impacts on: vulnerable populations, social customs and practices (i.e., travel bans, funerals, dealing with bodies), and grief and depression felt throughout society.

## Additional Resources

#### Additional Viewings

CrashCourse. (July 24, 2014). *Disease! Crash course world history 203* [Video]. YouTube. https://www.youtube.com/watch?v=1PLBmUVYYeg

#### **Additional Readings**

Florencio, J. (November 27, 2018). AIDS: Homophobia and moralistic images of 1980s still haunt our view of HIV – That must change. *TheConversation.com*. <a href="https://theconversation.com/aids-homophobic-and-moralistic-images-of-1980s-still-haunt-our-view-of-hiv-that-must-change-106580">https://theconversation.com/aids-homophobic-and-moralistic-images-of-1980s-still-haunt-our-view-of-hiv-that-must-change-106580</a>

Huremović, D. (May 2019). *Chapter 2 – Brief history of pandemics (pandemics throughout history).* National Center for Biotechnology Information. <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7123574/pdf/978-3-030-15346-5\_Chapter\_2.pdf">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7123574/pdf/978-3-030-15346-5\_Chapter\_2.pdf</a>

Jarus, O. (November 15, 2021). 20 of the worst epidemics and pandemics in history. Live Science. <a href="https://www.livescience.com/worst-epidemics-and-pandemics-in-history.html">https://www.livescience.com/worst-epidemics-and-pandemics-in-history.html</a>

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McDonald, G. (July 15, 2020). 5 advances that followed pandemics. History. https://www.history.com/news/pandemics-advances

Miller, B. (November 2, 2020). *Science denial and COVID conspiracy theories*. JAMA Network. <a href="https://jamanetwork.com/journals/jama/fullarticle/2772693">https://jamanetwork.com/journals/jama/fullarticle/2772693</a>

Pan American Health Organization (PAHO). (n.d.). *Debunking immunization myths*. https://www.paho.org/en/topics/immunization/debunking-immunization-myths

Piret, J. & Boivin, G. (2021). Pandemics throughout history. *Frontiers in Microbiology*, 11. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7874133/pdf/fmicb-11-631736.pdf

# 5.9 REQUIRED COURSE MATERIALS

In addition to the videos and reading links embedded into the chapter, you are required to complete the following course material:

# Required Course Readings

- Clamp, R. (March 5, 2020). Coronavirus and the Black Death: spread of misinformation and xenophobia shows we haven't learned from our past. *TheConversation.com*. <a href="https://theconversation.com/coronavirus-and-the-black-death-spread-of-misinformation-and-xenophobia-shows-we-havent-learned-from-our-past-132802">https://theconversation.com/coronavirus-and-the-black-death-spread-of-misinformation-and-xenophobia-shows-we-havent-learned-from-our-past-132802</a>
- De Witte, M. (April 30, 2020). Past pandemics redistributed income between the rich and poor, according to Stanford historian. Stanford News. <a href="https://news.stanford.edu/2020/04/30/pandemics-catalyze-social-economic-change/">https://news.stanford.edu/2020/04/30/pandemics-catalyze-social-economic-change/</a>
- McMullan, L., Blight, G., Gutierrez, P. & Levett, C. (April 29, 2020). How humans have reacted to pandemics throughout history A visual guide. *The Guardian*. <a href="https://www.theguardian.com/society/ng-interactive/2020/apr/29/how-humans-have-reacted-to-pandemics-through-history-a-visual-guide">https://www.theguardian.com/society/ng-interactive/2020/apr/29/how-humans-have-reacted-to-pandemics-through-history-a-visual-guide</a>
- Patterson, G., McIntyre, K., Clough, H. & Rushton, J. (April 12, 2021). Societal impacts of pandemics: Comparing COVID-19 with history in focus our response. *Frontiers in Public Health*, *9*. <a href="https://www.frontiersin.org/articles/10.3389/fpubh.2021.630449/full">https://www.frontiersin.org/articles/10.3389/fpubh.2021.630449/full</a>
- Varlik, N. (October 26, 2021). From Black Death to COVID-19, pandemics have always pushed people to honor death and celebrate life. *TheConversation.com*. <a href="https://theconversation.com/from-black-death-to-covid-19-pandemics-have-always-pushed-people-to-honor-death-and-celebrate-life-170517">https://theconversation.com/from-black-death-to-covid-19-pandemics-have-always-pushed-people-to-honor-death-and-celebrate-life-170517</a>

# **5.10 CHAPTER ASSIGNMENT**

# Plagues & Pandemics Assignment

This chapter's materials focused on four notable pandemics in human history. For this assignment you are required to select another pandemic (not among the four focused on in this chapter), conduct research on it, and create a voiceover slideshow presentation (using PowerPoint, Keynote, Prezi or Google Slides) that provides information and a detailed background on your chosen pandemic (see questions below). It is important to complete all chapter materials (chapter content, including all embedded links to readings and videos, and the required course materials) prior to starting the assignment.

Information about some pandemics may not be available, as data was never collected, documented, made public, etc. Some information about the pandemic may be speculative or theoretical in nature. Keep these factors in mind when selecting a pandemic for your assignment and framing your voice/slide content. If you start your research and find minimal and mostly speculative information, it is recommended that you switch to a different pandemic.

## Assignment Formatting, Style & Length

- Presentations must include a cover slide that identifies the topic of the presentation/which pandemic, whose presentation it is, and the course number.
- Be sure to include images and photographs (these must be properly sourced).
- Videos cannot be included in the presentation.
- Presentation must be 3-5 minutes in length (no longer than 5 minutes).
- Presentations created in PowerPoint, Keynote, or Google Slides should have between 6 and 8 content slides (10 slides maximum including a title page slide and a reference slide).
- Due to the expanding nature of each Prezi slides, assignments created in Prezi will likely have fewer than the 6 to 8 main slides (in order to fit within the presentation time limit).
- Presentations must include a reference slide (APA format).
- Use APA for in-text citation style on slides and for the reference slide.
- Avoid putting too much text on a slide. The voice over allows you to elaborate.
- Paraphrase and use point form as opposed to relying on direct quotes.
- Proofread slides for typographical errors and to make sure slide content is clear, well written, and intelligible.
- When recording your voiceovers, speak slowly and clearly. If you are rushing through your slide-notes

- then you have too much content. It is usually best to record your voiceovers one slide at time. This enables you to check how you sound, make adjustments, and re-record smaller amounts of your presentation.
- Submission must be in MP4 format (use "save as" or "export to" to convert to MP4 format or do a Google search for instructions).

## Steps to Completing the Assignment

- 1. Identify a pandemic that is not among the four focused on in the chapter materials.
- 2. Research the identified pandemic and find a minimum of 6 sources (in addition to the chapter materials) to help you answer the assignment questions below. No more than 2 of the sources can be media-type resources. The remainder must be academic sources (i.e., peer-reviewed journal articles and books) and reports from government and non-governmental organizations (i.e., NGOs).
- 3. Prepare a 3-5 minute presentation (see Assignment Formatting, Style & Length above for limits on number of slides for presentation submissions).
- 4. In the slides, address the questions below.
- 5. Support the points/arguments on slides with APA in-text citations that reference the materials you have found in your research, and those that are in the chapter. In-text citations to support your points/ <u>arguments are essential and required</u>. Be sure to use a diverse range of materials as opposed to relying heavily on one, or a few sources.
- 6. Develop an APA style reference section for all material cited (only material cited in the body of the presentation can be included in a reference section) and include that as your final slide.

## The following must be submitted for the assignment

A MP4 version of the slideshow presentation as detailed above.

## **Assignment Questions**

Questions do not need to be answered in order. Some answers can/should be combined on the same slide. Keep in mind that answers are provided both via the slide and the voice over, with the latter giving you the ability to expand on slide content. Answers may not be available for every question. If more than a few of the details required to answer the questions are missing, it is recommended that you either do more research or switch to a different pandemic for your presentation.

- 1. How/why is this considered a pandemic?
- 2. When did the pandemic start and end? How many waves occurred and when?

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- 3. Where is the pandemic believe to have originated?
- 4. How did the pandemic spread?
- 5. How many people were infected? Once infected, what percentage of people survived? Were there lasting health impacts of infection? What were they?
- 6. How many people died?
- 7. Is there a vaccine to prevent the disease? When was it developed? How effective is it?
- 8. Is there a cure once infected? When was it developed? How effective is it?
- 9. Does the disease persist in the 21st century? When were the most recent diagnosed cases? When was the latest outbreak? Where have recent diagnosed cases or outbreaks occurred?
- 10. How did humans respond to the pandemic?
- 11. What were the social, economic, and political impacts of the pandemic?
- 12. Identify 2 commonalities and 2 differences between the pandemic you identify and the COVID-19 pandemic.

# 5.11 REFERENCES & MEDIA ATTRIBUTIONS

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# **CHAPTER 6: GENOCIDE**



Jacqueline Lewis, Jillian Holland-Penney & Brandon Bernardon

# 6.0 INTRODUCTION

# **Chapter Introduction**

The crime of genocide was first recognized by the international community in 1948, when the United Nation's adopted the Genocide Convention. Although the origin of the term genocide only dates to 1944, actions that we now refer to as genocide have occurred throughout human history. This chapter explores the origins and meaning of the term and the international criteria for genocide. Several of the more well-known genocides in human history are discussed, including: the Armenian genocide; the Holocaust, the Rwandan genocide; and the genocide of Indigenous peoples in Canada. The chapter also examines how mass killings of particular groups are framed around perceptions of difference, typically tied to religious affiliation, sexual orientation, gender identity, and misleading constructions of race and ethnicity. The assignment at the end of the chapter provides the opportunity for students to learn about other genocides not covered in detail in the assigned course material.

<sup>(1)</sup> Chapter content, including videos and links to reading material, contains information that may be distressing to read and watch. Please take breaks while completing the chapter materials and utilize the <u>resources</u> and supports listed at the start of this book when necessary.

# **Chapter Objectives/Learning Outcomes**

After completing the chapter materials, you should have an understanding of:

- 1. The definition of genocide.
- 2. The UN International Criteria for Genocide.
- Examples of well-known genocides (e.g., the Armenian genocide, the Holocaust, the Rwandan genocide, and the genocide of Indigenous peoples in Canada).
- 4. Some common characteristics and features of genocides.

# Questions to Think About When Completing Chapter Materials

- 1. What types of language, behaviours, and decisions can eventually lead to a genocide? Provide two examples from the course materials to illustrate.
- 2. What are some common characteristics of genocides?
- 3. What is an example of a genocide that many people are unfamiliar with? Why do you think it is less familiar?
- 4. Why is it critical to teach and be educated on genocide and the history of genocide?
- 5. Explain how the actions (or lack thereof) of the Canadian government against Indigenous peoples have rarely (and only recently) been labelled as a genocide by the public, Canadian leaders and/or international community?

# **6.1 LEARN ABOUT GENOCIDES**

#### VIDEO: Raphael Lemkin Defines Genocide

In the following video Lemkin explains how and why he developed the concept of genocide.



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The term "genocide" was first developed by Polish lawyer Raphäel Lemkin in 1944 in response to the actions of the Nazi's during WWII and the mass murders of other groups throughout history (United Nations Office on Genocide Prevention and the Responsibility to Protect, n.d.—a; Genocide: An introduction, n.d.). For years Lemkin lobbied the United Nations to recognize genocide as a crime under international law. This occurred in 1948 with the adoption of the *U.N. Convention on the Prevention and Punishment of the Crime of Genocide (1948)* (Cassin, n.d.; United Nations, n.d.-b). Although the convention was ratified by only 149 States, all nations are "bound as a matter of law by the principle that genocide is a crime prohibited under international law" (United Nations, n.d.-b, para. 2).



Special Emblem of International Day of Commemoration and Dignity of the Victims of the Crime of Genocide and of the Prevention of this Crime.

#### **VIDEO:** What is Genocide?

The following video provides a brief introduction to genocide and why genocide education is important.



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#### DEFINITION OF GENOCIDE IN THE U.N. CONVENTION

The current definition of Genocide is set out in Article II of the Genocide Convention:

Genocide means any of the following acts committed with intent to destroy, in whole or in part, a national, ethnical, racial or religious group, as such:

- (a) Killing members of the group;
- (b) Causing serious bodily or mental harm to members of the group;
- (c) Deliberately inflicting on the group conditions of life calculated to bring about its physical destruction in whole or in part;
- (d) Imposing measures intended to prevent births within the group;
- (e) Forcibly transferring children of the group to another group.

(The content of this text box is attributed directly to the <u>United Nations (n.d.-c)</u>. Genocide Convention Fact-Sheet. UN.org.)

#### VIDEO: International Law in Action II – 1.3 Core Crimes Genocide

The following video from the Centre for Innovation at Leiden University, provides an explanation of the International Criteria for genocide.



One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=856#oembed-3

#### Click the link below to learn more about genocide:

Genocide: An Introduction

Genocides have been occurring since the beginning of human civilization, with one of the earliest known examples being the destruction of Carthage at the end of the Third Punic War in 149–146**BCE** (Kiernan, 2004). Some genocides are more widely known than others, usually due to death tolls, when/where they occurred, and the amount of existing documentation and evidence detailing what occurred. One of the central characteristics of genocides is the targeting, vilification, blaming, and scapegoating of people due to perceptions of difference, typically tied to religious affiliation, sexual orientation, gender identity, and certain

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constructions of race and ethnicity (Grobman, 1990). Once a specific group has been successfully targeted and labeled, the next step in the process is **dehumanization** (Roth, 2010). Successful dehumanization efforts facilitate the process of systematically removing the identified population through sterilization, deportation, and/or mass execution (Baum, 2012). The following parts of this chapter provide a brief background on four of the most devastating genocides in human history: The Armenian Genocide, The Holocaust, The Rwandan Genocide, and the Genocide of Indigenous Peoples in Canada. Unfortunately, there are many more.

#### **VIDEO**; Holocaust Lecture Series

The following video explains the importance of memorializing genocide to educate and prevent similar events from happening again.



One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=856#oembed-4

# 6.2 THE ARMENIAN GENOCIDE



Skulls of Armenians massacred in Urfa, Turkey surrounded by Armenian dignitaries and women from the women's shelter in Urfa's Monastery of St. Sarkis in June 1919.

Periodically over the centuries, the Armenian population in Ottoman Turkey were the targets of persecution. The first Armenian massacre in Turkey occurred under Abdul Hamid II between 1894 and 1896, taking the form of a statesanctioned **pogrom**, resulting in the death/murder of hundreds of thousands of Armenians and the destruction of their homes and villages (Genocide Studies Program, 2022; History.com Editors, 2010; Melson, 1982). Although the Armenians hoped their status in Turkey would change under the new "Young Turks" government that came into power in 1908, they continued to be seen, depicted, and

treated as a threat to the State (Genocide Studies Program, 2022; History.com Editors, 2010). During WWI, the Armenians were blamed for Turkey's military and economic losses and portrayed as traitors by Turkish military leaders, who feared they would conspire for independence with European States (Genocide Studies Program, 2022; Hovannisian, 2009; Kévorkian, 2011). The result was increased hostilities directed towards the Armenian population of Turkey.

In April of 1915, Turkish leaders began executing a plan to expel and massacre all Armenians from the country. This marked the start of what is referred to as the Armenian genocide (Kifner, n.d.; Armenian Genocide, n.d.). Through death marches across the Mesopotamian desert and targeted acts of violence by "killing squads/butcher battalions," 600,000-1.5 million Armenians were murdered (Armenian Genocide, n.d.; History.com Editors, 2010; Kifner, n.d.). The adults who survived were forcibly removed from Turkey, while children were kidnapped and assimilated into Islam and Turkish families (History.com Editors, 2010; Armenian Genocide 1915-1923, n.d.). The Ottomans eventually surrendered in 1918 (History.com Editors, 2010). Although most historians classify what occurred in Turkey as a genocide, as of 2021 the Turkish government has yet to recognize the Armenian Genocide and there are doubts that it ever will (Gutbrod & Wood, 2021; PBS News Hour, 2015).

#### VIDEO: Armenian Genocide – Lessons from History

The following video provides a summary of what happened in the Armenian genocide and the importance of acknowledging genocide and those who were murdered.



One or more interactive elements has been excluded from this version of the text. You can view them online here: <a href="https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=859#oembed-1">https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=859#oembed-1</a>

# 6.3 THE HOLOCAUST



Children within Auschwitz, wearing adult-size prisoner jackets, standing behind a barbed wire fence.

Jewish people have been the subject of prejudice and discrimination for centuries (History.com Editors, 2009b; Ludwig, 2016; The Holocaust, n.d.). The Holocaust, which occurred during WWII, is not only the most horrific example of anti-Semitism, it is the largest known genocide in human history (The Holocaust, n.d.; Roser et al., 2016; Sen Nag, 2018). During the Nazi movement's rise to power, Hitler targeted the Jewish population of Germany using a four-step process of dehumanization (Toth, 2020):

- 1. **Prejudice** (e.g., propagating the belief in the "inferiority" of Jewish people and the "superiority" of "native born Germans", especially "Aryan" people, etc.) (Ludwig, 2016).
- 2. **Scapegoating** (e.g., Jewish people were blamed for: Germany's defeat in WWI; most social and economic problems leading up to and during WWII, etc.) (Ludwig, 2016; The Holocaust, n.d.).
- 3. **Discrimination** (e.g., boycotting of Jewish owned businesses; excluding Jewish children from public education; passing discriminatory laws; expulsion from professions and opportunities to earn a living; forced wearing of a yellow Star of David; isolation and segregation, etc.)
- 4. **Persecution** (e.g., the forced removal from homes; belongings and assets confiscated; forced to live in

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crowded "ghettos" with inadequate living conditions that took the lives of hundreds of thousands of people, etc.) (Brooks, 2019; Warsaw Ghetto, n.d.; Toth, 2020; United States Holocaust Memorial Museum, n.d.).

The dehumanization and isolation of Jewish people in ghettos, was part of the Nazi's "final solution" to the "Jewish question" (Brooks, 2019; Warsaw Ghetto, n.d.; The Holocaust, n.d.). The next part involved deporting large numbers of people to concentration camps and ultimately mass executions (Boissoneault, 2016; Brooks, 2019). When Allied soldiers began liberating the camps in 1945, they witnessed the horror of the Nazi crimes including: hundreds of thousands of starving and sick prisoners living alongside thousands of dead bodies (Taylor, 2011; Brooks, 2019); gas chambers and high-volume crematoriums; thousands of mass graves; documentation of horrific medical experimentations; as well as other war crimes and crimes against humanity (Taylor, 2011; Brooks, 2019). By the end of WWII, the Nazis had killed over 6 million Jewish people, along with 5 million people from other minority populations including: Romani people, communists, members of the LGBTQ community, and people with disabilities (Buchholz, 2021; History.com Editors, 2009b).



Holocaust Memorial Center, Farmington Hills, MI, USA.

#### VIDEO: They're Taking us to our Death': How a Teenage Girl Escaped the Nazis

In this video Rose Lipszyc, a Holocaust survivor and educator, shares her story of how she escaped the Nazis.



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# 6.4 THE RWANDAN GENOCIDE



Human skulls and bones of those who were killed in the Rwandan genocide. Most of them were clubbed, hacked, stabbed or shot to death.

A complex interplay of a number of deep-seated social, economic and political forces throughout the history of Rwanda created the cultural dynamics that precipitated the Rwandan genocide (Alluri, 2009) (for details see the video "What Led to the Rwandan Genocide?" below). Rwanda society is comprised of three groups: the Tutsi, the Hutu and the Twa. The Hutu make up the majority (85%) of the Rwandan population. Although these identities existed prior to colonialization, they became much more rigidly entrenched and racialized under Belgian colonial rule (Tutsi in Rwanda, n.d.; University of Minnesota, n.d.). Tensions between the Hutu and Tutsi have a long history, rooted in colonialism, revolution (in 1959) (Newbury, 1995), and civil war (starting in 1990) (Alluri, 2009; Maron, n.d.), with conflicts and violence between the two groups occurring long before the 1994 genocide. The factor that appears to have sparked the genocide was the murder of the Rwandan president (Tutsi in Rwanda, n.d.).

On April 6, 1994, a plane carrying President Ntaryamira was shot down (Rwanda Genocide, 2019; History.com Editors, 2009a). Although those responsible for the assassination were never identified, some believe it was carried out by Hutu extremists in an attempt to gain public support for a planned massacre of the Tutsi population (Rwanda Genocide, 2019; History.com Editors, 2009a; Maron, n.d.). Shortly after the crash, members of the Rwandan armed forces (FAR) and Hutu militia groups (Interahamwe), carried out an organized and planned attack against the Tutsi people with the help of the Hutu population (Rwanda

Genocide, 2019; Tutsi in Rwanda, n.d.). They went door-to-door and set up roadblocks in order to find, identify, rape and slaughter Tutsi people.

Support for the genocide and encouragement to rape and murder was rallied by propaganda that portrayed Tutsi as outsiders, inferior, traitors, dangerous, "vermin" or "cockroaches" that needed to be exterminated (Maron, n.d.; University of Minnesota, n.d.). The violence was brutal and vicious, carried out with machetes, clubs and guns. The genocide lasted 100 days, ending in July 1994, when the Tutsi led Rwandan Patriotic Front (RPF) took control of Kigali, the capital of Rwanda (Rwanda Genocide, 2019; University of Minnesota, n.d.). An estimated 800,000 to one million Tutsi were slaughtered. Moderate Hutus were also murdered, including those who refused to participate in the genocide (Maron, n.d; University of Minnesota, n.d.). The mass rape of approximately 250,000 Tutsi women and girls resulted in two-thirds of them contracted the AIDS virus (Maron, n.d.; Tutsu in Rwanda, n.d., para. 11).

#### VIDEO: What Led to the Genocide in Rwanda?

This video provides a brief synopsis of the factors that led to the Rwandan genocide. (Warning: This video depicts images and videos of violence, dead bodies, and death).



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# 6.5 THE GENOCIDE OF INDIGENOUS PEOPLES IN CANADA

From the actions of European settlers during colonization Canadian Government policies, such as the Residential School (IRS) system and the Sixties Scoop, Indigenous peoples, as well as their cultures and ways of life, have been the target of systematic eradication (Fonseca, 2020; NCCIH, 2014). The experiences of Indigenous communities in Canada, especially experiences tied to the IRS and the Sixties Scoop, were referred to by the Truth and Reconciliation Commission (TRC) as cultural genocide (ATPN, 2015; Canada, n.d.; NCCIH, 2014; Staniforth, 2015). The findings of the National Inquiry into Missing and Murdered Indigenous Women and Girls (MMIWG) drew a different conclusion – that the Government of Canada perpetrated genocide against Indigenous peoples (MMIWG, 2019). As noted by Fannie Lafontaine (2021, para. 13), "Canada has demonstrated a continuing policy, with varying motivations but with an underlying intent that's remained the same – to destroy Indigenous peoples physically, biologically and as social units".



"The Scream" by artist Kent Monkman depicts the reality of Canadian Residential Schools and the atrocities committed by the Catholic Church and the Canadian government.©Kent Monkman. All rights reserved. Image used with permission.

The criteria set forth in the UN Convention on Genocide (1948) can be applied to the IRS system to illustrate the appropriateness of the term genocide to describe Canadian government policies, actions and inactions. The IRS resulted in Indigenous children being forcefully removed from their communities to be assimilated into a Euro-Canadian style of life, at institutions run by the State and religious organizations (Colborn, 2021; Fonseca, 2020; Lafontaine, 2021; NCCIH, 2014). Children were often deliberately malnourished, housed in cramped and dirty quarters, and not provided medical treatment when they became ill (Daniel, 2021; NCCIH, 2014). Although the members of the Catholic Church are largely responsible for the mental, physical, sexual, and spiritual abuse that occurred within these schools (Colborn, 2021), "the Canadian government was happy to leave these children to die because they were Indigenous" (Staniforth, 2015, para. 10).



Cree students at All Saints Residential School in Lac La Ronge, SK (March 1945).

As of June 2021, there were "4117 [documented] deaths of First Nations, Inuit and Métis children at residential schools across Canada" (vanbuekl, 2021, para. 4). This numbers grows with each site study (Giles, 2022; House, 2022; Stewart, 2022). The refrain "Every Child Matters" has been used to show support for the continued exploration of all IRS locations. The genocide against Indigenous peoples in Canada, however, is much larger than the IRS or the Sixties Scoop. It continues in many ways today, for example, through inadequate government policies and action to address the crisis of <u>murdered and missing Indigenous women</u>

and girls (MMIWG) (TVO Docs, 2019); and through insufficient government funding to address **structural racism**, evident in current living conditions in Indigenous communities throughout the country (i.e., water and air pollution, housing insecurity, inadequate educational and medical facilities, etc.), that continue to negatively impact the health and well–being and life-expectancy of Indigenous peoples (Richmond & Cook, 2016; NNCIH, 2014).

Click the links to learn more about the genocide committed against Indigenous peoples in Canada:

How Canada Committed Genocide Against Indigenous Peoples, Explained by the Lawyer Central to the Determination

#### VIDEO: Is It Really Genocide? In Canada?

language used when developing the RS school plan)

In the following video, Indigenous activists, artists, and journalists Ian Campeau, Sarain Fox, Tanya Talaga, Jesse Wente, and Riley Yesno explain how the actions committed against Indigenous populations in Canada meet the international criteria for genocide.



One or more interactive elements has been excluded from this version of the text. You can view them online here: <a href="https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=870#oembed-1">https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=870#oembed-1</a>

# **6.6 CHAPTER SUMMARY**

# **Key Summary Points**

- 1. Genocide refers to certain acts (outlined in the UN International Criteria for Genocide) that are committed with the purpose of destroying a national, ethnic, racial, or religious group.
- 2. Those victimized by genocides are deliberately targeted because of their real or perceived membership to a particular group.
- 3. Various genocides committed against distinct minority groups throughout history (e.g., Armenians, Jewish people, Tutsis, Indigenous peoples in Canada) have claimed the lives of millions of people and resulted in the displacement and trauma of those who survived.
- 4. Understanding the common characteristics of genocides, as well as the factors that lead up to them, is critical to prevent future atrocities.

## Additional Resources

#### **Additional Viewings**

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# 6.7 REQUIRED COURSE MATERIALS

In addition to the videos and reading links embedded into the chapter, you are required to complete the following course material:

# Required Course Reading

Mullings, M., Schneiderhan, E. & Walsh, B. (2019). Remembering genocide: UTM students in experiential sociology course analyze how we construct memories of the Holocaust. *University of Toronto Mississauga Magazine 18-19*. <a href="https://www.utm.utoronto.ca/alumni/sites/files/alumni/public/shared/">https://www.utm.utoronto.ca/alumni/sites/files/alumni/public/shared/</a>
<a href="UofT\_M\_magazine\_Spring\_2019.pdf">UofT\_M\_magazine\_Spring\_2019.pdf</a> (Read pages 20-21)

# 6.8 CHAPTER ASSIGNMENT

# Genocide Assignment

This chapter's materials focused on four of the larger and more well-known genocides. For this assignment you are required to choose another genocide (not among the four focused on in this chapter) and write a short essay in which you answer several questions about that genocide. It is important to complete all chapter materials (chapter content, including all embedded links to readings and videos, and the required course materials) prior to starting the assignment.

## Assignment Formatting & Style for Written Report:

- Assignments formatting requirements: Arial 12-point font; 1 inch/2.54 centimeter margins; single spaced; APA in-text citation style, reference section and cover page.
- Use proper essay/paragraph style.
- Clearly indicate which genocide you have chosen for your assignment.
- Paraphrase as opposed to relying on direct quotes.
- Proofread your submission to make sure it is clear, well written and intelligible.

## Assignment Submissions Must Include

- 1. Proper APA style cover page.
- 2. Written report addressing the questions below.
- 3. Proper APA reference section that contains all the material cited in the assignment.

## Steps to Completing the Assignment

- a. Identify a genocide that is not among the four focused on in the chapter materials.
- b. Research the identified genocide and find a <u>minimum</u> of 6 sources (in addition to the chapter materials) to help you to answer the assignment questions. No more than 2 of the sources can be media-type resources. At least 2 of your sources must be from academic, peer-reviewed sources (i.e., journal articles). The remainder can come from online reports from government and non-governmental organizations (i.e., NGOs).
- c. Write a 1000-word essay (give or take 100 words) on the genocide you have identified that answers the

- questions below (the questions need to all be addressed in your paper, but do not need to be answered in order).
- d. Support the points/arguments you make in your answers with in-text citations that reference the materials you have found in your research and those that are in the chapter. In-text citations to support your points/arguments are essential and required. Be sure to use a diverse range of materials as opposed to relying heavily on one, or a few sources.
- e. Develop an APA style reference section for all material cited (only material cited in the body of the paper can be included in a reference section).

#### Assignment Questions

- 1. What is the name of the genocide you identified?
- 2. When and where did the genocide occur?
- 3. How long did it last?
- 4. Who was targeted? How/in what way were they targeted?
- 5. What occurred? For example, how were the victims stereotyped, scapegoated, blamed, targeted, discriminated against, dehumanized?
- 6. Which social, economic, and political factors played a role in the genocide? How did they play a role/ what role did they play?
- 7. How many people were killed?
- 8. How did the genocide end?
- 9. How were the perpetrators brought to justice? If they were not, why not?
- 10. Is this mass killing event officially classified as a genocide? How does it fit the United Nations criteria for genocide? How does it not?

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# CHAPTER 7: END-OF-LIFE CARE: HOSPICE, PALLIATIVE CARE & MEDICAL ASSISTANCE IN DYING



Jacqueline Lewis & Jillian Holland-Penney

# 7.0 INTRODUCTION

# **Chapter Introduction**

As discussed in other chapters, death is a taboo topic of discussion and western societies have become death-denying or death-phobic, often resulting in a lack of death-related conversations. Although we may wish to avoid it, death is certain, whether it be our death or that of a loved one. Avoiding death-related discussions ultimately contributes to uncertainty, discomfort, and suffering at the end-of-life. When people do talk about death, it tends to be constructed as something to be feared, fought, and conquered. Conventional perspectives of death construct ideas about "proper" end-of-life care and experiences. These often fail to take individual wishes into account and can infringe on a person's right to choose how they want to die. This chapter examines several types of end-of-life care: palliative and hospice, including the role of death doulas. It also explores the option of medical assistance in dying (MAiD).

# Chapter Objectives/Learning Outcomes

After completing the chapter materials, you should have an understanding of:

- 1. The complexity of dying with dignity.
- 2. The diverse options at the end-of-life and the differences between them (i.e., palliative care, hospice, MAID/assisted dying).
- 3. Terminology, attitudes, and perspectives, as well as laws and policies pertaining to end-of-life care in Canada and other countries.
- 4. How social and cultural responses/constructions of death can impact end-of-life experiences and care.

# Questions to Think About When Completing Chapter Materials

- 1. What does death with dignity, or a dignified death, mean to you?
- 2. How can palliative, hospice care and medical assistance in dying (MAiD) help a person die with dignity?
- 3. What are you rights under Canadian law with regard to receiving medical assistance in dying (MAiD)? What restrictions are in place that could prevent a person from accessing MAiD? What recommendations would you make for further policy change?
- 4. Compare and contrast two examples of assisted dying laws from other countries.

# 7.1 WHAT IS DYING WITH DIGNITY?

"Our most cruel failure in how we treat the sick and the aged is the failure to recognize that they have priorities beyond merely being safe and living longer; that the chance to shape one's story is essential to sustaining meaning in life; that we have the opportunity to refashion our institutions, our culture, and our conversations in ways that transform the possibilities for the last chapters of everyone's lives" (Gawande, 2017, p. 243).

# Dying with Dignity

Personal or emotional dignity is tied to a person's sense of feeling worthy, esteemed, and respected. It is subjective in nature, varying from person to person, and influenced by a variety of factors including interpersonal relations and culture (e.g., beliefs, mores, values, social-customs, religious beliefs and practices) (Autiero, 2020; Badcott, 2003). When using terms like dignified death, death with dignity, dying with dignity, or dignity in dying, we are talking about personal dignity as we approach the end of life, the experience of dying in a manner that the person who is dying feels is dignified, which is considered an important



Person in Blue Scrub Suit Holding the Hand of a Patient.

attribute of dying well (Guo & Jacelin, 2014). Definitions of dying with dignity vary and can be associated with a variety of factors including: the impact of the illness (on cognitive and physical abilities) (Chochinov et al., 2002); a sense of autonomy and self-determination (Horn & Kerasidou; 2016; Meier et al., 2016); being treated with respect and understanding (Chochinov, 2002); the ability to participate in activities the dying person finds meaningful (e.g., those that bring them joy, happiness, fulfillment, contentment) (Meier et al., 2016). It can also be tied to having one's wishes respected about one's final days, so that death can be met on one's own terms.

Caregivers (family, medical personnel) typically play a pivotal role in a dying person achieving a dignified

#### 170 | 7.1 WHAT IS DYING WITH DIGNITY?

death. Even though caregivers may have their own understanding of "dying with dignity" and place a priority on different factors (i.e., their own personal definition of quality of life) (Meier et al., 2016), dignity in dying requires that others ask, listen, respect and honour the dying persons wishes (including end-of-life choices) (Dying with Dignity, n.d.-a). Since dying with dignity can be tied to maintaining a sense of personal integrity, which can be nurtured, or not, by caregivers, it is also important that caregivers honour aspects of the dying individual as they once were (Leung, 2007). All of this means that the experience of death with dignity can easily and (un)knowingly be denied a person through silence, a failure to listen, lack of communication and/ or not honouring and respecting the wishes of the dying individual or not treating them with respect and understanding (Dying with Dignity, n.d.-a).

In terms of end-of-life care, dying with dignity consists of honouring a person's choices and wishes about how, where, and with whom they wish to die. The assurance that everything will be done as per their specifications both before and after death is also an essential part of a dignified death. This can include: upholding advanced directives; wishes laid out in documented end-of-life and estate plans/wills; preserving dignity and privacy of the body after death; observing any specified cultural and religious practices; and giving loved ones the opportunity to grieve (SCIE, 2020). Dying with dignity ultimately works to create not only a "good death" for the dying individual, but it can also lessen the grief and suffering among loved ones left behind (Wilson et al., 2019).

# 7.2 PALLIATIVE CARE

#### Characteristics of Palliative Care

The aim of palliative care is to enhance quality of life and promote patient dignity (Ho et al., 2017). Its defining principles include controlling physical symptoms and supporting psychological and spiritual needs. These services are delivered by multidisciplinary teams of experts and can take place in a hospital, hospice, and at home (see next Chapter section). Although often thought to be a service only for the dying, palliative care is not only about end-of-life care (Covenant Health Canada, 2019; Collins, 2017; Health Canada, 2018).

#### Palliative Care Efforts Focus On:

- · Improving quality of living and dying
- Placing patient values and wishes at the forefront of treatment considerations
- Managing stress
- Comforting patients
- Treating and controlling symptoms
- Reducing pain and suffering
- Mitigating the consequences of a disease
- Providing psychological, social, emotional, spiritual, and practical support for patients and their families

(Covenant Health Canada, 2019; Health Canada, 2018).

#### VIDEO: What Really Matters at The End of Life

In the following TED talk Dr. B.J. Miller, a hospice and palliative medicine physician, talks about how he aims to create dignified, graceful, end-of-life experiences for his patients.



One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=888#oembed-1

# 7.3 WHAT IS HOSPICE CARE?

# **Hospice Care**

The modern-day concept of hospice as a place for endof-life care began with the work of Dr. Cicely Saunders of
the UK. Focused on providing the terminally ill with
end-of-life care, she founded St. Christopher's Hospice
on London UK in 1967 (CHPCA, n.d.-a; CHPCA, n.d.b; Lowey, 2020). In Canada, hospice care started in the
mid-1970s as hospice-palliative care units in hospitals.
The first community-based hospice in Ontario opened in
1979 in the Windsor-Essex region. Hospice of Windsor
and Essex County has been serving the local community
since that time and now has two residential campuses,
one in Windsor and one in Erie Shores (Williams et al.,
2010) (see image below).



Two people holding hands.

Hospice Care is one type of end-of-life care program that incorporates a palliative philosophy of care and is used by people with serious illnesses who are nearing the end of life (Lowey, 2020; National Institute on Aging, 2021). It is both a type of care and a philosophy of care that focuses on the needs of the terminally ill, including pain and symptom management and psychosocial needs (psychological, emotional, spiritual, interpersonal) (Lowey, 2020; Powell, 2015).



The Hospice of Windsor and Essex County.

# Similarities between Hospice and Palliative Care:

- Provides specialized care and support for individuals living with serious illnesses.
- Main goal is to improve the quality of life of patients via interventions that focus on improving comfort and reducing the complications associated with illness.
- Programs are family oriented.
- Uses a team approach, typically a physician, nurse, and social worker.
- Can occur at home, in an assisted living facility, nursing home, hospital, or hospice residential facility.

(Lowey, 2020; National Institute on Aging, 2021)

# Differences between Hospice and Palliative Care:

- Hospice requires patients to forgo all medical treatments that are life-sustaining or curative. Focus shifts completely to comfort-oriented care. In contrast, with palliative care patients can receive life-sustaining or curative treatments alongside palliative care.
- Hospice is usually reserved for people who have a prognosis of 6 months or less to live. In contrast, there are no time limits with palliative care.

(Lowey, 2020; National Institute on Aging, 2021)

#### Click the link below to learn more about palliative care:

10 Myths About Palliative Care

#### Click the link below to read a detailed explanation of what to expect at the end of life:

Final Days

#### VIDEO: Indigenous Voices: Caring for the Patient and Family

In the following video from the Canadian Virtual Hospice, Indigenous peoples from various Nations and communities describe how end-of-life care for Indigenous individuals in Canada should align with their beliefs and practices.



One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=892#oembed-1

#### VIDEO:In-home Palliative Care – Marie's Story

In this video Marie tells the story of how/why she and her husband Doug (diagnosed with stage 4 lung cancer) chose in-home palliative care as Doug's end-of-life care option.



One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=892#oembed-2

# 7.4 PALLIATIVE CARE IN CANADA

In 2017, the Act providing for the development of a framework on palliative care in Canada, was passed by Parliament (Health Canada, 2018). After consulting with Provincial and Territorial governments and various other groups, Health Canada eventually provided the foundation for the "Framework on Palliative Care in Canada" (Health Canada, 2018). One of the features of the framework was the formation of guiding principles that are fundamental to the provision of high-quality palliative care in Canada (Health Canada, 2018).

#### The Guiding Principles of Palliative Care in Canada

- Palliative care is person- and family-centred care.
- Death, dying, grief and bereavement are a part of life.
- Caregivers are both providers and recipients of care.
- Palliative care is integrated and holistic.
- Access to palliative care is equitable.
- Palliative care recognizes and values the diversity of Canada and its peoples.
- Palliative care services are valued, understood, and adequately resourced.
- Palliative care is high quality and evidence based.
- Palliative care improves quality of life.
- Palliative care is a shared responsibility.

(Health Canada, 2018)

# Issues Facing Palliative Care in Canada

Although there have been changes and improvements to palliative care in Canada since it was first introduced in the mid-1970s, various reports have demonstrated gaps in access and quality of palliative care across Canada. A report by the Canadian Institute for Health Information (CIHI) (2018), for instance, found that:

 While 75% of Canadians would prefer to die at home, only about 15% have access to palliative home care services.

- Recipients of home palliative care services are 2.5 times more likely to die at home and are less likely to receive care in an emergency department or intensive care unit.
- Cancer patients are up to 3 times more likely to receive palliative care, even though approximately 89% of people with life-limiting illness, such as a progressive neurological illness, organ failure, or frailty, were not able to benefit from palliative care.

Several recommendations have been made by palliative care organizations to overcome these gaps in access and quality of care. They include "establishing consistent definitions and measures of palliative care, improving palliative education for health professionals, ensuring adequate training for caregivers and increasing awareness among patients and their families" (CIHI, 2018, p. 41).

# 7.5 MEDICAL ASSISTANCE IN DYING (MAID) IN CANADA

# Meaning of Medical Assistance in Dying (MAiD)

According to the Canadian law (n.d.-a), MAiD is the process whereby a person seeks and obtains medical assistance in ending their life. There are two legal forms of MAiD, both of which involve a medical practitioner (i.e., a physician or nurse practitioner):

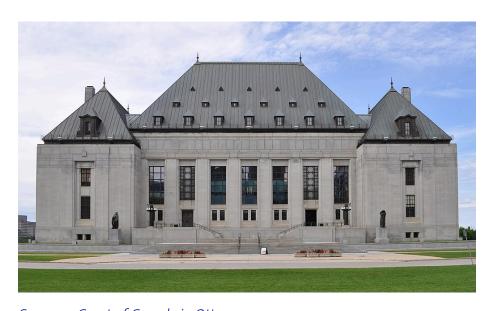
**Clinician-Administered MAiD:** A medical practitioner administers the substance that results in death (e.g., injection of substance).

**Self-Administered MAiD:** A medical practitioner prescribes or provides a substance that the person then takes in order to end their life.

Click the following link to learn why we use the term medical assistance in dying in Canada:

Language Matters: Why We Use the Term 'Medical Assistance in Dying

# Canadian MAiD Legislation



Supreme Court of Canada in Ottawa.

On June 17, 2016, Bill C-14 received royal assent, making medical assistance in dying (MAiD) legal in Canada

(Canada, n.d.-b). This legislative change was the result of the Supreme Court of Canada ruling in <u>Carter v. Canada</u> (2015). In their ruling the Supreme Court stated that Canadian "law must permit some form of physician-assisted dying" (Canada, n.d.-b, para. 6). The Court gave the government 12 months to rewrite the law. In January 2016, that deadline was extended by four months. At that time, the Supreme Court also granted an exemption that allowed people to access MAiD by applying to the Superior Court in their jurisdiction, until the new law came into force (Canada, n.d.-b).

Various amendments have been made to the MAiD legislation since enacted. The most recent changes occurred on March 17, 2021, when the Parliament of Canada (2021) passed the revised MAiD legislation. The key changes in the new legislation relate to: eligibility criteria; the assessment process; procedural safeguards; advance requests; and reporting/monitoring/analysis (Parliament of Canada, 2021; Dying with Dignity Canada, n.d.-a).

#### Click the following links to learn more about MAID in Canada:

Canada's New Medical Assistance in Dying Law
Get the Facts: Canada's Medical Assistance in Dying Law
Medical Assistance in Dying

Click the following link to learn about opposition to Canadian MAiD legislation:

How can Canada Safeguard those Marginalized by Society as MAiD Expands?

# 7.6 DYING WITH DIGNITY ADVOCACY ORGANIZATIONS

As discussed at the start of this chapter, notions of dying with dignity or death with dignity are tied to the quality of the dying process. These terms, however, have also become synonymous with the right to assisted death movement. Dying with Dignity (n.d.-b) is a Canadian based organization, while Death with Dignity (n.d.-b) is a U.S. organization. Both are leaders in their respective countries in terms of end-of-life advocacy, education, and support. Their emphasis is on choice

DYING WITH DIGNITY

Dying with Dignity Canada Logo. © Dying with with Dignity Canada (n.d.). All rights reserved. Image used with permission.

and the right to choose one's own good death, whether that be a natural death from age, disease/illness, accident, or medically assisted dying.

Dying with Dignity Canada (n.d.-b) is also fighting for the rights of people who want MAiD to be able to die where they want. Currently, there are many institutional and community settings (e.g., care homes, hospices, religious oriented hospitals) that will not permit MAiD on their premises. This means that people in very fragile states, near the end of life, must be relocated if they wish medical assistance in dying. In response, there is an initiative to create MAiD suites, where people can receive assistance in dying in a supportive, home-like setting (e.g., MAiDHouse, and funeral home MAiD suites).

#### Click the following link to learn more MAiDHouse:

Medically Assisted Death Non-Profit Says Fear is Hampering Its Search for Permanent Space

# 7.7 ASSISTED DYING AROUND THE WORLD

In addition to Canada, a number of countries around the world have legalized some form of assisted dying, including Switzerland, the Netherlands, Spain, Belgium, Luxembourg, Colombia, Australia, France, New Zealand, and parts of the USA (Roehr, 2021; Euthanasia, 2021). Each country has its own restrictions, rules, and regulations regarding when, how, and where assisted dying is permitted, as well as who is eligible to receive it (Roehr, 2021; Euthanasia, 2021). There is also a range of terms used to refer to the various processes tied to assisted dying.



Elderly couple holding hands in hospital.

#### **Assisted Dying Terminology**

#### **Correct and accurate terms include:**

- Physician-Assisted Death
- · Physician-Assisted Dying
- · Aid in Dying
- Physician Aid in Dying
- Medical Aid in Dying (MAiD) (Most commonly used in Canada)
- Voluntary Assisted Dying (VAD) (Most commonly used in Australia)

#### Inaccurate and outdated terms:

- Assisted Suicide
- Doctor-Assisted Suicide
- Physician-Assisted Suicide
- (Active) Euthanasia

(Death with Dignity, n.d.-a; Glossary of Terms, n.d.; Ubel, 2013)

#### Click the link below to learn more which countries permit assisted dying:

Assisted Dying Around the World

#### Switzerland & "Suicide Tourism"

In Switzerland, there is no specific law permitting or outlawing assisted dying (Roehr, 2021). Under Swiss Criminal Law, assisted dying has been tolerated since 1937, provided that the person who is providing the required assistance has no selfish motive (Blouin, 2018; Roehr, 2021). Switzerland is one of a few countries that permits non-residents to access assisted dying, earning the country the reputation of a "suicide tourism" destination (Blouin, 2018).



<u>Dignitas</u> is a Swiss non-profit members' society consisting of qualified Swiss doctors who provide assisted dying to those who fit the criteria.

#### Click the link below to learn more the Swiss model of the right to die:

Suicide Tourism" & Understanding the Swiss Model of the Right to Die

# The United States of America & Oregon

Assistance in dying is available in a number of U.S. states including: California, Colorado, Hawaii, Maine, New Jersey, New Mexico, Oregon, Vermont and Washington D.C. (Death with Dignity, n.d.-b). The first U.S. state to officially legalize assisted dying was Oregon (Death with Dignity, n.d.-b; Roeher, 2021). In November 1994, the Oregon Death with Dignity Act (DWDA), a citizen's initiative, was passed by Oregon voters (Oregon, n.d.). After some delay, the law was enacted on October 27, 1997 (Oregon, n.d.).

The DWDA allows terminally ill residents of Oregon to end their lives through the voluntary self-administration of lethal medications prescribed by a physician if they meet the required criteria (Oregon, n.d.). The criteria stipulates that a patient must: be 18 years of age or older; a resident of Oregon; capable of making and communicating health care decisions to health care practitioners; and diagnosed with a terminal

illness that will lead to death within six months (Oregon Health Authority, 2021). "Since the law was passed in 1997, a total of 2,895 people have received prescriptions under the DWDA and 1,905 people (66%) have died from ingesting the medications" (Oregon Health Authority, 2021, p. 5). The following videos tell the stories of a young woman and an elderly couple who chose to use Oregon's Death with Dignity option.

#### VIDEO: Brittany Maynard – A Video for My Friends

In the following video Brittany Maynard, a young American woman with terminal brain cancer, talks about her decision to end her life "when the time seems right" and why she became an advocate for the legalization of assisted death.



One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=904#oembed-1

#### VIDEO: Oregon Couple Chooses 'Death with Dignity' on Same Day

The following video covers the story of a terminally ill Oregon couple, who is believed to be the first couple to die on the same day under Oregon's Death with Dignity law. Their daughter produced a documentary about their experience (there is a link to that full video in the Recommended Resources section of this Chapter).



One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=904#oembed-2

# 7.8 CHAPTER SUMMARY

# **Key Summary Points**

- 1. Understanding the concept of dying with dignity and the importance of dignity at the end of life, can help people who are dying and their loved ones better align their end-of-life care with personal wishes/preferences.
- Palliative care does not necessarily mean an individual needs end-of-life or hospice care; whereas hospice is end-of-life care. Medical assistance in dying is about ending life or hastening death. All are focused on the dignity of people who are ill and/or people who are dying.
- 3. Assisted dying is available in a growing number of countries/regions around the world. Advocacy organizations that have played a role in bringing some of this legislation forward, also assist with education efforts and provide support for people wishing assistance in dying and their families.

#### Additional Resources

#### Additional Viewings

Shared Wisdom Network. (2018). *Living & dying: A love story – Full documentary free to watch* [Video]. Vimeo. <a href="https://vimeo.com/257939456">https://vimeo.com/257939456</a>

The Fifth Estate. (August 11, 2016). Assisted suicide: The life and death of Gloria Taylor [Video]. YouTube. <a href="https://www.youtube.com/watch?v=7blnXINYTOM">https://www.youtube.com/watch?v=7blnXINYTOM</a>

The New Yorker. (June 23, 2021). *Documenting her wife's death on social* media [Video]. YouTube. <a href="https://youtu.be/1i-TvqmjsBw">https://youtu.be/1i-TvqmjsBw</a>

#### **Additional Readings**

Canadian Institute for Health Information (CIHI). (2018). *Access to palliative care in Canada*. <a href="https://www.cihi.ca/sites/default/files/document/access-palliative-care-2018-en-web.pdf">https://www.cihi.ca/sites/default/files/document/access-palliative-care-2018-en-web.pdf</a>

Gentleman, A. (November 18. 2009). Inside the Dignitas house. The Guardian. https://www.theguardian.com/society/2009/nov/18/assisted-suicide-dignitas-house

#### Websites

Canadian Virtual Hospice. (n.d.). http://virtualhospice.ca/

Canadian Hospice Palliative Care Association (CHPCA). (n.d.-a). Historical timeline.

https://www.chpca.ca/about-us/

Death with Dignity. (n.d.-b). Our history. https://deathwithdignity.org/history/

Dying with Dignity. (n.d.-a). https://www.dyingwithdignity.ca

Health Canada. (2018). Framework on palliative care in Canada. https://www.canada.ca/content/dam/hcsc/documents/services/health-care-system/reports-publications/palliative-care/framework-palliative-carecanada/framework-palliative-care-canada.pdf

Ontario. (December 2021). Ontario Provincial Framework for Palliative Care. Ministry of Health. https://tinyurl.com/dfap2zwv

# 7.9 REQUIRED COURSE MATERIALS

In addition to the videos and reading links embedded into the chapter, you are required to complete the following course material:

# **Required Course Viewings**

Canadian Virtual Hospice. (January 21, 2008). Canadian Virtual Hospice palliative care video [Video]. YouTube. <a href="https://youtu.be/ZWLoQkJD0WA">https://youtu.be/ZWLoQkJD0WA</a>

Covenant Health Canada (October 3, 2019). What is palliative care [Video]. YouTube. <a href="https://youtu.be/Mc5ImaOciR4">https://youtu.be/Mc5ImaOciR4</a>

Goldman, B. (Host). (August 24, 2018). White coat black art [Audio podcast episode]. 'Going out with my boots on': Tim Regan used his last days to lobby for a clearer path to assisted death. CBC Radio. <a href="https://podcast-a.akamaihd.net/mp3/podcasts/whitecoat-h0SkFJP9kp6abaN.mp3">https://podcast-a.akamaihd.net/mp3/podcasts/whitecoat-h0SkFJP9kp6abaN.mp3</a>

# Required Course Readings

- Aleccia, J. (May 15, 2019). 'Living their values': Palliative care power couple faces cancer at home. KHN. <a href="https://khn.org/news/living-their-values-palliative-care-power-couple-faces-cancer-at-home/">https://khn.org/news/living-their-values-palliative-care-power-couple-faces-cancer-at-home/</a>
- Canada. (June 20, 2016). *End-of-life care*. https://www.canada.ca/en/health-canada/topics/end-life-care.html
- Collins, A. (November 1, 2017). Five common myths about palliative care and what the science really says. *TheConversation.com*. https://theconversation.com/five-common-myths-about-palliative-care-and-what-the-science-really-says-82248
- Grant, M., Collins, A. & Philip, J. (October 29, 2017). What is palliative care? A patient's journal through the system. *TheConversation.com*. <a href="https://theconversation.com/what-is-palliative-care-a-patients-journey-through-the-system-82246">https://theconversation.com/what-is-palliative-care-a-patients-journey-through-the-system-82246</a>
- Gunderman, R. (January 12, 2015). Last wishes add clear choices: learning how to talk about end-of-life care. *TheConversation.com*. https://theconversation.com/last-wishes-and-clear-choices-learning-how-to-talk-about-end-of-life-care-35665
- Hannig, A. (June 2, 2020). Dying virtually: Pandemic drives medically assisted deaths online. *TheConversation.com*. <a href="https://theconversation.com/dying-virtually-pandemic-drives-medically-assisted-deaths-online-139093">https://theconversation.com/dying-virtually-pandemic-drives-medically-assisted-deaths-online-139093</a>
- Lupton, A. (October 26, 2021). Funeral homes pivot to offer rooms for medically assisted deaths. CBC News.

- https://www.cbc.ca/news/canada/london/funeral-homes-pivot-to-offer-rooms-for-medically-assisteddeaths-1.6224353
- Moura, C. (January 25, 2021). Dear Grandma. Canadian Medical Association Journal, 193(4). https://www.cmaj.ca/content/cmaj/193/4/E139.full.pdf
- Ontario. (n.d.). Medical Assistance in Dying. Ministry of Health. https://www.health.gov.on.ca/en/pro/ programs/maid/
- Presern, E. (May 10, 2021). Palliative care: Is it time for health professionals to talk openly about psychedelic therapy? British Journal of General Practice, 71(708) 318-319. https://bjgp.org/content/bjgp/71/708/ 318.full.pdf
- Wilhelm, T. (August 24, 2018). Windsor's first death doula helps people plan their exits. Windsor Star. https://windsorstar.com/news/local-news/windsors-first-death-doula-helps-people-plan-theirexits#:~:text=Whether%20it's%20planning%20a%20living,help%20people%20do%20dying%20right.
- Wilkinson, D. & Savulescu, J. (April 27, 2021). End-of-life care: People should have the option of general anaesthesia as they die. The Conversation.com. https://theconversation.com/end-of-life-care-people-shouldhave-the-option-of-general-anaesthesia-as-they-die-159653

# 7.10 CHAPTER ASSIGNMENT

# **End of Life Care Assignment**

In this chapter you learned about various options for end-of-life care, including hospice care, palliative care and medical assistance in dying (MAiD). The chapter's assignment involves doing some research and writing a report on a local organization that provides palliative (at home or in a dedicated health care facility), hospice, and/or MAiD-related services. It is important to complete all chapter materials (chapter content, including all embedded links to readings and videos, and the required course materials) prior to starting the assignment.

### Assignment Formatting & Style for Written Report

- Assignment formatting requirements: Arial 12-point font; 1 inch/2.54 centimeter margins; single spaced; APA in-text citation style, reference section and cover page.
- Use proper essay/paragraph style.
- Paraphrase as opposed to relying on direct quotes.
- Proofread your submission to make sure it is clear, well written and intelligible.

### Steps to Completing the Assignment

- a. Find a local organization/service to focus on for your assignment.
- b. Conduct research on that organization/service.
- c. Write a 750-1000 word essay where you address the following questions:
  - i. When and where did this organization originate?
  - ii. What was/were the motivation(s) for the development of this organization/service?
  - iii. Who/what oversees the running of this organization/service?
  - iv. How is the organization funded? Are they private or public? Are there fees tied to the service(s) provided? If so, what are they?
  - v. What type of care does this organization provide?
  - vi. How does one go about accessing the care services provided? What criteria must be met in order to receive the care this organization provides?
  - vii. Is this a stand-alone organization/service or is it connected with other associated services? If connected to others, what are the inter-connections? How are the connections meant to assist people who are ill and/or near the end-of-life and their loved ones. Is there more than one location?

#### Where?

- viii. Can you volunteer for these organizations? If so, what is the application process?
- d. Support information/points you make in your essay with in-text citations that reference the materials you have found in your research, and those that are in the chapter. <u>In-text citations that source/support your information/points are essential and required</u>. Be sure to use a diverse range of materials as opposed to relying heavily on one, or a few sources.
- e. Develop an APA style reference section for all material cited (only material cited in the body of the paper can be included in a reference section).

## Assignment Submissions must Include

- 1. A proper APA style cover page.
- 2. An essay in which you address the questions detailed in C above.
- 3. A reference section containing cited material, both chapter materials and those you found in your research.

# 7.11 REFERENCES & MEDIA ATTRIBUTIONS

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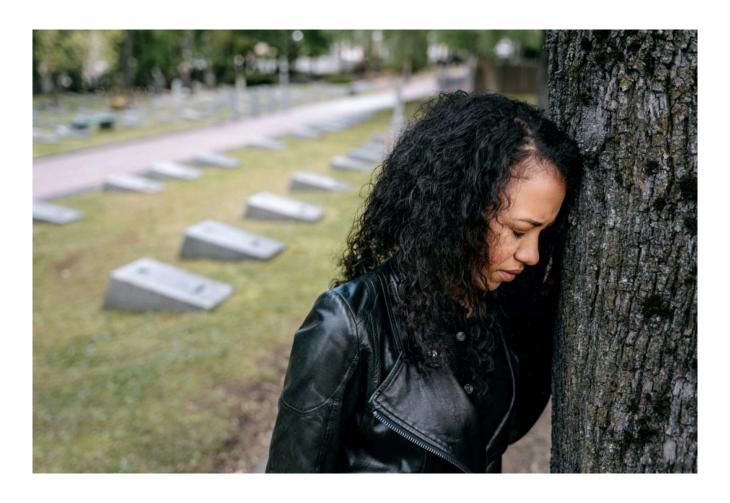
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# CHAPTER 8: GRIEF, LOSS & BEREAVEMENT



Jacqueline Lewis & Jillian Holland-Penney

## 8.0 INTRODUCTION

#### **Chapter Introduction**

At various points in our lives, we all will experience loss, grief, and bereavement. Despite the universal nature of these experiences, we shy away from them or turn a blind eye when others are suffering. When it is us, we often feel lost and isolated with nowhere to turn. Obviously, grief and loss are difficult and challenging experiences to work through, but life for the bereaved can be enhanced by understanding how to recognize and respond to grief. This chapter explores the concepts of grief, mourning, and bereavement and addresses some important questions about these human experiences. It also examines the relationship between grief, loss, and the COVID-19 pandemic.

#### **Chapter Objectives/Learning Outcomes**

After completing the chapter materials, you should have an understanding of:

- 1. What grief, mourning, and bereavement are, including the relationships between the concepts.
- 2. The different and appropriate ways to support those experiencing loss and grief.
- 3. How to navigate grief on social media.
- 4. The relationship between loss, collective/national grief, and the COVID-19 pandemic.

## Questions to Think About When Completing Chapter Materials

1. In what ways can the use of social media help the grieving process? In what ways can it hinder it? How might you change your behaviour and language on social media given what you are learning in this chapter?

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- 2. Reflect on your experiences during the COVID-19 pandemic. What types of losses have you experienced? How did you grieve these losses? What do you think could have been done to support you better? How have you supported family and friends with their loses?
- 3. How can you take what you've learned about supporting loved ones through grief and implement that knowledge into your own life?

# 8.1 DEFINING LOSS, GRIEF, & BEREAVEMENT

#### What is Grief?

Grief is the psychological, emotional, physical and social, reaction to loss (Caddell, 2021; CAMH, n.d.). Although the experience of grief is unique to each individual person, there are some commonalities (*Grief – How to support the bereaved*, n.d.). Some common reactions associated with grief include: "shock, disbelief and confusion; anger; trouble concentrating and focusing on tasks; altered patterns of eating and sleeping; physical changes such as dizziness, headaches or upset stomach; sadness and yearning; memories and thoughts about who or what has been lost; and withdrawing from usual activities" (CAMH, n.d., para. 4).



An older women crying.

## What is Mourning?

The outward expression of grief is referred to as mourning. There are individual, cultural, and religious variations in terms of the physical manifestations of grief (See Chapter on Cultural and Religious Beliefs and

Death-Related Practices). Common forms of mourning include: "crying, and expressing grief through art or writing, rituals, and/or religious practices such as prayer" (CAMH, n.d., para. 6).



Women kneeling in front of a gravestone.

#### What is Bereavement?

Bereavement is the period of sadness and sense of loss felt after experiencing a loss in one's life. The loss does not necessarily have to involve death. Instead, bereavement can follow other life transitions or change events, such as the ending of significant relationships (e.g., with spouse or friend) or a relocation of oneself or others to a new area or type of living situation. It can also be tied to loss of parts of oneself, due to changes in life circumstances or physical/psychological health. Both mourning and grief are "part of the bereavement process" (Kakar & Oberoi, 2016, p. 371). While bereavement is the broader term used to refer to the internal process that an individual experiences following a loss of any kind, grief is a part of the pain and suffering that constitutes bereavement following a loss (Kakar & Oberoi, 2016).

## 8.2 UNDERSTANDING GRIEF



National Grief & Bereavement Day Poster. ©Canadian Hospice Palliative Care Association (2021). All rights reserved. Image used with permission.

There is no definitive set of criteria for the characteristics of grief. Important things to keep in mind when experiencing or helping someone through the bereavement process is that grief:

• Does not follow a linear process.

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- Can include different types of change or loss that don't involve death (e.g., loss of a limb, health/abilities, home, job, routine, etc.).
- Is an ongoing process. It does not have a timeline or expiration date.
- Never looks the same, even for the same person. Each person's experience of grief is unique to them.

(Haley, 2019; Phillips, 2021; Grief, n.d; Caddell, 2021).

#### Theories of Grief

One of the most widely known people associated with understanding dying and grief is Elizabeth Kubler-Ross, who was a pioneer in palliative care. Her work brought attention to the subject of illness and dying, challenged social norms regarding talking about death (LadyScience, 2021), and caused "a public outcry for compassionate care of the dying" (Newman, 2004, para. 2). It also altered the way medical staff attend to those that are dying (Newman, 2004). Although her original model of dying and grief has been the subject of criticism, her work in the field helped inspire others', resulting in several theories of grief and bereavement including:

- 1. Bowlby's Attachment Theory (1969-80)
- 2. Parke's Psycho-Social Elaborations (1972)
- 3. Worden's Four Tasks of Mourning (1991)
- 4. Silverman and Klass (1996)
- 5. Stoebe and Schutt (1999)

(Thompson, 2016: click to learn more about these models – optional reading material)



Sorrowed man with emotive words.

#### Click the links below to learn more about loss and grief:

Grief Never Ends, and That's Okay Untangling Trauma and Grief After Loss

#### VIDEO: How Grief Feels - Robbie Stamp

In the following video, Robbie Stamp talks about the experience of grief, how it changes our perception of the world and how we can all support those who are grieving.



One or more interactive elements has been excluded from this version of the text. You can view them online here: <a href="https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=925#oembed-1">https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=925#oembed-1</a>

## 8.3 SUPPORTING THE BEREAVED



Woman consoling man.

There's no perfect combination of words that will take away a grieving person's pain, but there are ways we can support them and show we care (Cruz, 2019). Calling, texting, or showing up face-to-face, for instance, are some of the best things we can do for someone who is grieving (Cruz, 2019). We can also send cards and/ or gifts, anticipate their needs, check up on them, and listen with compassion (Grief, n.d; Cruz, 2019). There are, however, things that should be avoided, including: trying to "fix" their grief, not saying the deceased person's name, making it about us (Cruz, 2019), and/or encouraging them to "move on" (See video below).

#### Click the links below to learn more about how to support those experiencing loss:

What to Say When Someone Dies
Grief – How to Support the Bereaved

#### VIDEO: We Don't "Move on" From Grief. We Move Forward With It

In the following TED talk, writer and podcaster Nora McInerny discusses life and death, encouraging us to shift how we approach grief.



One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=928#oembed-1

## 8.4 GRIEF & SOCIAL MEDIA



Man covering his face.

In the 21st century, social media has not only become a key component in the everyday lives of many people, it also has therapeutic benefits for people who are grieving (Kakar & Oberoi, 2016). It provides a forum for the grieving person to post photos, comments, and memorials to express their respect and love for the deceased (Kakar & Oberoi, 2016). Social media also serves as a useful tool in disseminating information regarding funeral arrangements (Hiss, 2021). Despite the benefits social media may provide, there are things that should be avoided. These include: posting comments such as "they're in a better place," especially if those posting are not familiar with the bereaved person/family's beliefs (Hiss, 2021); asking the bereaved invasive, personal questions; and sharing information about the deceased in an online platform. It is the deceased person's closest family members who should be deciding when, what, and how they want to post about their loved one (Hiss, 2021).

Click the links below to learn more about grief and social

#### media:

11 Etiquette Rules You Need for Dealing with Death on Social Media Mourning with Social Media: Rewiring Grief

## 8.5 HEALING FROM COVID-19

#### COVID-19 Related Loss

Much of the media coverage on the COVID-19 pandemic has focused on the number of people who are gravely ill and who have died from the virus. As of April 2022, the worldwide death toll is over six million (WHO Coronavirus Dashboard). Although we see and hear these numbers daily, we rarely hear about those who are experiencing mourning and grief. According to Cadell (2021, para. 11), "it is estimated that for every one person who dies, there are five left grieving those loses." However, as noted in the previous sections of this chapter, grief is not just a reaction to death but can also be tied to other forms of loss.

During the COVID-19 pandemic, many people have experienced loss on multiple levels. There is the



Woman wearing a mask staring out the window during a lockdown.

loss tied to physical, economic, and housing security. There is the psychological toll tied to a lack of emotional and physical connection, relationships, and mental health support that help us through difficult times (Cadell, 2021; CMHA, 2014). We are also losing a sense of predictability in or control over our lives, including our ability to protect our loved ones, especially the most vulnerable (children, elderly) (Weir, 2020). And there are the losses associated with the pandemic's impact on healthcare, education, and world economic stability and peace (Weir, 2020). Not only does postponing, curtailing, or eliminating end-of-life rituals impact both how we mourn the dead and grieve, it impacts how we grieve all of these losses (Cadell, 2021; Phillips, 2021).

#### The Need for a National Grief Strategy

The COVID-19 pandemic has shed light on the importance and necessity of the government implementation of a national grief strategy (Cadell, 2021). This strategy could include public awareness campaigns, educational initiatives, and increased funding for grief-related research. Such a strategy would help us to better understand and deal with grief, recognize grief in ourselves, and better support one another through

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grief (Cadell, 2021, p.). Since the <u>Canadian Grief Alliance (CGA)</u> was formed by the Canadian Virtual Hospice in 2020, it has called for government funding of a national strategy (Cadell, 2021). As of March 2022, the CGA is still waiting for government funding and action. In the interim, every November since 2017, the CHPCA has sponsored a National Grief and Bereavement Day to encourage "Canadians to engage government and all sectors of Canadian society in a national dialogue to identify and support access to necessary resources for those living with grief and bereavement" (CHPCA, n.d.-b, para. 1) (See Grief and Bereavement Day Poster in Chapter Section on Understanding Grief). The importance of the initiative has grown exponentially due to COVID-19.

Click the links below to learn more about grief in relation to the COVID-19 pandemic:

Grief & COVID-19: Mourning Our Bygone Lives Loss, Grief & Healing

## 8.6 CHAPTER SUMMARY

## **Key Summary Points**

- 1. Grief, mourning and bereavement are inter-related concepts tied to loss.
- 2. There are many ways to support people who are grieving. Some of the best ways include calling, texting, or showing up face-to-face. Don't worry about getting it 100% right.

  Reaching out is the important thing.
- 3. Social networking sites/social media have presented new opportunities for those who are grieving to share and express themselves.
- 4. The COVID-19 pandemic has contributed to collective grief among the entire world, with many experiencing losses in various forms. It also sheds light on the need for a national grief strategy.

#### Additional Resources

#### Additional Viewings

TEDx Talks. (May 5, 2017). When someone you love dies, there is no such thing as moving nn – Kelly Lynn [Video]. YouTube.com. https://youtu.be/kYWlCGbbDGI

#### **Additional Readings**

Canadian Mental Health Association (CMHA). (2014). *Grieving*. https://cmha.ca/wp-content/uploads/ 2016/02/Grieving-NTNL-brochure-2014-web.pdf

Centre for Addiction and Mental Health (CAMH). (2018). *Grieving – Where to go when you're looking for help*. https://www.camh.ca/-/media/files/community-resource-sheets/grieving-resources-pdf.pdf

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Canadian Virtual Hospice. (n.d.). Because losing someone is hard. https://mygrief.ca/

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What's your grief. (n.d.). https://whatsyourgrief.com/

## 8.7 REQUIRED COURSE MATERIALS

In addition to the videos and reading links embedded into the chapter, you are required to complete the following course material:

#### **Required Course Viewings**

NBC News. (June 14, 2018). *How grief affects your brain and what to do about it* [Video]. YouTube. <a href="https://youtu.be/eEcaUhxAH2g">https://youtu.be/eEcaUhxAH2g</a>

TEDx Talks (September 9, 2020). The journey of grieving, feeling and healing | Dr. Edith Eva Eger [Video]. YouTube. https://www.ted.com/talks/dr\_edith\_eva\_eger\_the\_journey\_of\_grieving\_feeling\_and\_healing (Watch to 11 minute mark).

#### Required Course Readings

Cadell, S. (February 16, 2021). Coping with loss: We need a national strategy to address grief beyond the coronavirus pandemic. *TheConversation.com*. <a href="https://theconversation.com/coping-with-loss-we-need-a-national-strategy-to-address-grief-beyond-the-coronavirus-pandemic-153824">https://theconversation.com/coping-with-loss-we-need-a-national-strategy-to-address-grief-beyond-the-coronavirus-pandemic-153824</a>

Conrad, M. (June 17, 2021). What is anticipatory grief and ow does it work? *Forbes*. <a href="https://www.forbes.com/health/mind/what-is-anticipatory-grief/">https://www.forbes.com/health/mind/what-is-anticipatory-grief/</a>

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McLeod, A. (October 30, 2017). What Chinese philosophers can teach us about dealing with our own grief. *TheConversation.com*. <a href="https://theconversation.com/what-chinese-philosophers-can-teach-us-about-dealing-with-our-own-grief-85959">https://theconversation.com/what-chinese-philosophers-can-teach-us-about-dealing-with-our-own-grief-85959</a>

## 8.8 CHAPTER ASSIGNMENT

## Grief & Loss & Bereavement Assignment

As you learned in this chapter, although there is a tendency to think of experiences of loss and grief as associated with the death of a loved one or someone we cared for or admired, we experience many other forms of grief and loss in our lives. This chapter's assignment is to create a memory object tied to someone or something you have lost during the COVID-19 Pandemic. It can be any kind of loss you have experienced. It can be the loss of a person you love due to death or other reasons (relocation, end of relationship, disagreement, etc.); loss of connections with people; loss of something you did; loss of parts of your identity; loss of a job; loss of a habit you had; the loss of experiences, etc.

According to artist Alinah Azadeh, when we create memory objects, we "use our hearts, hands, and minds to create small objects that help us to both separate from and honour the things we choose to make our memory objects about" (Craftspace, n.d.). The goal of this creative exercise is to celebrate who/what was lost or those things that we miss, through the process of binding and wrapping of symbolic objects. It is important to complete all chapter materials (chapter content, including all embedded links to readings and videos, and the required course materials) prior to starting the assignment.

VIDEO: Craft in Common: Loss – Wrapping an Object as a Symbol of Loss

#### Steps to Completing the Assignment

- a. Watch the video above (Craftspace. (n.d.). *Craft in Common with artist <u>Alinah Azadeh</u>* [Video]. Vimeo. https://vimeo.com/433631731)
- b. Identify a loss you have had and a symbolic object to wrap, that you wish to use for this assignment.
- c. Gather a piece of fabric and a length of material (e.g., rope, yarn, strip of fabric, etc.) that can be used to bind, as detailed in the video. You can use pieces of fabric or clothing that are personal to you and/or tied to the loss or that you have around your house. You can also go to a local craft or fabric store to find materials that speak to your needs.
- d. Decide if you wish to complete this exercise on your own, with other people you know, and/or others in this course.
- e. Follow Alinah Azadeh's instructions in the video to create your memory object.
- f. Take 2-3 photographs of your completed object that show it from various perspectives, to submit with your assignment.
- g. Write a 500-750 word reflection piece about your experience completing this assignment. Be sure to

identify what type of loss you created the memory object for; what object you wrapped; why you chose the object to wrap; what the process of creating a memory object was like for you, how completing it made you feel, etc.

## Assignment Submissions must Include

- 1. A proper APA style cover page.
- 2. A reflection paper.
- 3. Two-three images of your memory object.

Click this link to view images of Alinah Azadeh's art installation The Gift.

## 8.9 REFERENCES & MEDIA ATTRIBUTIONS

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# CHAPTER 9: MEMORIALS, COMMEMORATION & REMEMBRANCE



Jacqueline Lewis, Jillian Holland-Penney & Jackie Durocher

## 9.0 INTRODUCTION

#### **Chapter Introduction**

There are diverse human means of remembrance and commemoration. We engage in everyday acts of remembrance when we go the cemetery to visit a deceased loved one, or when we light a candle and say a prayer to honour a dead relative on the day of their death. When tragedy strikes our community or our nation, we may gather in symbolic settings with flowers, candles, placards, our voices, or our silence. We may join with others to honour the dead and rally against the injustice at the heart of the tragedy (e.g., lax gun control laws, lack of attention to climate change, a company's poor employee safety standards, government policies or actions, etc.). We may also be motivated to create a memorial to commemorate lives lost. This chapter explores the types and purposes of memorials from the early 1900s to present day. Specific attention is paid to memorials honouring human losses from war, genocide, and pandemics.

#### **Chapter Objectives/Learning Outcomes**

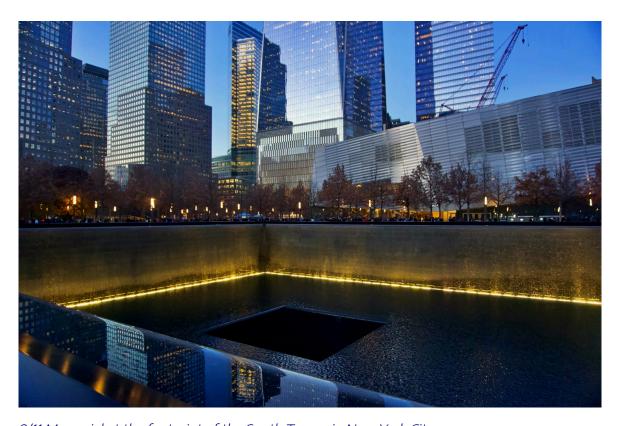
After completing the chapter materials, you should have an understanding of:

- 1. The concepts of memorials, living memorials, commemoration, remembrance, and monuments.
- 2. The different forms that memorials can take, including examples of each.
- 3. The various purposes that memorials serve.
- 4. The changing nature of memorials since the early 1900s, and why those changes have occurred.

## Questions to Think About When Completing Chapter Materials

- 1. Identify two memorials or monuments covered in the course material, one that is more traditional and one that is more contemporary. Based on your experience of viewing the memorials, how would you interpret their meaning and purpose?
- 2. After reviewing the examples of memorials within this chapter, which memorials would you visit in the future and why?
- 3. Identify two key things about traditional memorials that you learned from the course material. Why do you think you had never thought of these things before?
- 4. Thinking about the specific genocides covered in the Chapter on Genocide, what was your response/reaction to learning about the memorials to honour those who were killed?

# 9.1 DEFINING MEMORIALS & COMMEMORATION



9/11 Memorial at the footprint of the South Tower, in New York City.

Memorials, living memorials, commemoration, remembrance, and monuments are interrelated concepts, but it is important to understand the distinctions between them.

#### **Memorials**

Memorials are things created to honour and remember the dead. They "are the products of collective memory of social groups or [of] collective importance of an event, person, or circumstance, linking the past to the present and future" (Attwa, et al., 2022, p. 1). Memorials can take many forms (Bruggeman, 2020). Although some are permanent (e.g., official memorials, grave markers, dedicated park benches, or trees – See bottom right image below) or living creations (e.g., a memorial garden), others can take the form of remembrance gatherings, including the smaller/personal events hosted by families to honour the death of a loved one.

## **Living Memorials**

Living memorials vary in form. They can be "a location or monument where people gather" (Benjamin, June 24, 2020, p. 2). They are memorials that can grow, change, or evolve over time. Examples include: adding panels to the NAMES Project AIDS Memorial Quilt (See Chapter section on Pandemic Memorials); adding names to plaques, such as the ones that are part of the Ian Anderson Hospice Memorial Garden (See top left image below); as well as leaving flowers, notes, teddy bears, etc. at static memorial sites, such as the Vietnam memorial in Washington DC. Living memorials can also be spontaneous in nature, such as those that take shape and grow in the aftermath of acts of violence, accident or mass death events. Examples include the temporary memorials to honour the victims of the Pulse Nightclub shooting in Orlando FL (See top right image below), and those in Minneapolis MN to honour the life and protest the killing of George Floyd by police (See bottom left image below).

#### Commemoration

Commemoration is the act of remembering, honouring or showing "respect to a person or event." Acts of commemoration can include both special actions, like ceremonies or celebrations and "the creation of an object, work of art, writing, music, or a memorial" (Australian War Museum, n.d, para. 1).

#### Remembrance

Remembrance is more than the act of remembering. It is about "keeping a memory alive [of a person or event], or at least not allowing ourselves to overlook...[or forget what has] happened in the past" (COE, n.d., para. 1).

#### **Monuments**

The term monument typically refers to a structure, edifice or a figurative object (e.g., statue, structure, building) that is constructed to commemorate a notable individual or event (Attwa et al., 2022; Bruggeman, 2020). The definition of who or what is considered notable of being remembered is determined by the individuals who commission the work (Murphy, 2021), and thus the subject of contestation and debate (Lewis & Fraser, 1996).





Examples of different types of memorials. Top left: © Ian Anderson House (2020). All rights reserved. Image used with permission.

## 9.2 MEMORIALS & MEMORIALIZATION

## Honouring the Dead

Humans have honoured their dead in a variety of ways over time (Powell, 2018). We mark death often through memorials, with urban landscapes containing a variety of commemorative objects. Some memorials are for individual loved ones. Others are more public in nature, commemorating people and events who are defined as important (e.g., statues, naming of buildings) and/or larger groups of people who died either together or from a common cause (e.g., war, genocide, violence, terrorism, disease, natural disasters, mass causality events, etc.). At their most basic level, memorials to loved ones serve to remind us of the person(s) we have lost, the frailty of life, and/or the inevitability of death. Larger public memorials play a broader range of roles including: honouring, commemorating, and remembering the dead; aiding the understanding significant human events; the construction of official and counter narratives; creating symbolic representations; and stimulating dialogue (Clark, 2013; Cudny & Appelblad, 2019).

#### The Birth of Modern-Day Memorials

The birth of modern-day forms of memorial and commemoration began after 1918 (Powell, 2018). Most of the WWI memorials constructed in the years between the two world wars relied on more traditional modes of representation and symbolism. They borrowed heavily from ancient Greece and Rome, and spoke to the conservative orientation of the time (Manitoba, n.d.). Many of the monuments created are statuesque in nature, often depicting a male person or persons atop a pedestal. These strongly gendered, conservative expressions of public remembrance are attempts "to set our understanding of what has happened in stone, beyond interpretation, investigation and critique" (Younge, 2021, para 1; Mitchell, 2003). The nature and form of these historical monuments, including who is depicting and who is not, is intended to "to secure narratives of nation-building" patriotism, and white, male/patriarchal power (Murphy 2021, p.1147; Mitchell, 2003).

### **Contested Memory**

Public monuments and memorials can be powerfully symbolic. Having a white, rich, man memorialized in metal or stone, set on a pedestal in a central public space "makes a deliberate, eminently visible claim about to whom the space belongs, and thus who belongs here and who does not" (Murphy, 2021, p.1149). Efforts to

write the past in stone, however, are destined to provoke controversy, hostility or fade into irrelevancy (Benjamin, June 24, 2020). Since history is a social construct (Kasabavo, 2008), who, what, and in what format someone or something is memorialized is subject to re-evaluation, re-examination, reinterpretation, and debate (Lewis & Fraser, 1996). The meaning attributed to more static older monuments and memorials, and the historical people and events they represent, is therefore open to contestation, something we have increasingly bore witness to since the mid-1960s (Benjamin, June 24, 2020). In recent years, there have been numerous headlines about the defacing and destruction (Bruggeman, 2020) of regional and national monuments (e.g., Lurie, September, 8, 2020) and the call for the removal of statues (e.g., Smith, October 17, 2021) that were erected to honour people and/or events whose celebrity was built on colonization and/or the crushing of racialized and Indigenous peoples and their cultures (Grovier, June 12, 2020, para 7). The hotly contested nature of the politics of memory is not new. The basis of the contestation is "not just what monuments are, but more importantly, what monuments are intended to do for and within the body politic" (Murphy, 2021, p.1144).

## Contemporary Memorials and Counter Narratives

Memorials rarely reflect consensus and are never silent (Bruggeman ,2020). In most contemporary memorials we witness a shift away from traditional motifs toward memorials and monuments that are more abstract in their design (Kerby, et al., 2021). As noted by Kerby (2021, p.7), "abstraction is better placed to challenge hegemonic views of the past...and...with the complexity of historical events." This purposeful alteration in memorial style is meant to change the relationship between the memorial and the audience. Rather than instructing audiences as to what to think, feel, and remember, contemporary memorials and monuments are typically designed to embrace ambiguity and resist closure, thereby encouraging viewers to actively engage in reflection and interpretation (Kerby et al., 2021). Many contemporary memorials not only engage with the viewer, they also symbolically and metaphorically challenge or counter existing relations of power and official narratives regarding what and who should be memorialized (Lewis & Fraser, 1996), demanding inclusivity in collective memory (Bruggeman, 2020). In doing so, such efforts by special interest and grassroots groups serve to initiate dialogue, and in the process engage the viewer as an active participant in the reconstruction of public memory (Kerby, 2021; Lewis & Fraser, 1996).

## 9.3 OFFICIAL MONUMENTS & CANADIAN WAR MEMORIALS

Official memorials serve as reminders to the public of significant historical events and people (Bonder, 2009). According to the Government of Canada (July 6, 2020), official memorials consist of public monuments, ceremonies, or testaments that pay tribute to important persons or events. Remembrance Day, observed each year in Canada on November 11, serves to remember both past and ongoing war-related sacrifices (NSLA, n.d.). It is celebrated through national ceremonies, the wearing of poppies, and the reading of "In Flander's Fields" by Lieutenant-Colonel John McCrae (NSLA, n.d.).

War memorials are another type of official memorial used around the world to commemorate the events of passed wars and the lives that were lost. The Canadian War Museum, for example, memorializes the lives of Canadians who have been impacted across all wars throughout history (Canadian War Museum, n.d.). The "Tomb of the Unknown Soldier", near the parliament buildings in Ottawa, holds the unidentified remains of a Canadian solider repatriated on May 23, 2000 (Canada, n.d.-d) (there are similar memorials around the globe, including a Tomb of the Unknown Solider in Arlington National Cemetery in Washington DC). Some of the most significant war memorials in Canada honour those who lost their lives in WWI. For instance, the Peace Tower of Canada's Parliament Hill was built to memorialize WWI losses and includes Books of Remembrance that contain the names of those who have died fighting for Canada since Canadian Confederation (Canadian War Museum, n.d.). There are also Canadian memorials that honour specific groups of veterans or other people from Canada who served in various wars (e.g., The National Aboriginal Veterans Monument, The Nurses' Memorial).

#### View the following slideshow to see different examples of Canadian War memorials:



One or more interactive elements has been excluded from this version of the text. You can view them online here: <a href="https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=955">https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=955</a>

Canadian war memorials reinforce the notion of patriotism and a common sense of belonging, tied to military service and the lives lost in the battle for the freedom of the nation (Powell, 2018). WWI monuments, especially those constructed in the years between the two World Wars, mark the start of an age of memorialization, which framed the War as part of a national coming of age. At the end of WWI, many

Canadians had family members who would never return from the battlefield, as dead bodies were not brought home. An effort was made to identify and register all graves for British Commonwealth citizens (which included Canadian's) and the moving of their bodies to Imperial War Cemeteries in Europe (Manitoba, n.d.). These factors precipitated the construction of Canadian war memorials both abroad and at home (Manitoba, n.d.).

WWI memorials were meant to represent the values of the time in which they were built and the views of the people who commissioned and built them. These memorials provided a justification of the war, consoled citizens, and helped construct Canadian nationalism (Powell, 2018). The official site of the Battle at Vimy Ridge (1917), the eventual location of the Canadian National Vimy Memorial in France, serves as part of the foundation for Canadian national identity. The battle has been (and still is) referred to as "the birth of a nation" and as "Canada's coming of age", because it was the first battle in which members from all Canadian troops fought side-by-side as a single Corp and succeeded in their mission (CBC News, April 6, 2017). According to Powell (2018, p. 40), "the Great War provided an opportunity to create a national consciousness that would unite a deeply divided nation under a single Canadian identity with a single collective national history."

Click the link to learn more about the importance of remembering and memorializing war: The World Remembers

#### VIDEO: Why the Battle of Vimy Ridge Matters

The following video provides some history on the Battle of Vimy Ridge in WWI and explains why it is important to remember that event.



One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=955#oembed-1

## 9.4 GENOCIDE MEMORIALS, COMMEMORATION & REMEMBRANCE



Image of one part of the Dutch Homomonument, a memorial to members of the LGBTQ community killed by the Nazis during WWII.

"Genocide is an internationally recognized crime where acts are committed with the intent to destroy, in whole or in part, a national, ethnic, racial, or religious group" (United States Holocaust Memorial Museum, n.d., para. 1).

Genocide memorials take a number of forms, including: memorial museums (e.g., Unites States Holocaust Memorial Museum in Washington DC); carefully preserved historical landmarks (e.g., Anne Frank House in Amsterdam, The Netherlands; the Nazi death camp <u>Auschwitz-Birkenau</u>); monuments (e.g., The Tsitsernakeberd Memorial Complex in Yerevan, Armenia, see image below; The Homomonument in Amsterdam, The Netherlands, see image above and to the right); and designed physical spaces (e.g., The National Holocaust Museum in Ottawa, Canada, see image below; The Berlin Holocaust Memorial in Germany, view through link at bottom of page).



Image of one part of the Dutch Homomonument, a memorial to members of the LGBTQ community killed by the Nazis during WWII.

These memorials, in their various forms, are "dedicated to historical events of mass suffering" (Lachenro, 2017, p. 1). They work to increase public knowledge regarding the atrocities committed against specific targeted groups of people (see Chapter on Genocide). Some, such as the Kigali Genocide Memorial in Rwanda, also serve as the final resting places for victims of the genocide (KGM.rw). Despite the uniqueness of each, genocide memorials are meant to serve as agents of reflection and dialogue (Bonder, 2009), "to function as a form of symbolic reparation for the harm done,...and a guarantee of its non-reoccurrence" (Whigham, 2017, p. 107). The knowledge and information shared, the visceral experience of visiting memorials and participating in witnessing atrocities inflicted on humans by other humans, the commemoration and honouring of lives lost, are all meant to "remind, warn, advise, and call to action" (Bonder, 2009, p. 67) and to ensure we never forget.



Image of the The Tsitsernakeberd Memorial Complex in Yerevan, Armenia.

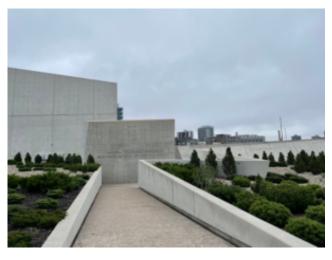


Image of the National Holocaust Monument in Ottawa, ON.

Click the following links below to learn more about memorials to genocide:

On Memory, Trauma, Public Space, Monuments and Memorials

Ständige Konferenz der Leiter der NS-Gedenkorte

#### im Berliner Raum

(Instructions: click on all 4 images in the center white block to learn more about the 4 monuments that are part of the Berlin Holocaust Memorial. After each click, read the white text block contents and scroll through the photo series within each block using the side arrows. Be sure to switch the language preference in the top right).

## 9.5 INDIGENOUS MEMORIALS, COMMEMORATION & REMEMBRANCE IN CANADA

#### "Every Child Matters"

In 2021, Canadians were shocked to learn of the bodies being exhumed on the properties of previous Residential Schools across the country (Voce et al., September 6, 2021). This shock gave rise to many grassroots memorials in support of Indigenous communities in Canada (Smith, September 28, 2021). The "Every Child Matters" slogan has been used on Orange Shirt Day (which became officially known as the National Day for Truth and Reconciliation in 2021). This Memorial Day, held each year on September 30th, and the symbolic wearing of orange shirts, are the basis of grassroots efforts that serve to remember and honour the children who died in Canadian Residential Schools, the survivors, and their families (Smith, September 28, 2021, Voce et al., September 6, 2021). The memorial provides a counter narrative to official Canadian polices that resulted in genocide and a



Image of banners commemorating the National Day for Truth & Reconciliation to memorialize the lives lost and impacted by the Canadian Residential School System.

continued failure on the part of the federal government to provide an adequate response (e.g., release of government Residential School documents/records; cease court actions by the federal government to fight a Canadian Human Rights Tribunal ruling regarding the provision of services to Indigenous children living on reserves, etc.) (MacDonald, June 24, 2021). In 2021, in honour of Orange Shirt Day, a living monument to the Residential School victims was created out of children's toys and shoes on Parliament Hill in Ottawa. It served as a powerful visualization of losses endured by Canadian Indigenous peoples (Perez, 2021). The living memorial stayed in place for three weeks' time (Parliament Hill Memorial, October 22, 2021).

## Murdered and Missing Indigenous Women and Girls (MMIWG)



Image of art installation by Indigenous artist Jaime Black to commemorate and offer remembrance to the MMIWG.



Interactive image of the BC Memorial Quilt honouring the lives of the MMIWG in Canada. Click on image to scroll through closeups of the individual pieces that make up the Quilt.

Indigenous woman and girls go missing or are found

murdered at alarming rates, unparalleled to any other community group in Canada (MMIWG, 2019; Native Women's Wilderness, n.d.) (See Chapter on Genocide). This problem went largely unrecognized for many years, despite numerous cries for help from Indigenous communities (NWAC, n.d.). There have been several grassroots and living memorials created to honour the missing and murdered women and girls, draw attention to the crisis, as well as provide a counter narrative to that provided by government and police. The Red Dress project is one example that draws attention to the racialized and gendered disparity impacting Canadian Indigenous women and girls (Black, n.d.). Another example is the BC Memorial Quilt (See image above) that

Click the links below to look at some of the artistic representations that memorialize the loss of these missing and murdered Indigenous women and girls:

was created by 90 families whose female relatives are missing or were murdered (British Columbia, 2016).

Monuments Honouring MMIWG

<u>B.C. Memorial Quilts Honouring Indigenous Women and Girls</u> (Scroll for close—up memorial content of the individual patches of the larger quilt shown above).

 $\underline{\textit{Courage} \mid \textit{MMIWG}} \text{ (Instructions: click view full project, scroll through images, and read stories)}.$ 

## 9.6 PANDEMIC MEMORIALS, COMMEMORATION, & REMEMBRANCE

#### **HIV/AIDS**



*Image of AIDS memorial in Barbara Hall Park, Toronto ON.*©The 519. All rights reserved. Image used with permission.

The NAMES Project AIDS Memorial Quilt, an enormous, travelling, grassroots, living memorial, "is a monumental testament to lives lost to AIDS" (Lewis & Fraser, 1996, p. 434). The Quilt was conceived of in 1985 and has steadily grown since then. It is so large now that it cannot be displayed in its entirety, as occurred regularly in the late 1980s through the 1990s (see photo to right). Currently, over 110,000 people who have died from AIDSrelated illnesses are represented on the 50,000 individual three-by-six-foot panels that make up the Quilt (National AIDS Memorial, n.d.). The Quilt continues to grow as panels are made and contributed by families and friends. Through the signature squares at Quilt displays, viewers are



Image of the NAMES Project AIDS Memorial Quilt on display in Washington DC, October 1992.

offered an opportunity to express themselves and/or record their experiences of the Quilt (Lewis & Fraser, 1996). This grassroots memorial serves to educate and promote awareness about HIV/AIDS and the HIV/ AIDS pandemic (Balsamo & Ferreira, 2020). It also serves as a political tool and a therapeutic outlet. Its existence, growth and annual displays are a means by which to illustrate the magnitude of the loss of life, to counter official narratives and silences, as well as bring attention to the lack of government response to the health crisis (Barajas, 2021; Lewis & Fraser, 1996). Due to the Quilts size, and the fact that each individual panel is the size of a grave, the Quilt is also a powerful symbol to commemorate the dead. Quilt exhibits provide a space for people to gather and grieve together, while also promoting social action and awareness of the pandemic (Lewis & Fraser, 1996).

#### Click the link below and scroll down to view the individual stories of people represented on the Quilt panels

Forty Years: Forty Powerful Quilt Stories

#### VIDEO: Video Essay of the AIDS Memorial Quilt: Origins, Legacy, Futures

The following video provides some of the history and significance behind the AIDS Memorial Quilt.



One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=971#oembed-1

#### COVID-19 Pandemic



Image of COVID-19 Memorial Field of White Flags at the Washington Monument, September 2021.

Grassroots memorials have begun appearing throughout the world to honour lives lost during the COVID-19 pandemic (Barajos, 2021). These memorials allow people to remember and mourn their loved ones who have died, whose lives they may not have been able to adequately honour due to COVID-19 public health restrictions. COVID-19 memorials also provide the public with an opportunity to grieve the various losses they have experienced throughout the pandemic (e.g., freedom of movement and association, loss of job, loss of home, loss of social life, etc.) (Barajos, 2021) (See Chapter on Plagues & Pandemics). Since the COVID-19 pandemic is ongoing, many of these memorials and commemorations take the form of living memorials. We see memorial flags, hearts, and ribbons as symbols for the pandemic around the world (Barry, October 2021). One large scale COVID-19 memorial, representing the more than 740,000 Americans who had died as of October 2021 (Nearly 1 million US deaths as of April 2022), covered the National Mall in Washington DC (See photo above) (Barry, October 2021). In London UK, the

<u>National COVID Memorial Wall</u> is a living memorial, providing space for bereaved individuals to paint red and pink hearts in remembrance of their loved ones (*The National COVID Memorial Wall*, n.d.).

#### Click the links below to learn more about COVID-19 and memorials:

<u>How Do You Mourn a Pandemic?</u> <u>Why We Need COVID Memorials Now – And For The Future</u>

## 9.7 CHAPTER SUMMARY

### **Key Summary Points**

- 1. Although memorials, living memorials, commemoration, remembrance, and monuments are interrelated concepts, it is important to understand the distinctions between them.
- 2. Memorials can take a variety of forms: personal, official, grassroots, counter, living or some combination.
- 3. Memorials serve a variety of purposes: honouring, commemorating, and remembering the dead; aiding in an understanding of significant human events; the construction of official and counter narratives; the creation of symbolic representations; and stimulating of dialogue. Through tying together the past and the present, they encourage viewers to critically engage with past events.
- 4. The creation of monuments and memorials has steadily grown since the end of WWI, with the style and form changing from static structures, statues and edifices to more abstract designs. Rather than instructing audiences as to what to think, feel, and remember, contemporary memorials and monuments are designed to embrace ambiguity and resist closure, thereby encouraging viewers to actively engage in reflection and interpretation.

#### **Additional Resources**

Canada. (n.d.-a). Memorials in Canada. <a href="https://www.canada.ca/en/services/defence/caf/militaryhistory/memorials-monuments-cemeteries/memorials-canada.html">https://www.canada.ca/en/services/defence/caf/militaryhistory/memorials-monuments-cemeteries/memorials-canada.html</a>

Gurler, E. & Ozer, B. (August 20, 2013). The effects of public memorials on social memory and urban identity. *Social and Behavioral Sciences*, 82, 858-863. <a href="https://doi.org/10.1016/j.sbspro.2013.06.361">https://doi.org/10.1016/j.sbspro.2013.06.361</a>

Lewis, J. & Fraser, M. (December 1996). Patches of grief and rage: Visitor responses to the NAMES Project AIDS Memorial Quilt. *Qualitative Sociology*, 19(4), 433-451. https://doi.org/10.1007/BF02393368

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Popescu, D. & Schult, T. (2020). Performative Holocaust commemoration in the 21st century. *Holocaust Studies*, 26(2), 135-151. https://doi.org/10.1080/17504902.2019.1578452

## 9.8 REQUIRED COURSE MATERIALS

In addition to the videos and reading links embedded into the chapter, you are required to complete the following course material:

#### **Required Course Viewings**

The Tragically Hip. (December 6, 2021). The Tragically Hip — Montréal (Live from Molson Centre, Montreal, 2000) [Video]. YouTube. <a href="https://youtu.be/Palb52ILCgw">https://youtu.be/Palb52ILCgw</a>

#### Required Course Readings

British Columbia. (May 10, 2016). *B.C. unveils quilt honouring Indigenous women and girls*. https://news.gov.bc.ca/releases/2016ARR0033-000749

Bruggeman, S. (2020). Memorials and monuments. *Parks Stewardship Forum*, *36*(3): 465–470. https://escholarship.org/uc/item/9m20m5jp

Guichaoua, A. (May 5, 2021) In Rwanda genocide commemorations are infused with political and diplomatic agendas. *TheConversation.com*. <a href="https://theconversation.com/in-rwanda-genocide-commemorations-are-infused-with-political-and-diplomatic-agendas-160283">https://theconversation.com/in-rwanda-genocide-commemorations-are-infused-with-political-and-diplomatic-agendas-160283</a>

McPhee, D. (April 23, 2018). The National Day of Mourning is a reminder workplaces should be safe. *TheConversation.com*.

https://theconversation.com/the-national-day-of-mourning-is-a-reminder-workplaces-should-be-safe-95186

Monuments honouring MMIWG. (2021). KairosCanada. <a href="https://www.kairoscanada.org/missing-murdered-indigenous-women-girls/monuments-honouring-mmiwg">https://www.kairoscanada.org/missing-murdered-indigenous-women-girls/monuments-honouring-mmiwg</a>

Schwab, R. (2004). Acts of remembrance, cherished possessions, and living memorials. *Generations: Journal of the American Society of Aging*, 28(2), 26-30. https://www.jstor.org/stable/26555301

The importance of remembrance. (n.d.). The Remembrance Process. <a href="https://www.remembranceprocess.com/">https://www.remembranceprocess.com/</a> why-remembrance/

## 9.9 CHAPTER ASSIGNMENT

#### Memorials, Commemoration & Remembrance Assignment

This chapter's materials focused on several types of memorials (official, grassroots, and personal). For this assignment, you are required to identify an official or grassroots "working memorial" (Bodner, 2009, p. 66 & 67) notfocused on within the course materials and conduct research on it. Then, choose between two assignment options: (1) create a voiceover slide presentation (see instructions for Option 1 below); or(2) write a short essay (see instructions for Option 2 below) based on your research that addresses a series of questions. The working memorial can be one associated with the topic you chose for your genocide assignment, or it can memorialize something altogether different. It is important to complete all chapter materials (e.g., chapter content, including all embedded links to readings and videos, and the required course materials) prior to starting the assignment.

#### Options for Assignment #9

#### Option 1

Select a memorial and conduct research on it (as detailed above). Then, create a voiceover slideshow presentation using PowerPoint, Keynote, Prezi, or Google Slides that addresses the series of questions outlined below.

#### Assignment Formatting, Style & Length for Option 1

- Clearly indicate the memorial that is the focus of your presentation on your cover page slide.
- Be sure to include images and photographs (these must be properly sourced).
- Videos cannot be included in the presentation.
- Presentation must be 3-5 minutes in length (no longer than 5 minutes).
- Presentations created in PowerPoint, Keynote, or Google Slides should have between 6 and 8 content slides (10 slides maximum including a title page slide and a reference slide).
- Due to the expanding nature of each Prezi slides, assignments created in Prezi will likely have fewer than the 6 to 8 main slides (in order to fit within the presentation time limit).
- Presentations must include a cover slide that identifies the topic of the presentation, whose presentation it is, and the course number.

- Presentations must include a reference slide (APA format).
- Use APA for in-text citation style on slides and for the reference slide.
- Avoid putting too much text on a slide, as the voice over allows you to elaborate.
- Paraphrase and use point form as opposed to relying on direct quotes.
- Proofread slides for typographical errors and to make sure slide content is clear, well written, and intelligible.
- When recording your voiceovers: speak slowly and clearly. If you are rushing through your slide-notes, then you have too much content. It is usually best to record your voiceover for slides one at time. This enables you to check how you sound, make adjustments and re-record smaller amounts of your presentation.
- Submission must be in MP4 format (use "save as" or "export to" to convert to MP4 format or do a Google search for instructions).

#### Steps to Completing Option 1 Assignment

- a. Identify a "working memorial" (Bodner, 2009) that is not among those focused on in the chapter materials.
- b. Research the identified memorial and find a minimum of 6 sources, in addition to the chapter materials, to help you to answer the assignment questions below. No more than 2 of the sources can be media-type resources. The remainder must be academic sources (i.e., journal articles and books) and reports from government and non-governmental organizations (NGOs).
- c. Prepare a 3-5 minute presentation (see Assignment Formatting, Style & Length above for limits on number of slides for presentation submissions).
- d. In the slides, address the questions below. Questions do not need to be answered in order. Some can/ should be addressed on the same slide as others.
- e. Support the points/arguments on slides with APA in-text citations that reference the materials you have found in your research, and those that are in the chapter. <u>In-text citations to support your points/</u> arguments are essential and required. Be sure to use a diverse range of materials as opposed to relying heavily on one, or a few sources.
- f. Develop an APA style reference section for all material cited and include that as your final slide (only material cited in the body of the presentation can be included in a reference section).

#### The following must be submitted for Option 1 assignments

• A MP4 version of the slideshow presentation as detailed above.

#### Assignment Questions for Option 1

- 1. What is the name of the memorial?
- 2. Where is the memorial located?
- 3. What/who does it memorialize/commemorate?
- 4. When was it made available for public viewing?
- 5. What makes it a memorial (see Bodner, 2009 and Bruggeman, 2020)?
- 6. Who is the intended audience?
- 7. What message is the memorial meant to convey to its intended audience?
- 8. Is this an official or grassroots memorial? Explain.
- 9. How does the memorial and its design establish dialogues with, and present questions about, the past, the present, and future (Bodner, 2009)?
- 10. What does the memorial leave out?
- 11. Is this memorial for a contested event or is there relative consensus regarding the event being commemorated?
- 12. If there is relative consensus, can you envision a time when that may not be the case? Explain.
- 13. If it is contested, has it always been contested? If so, why do you think that is the case? If not, when, why and how did the re-definitional process begin? What changed?
- 14. Is there a consensus over how the event is memorialized (the memorial design, location, etc.) or are there disagreements (i.e., is it design and/or location contested)? Elaborate and explain. Be sure to make use of the Bodnar (2009) and Bruggeman (2020) readings when framing your answer.
- 15. How is this memorial an example of a working memorial? Be sure to make use of the Bodnar (2009) reading when framing your answer.

#### Option 2

Select a memorial and conduct research on it (as detailed at the top of the assignment). Then, write a short essay (1000 words) that addresses the questions outlined below.

#### Assignment Formatting & Style for Option 2 Report

- Assignments formatting requirements: Arial 12-point font; 1 inch/2.54 centimeter margins; single spaced; APA in-text citation style, reference section and cover page.
- Use proper essay/paragraph style.

- Clearly indicate which memorial you have chosen for your assignment.
- Paraphrase as opposed to relying on direct quotes.
- Proofread your submission to make sure it is clear, well written, and intelligible.

#### Steps to Completing Option 2 Assignment

- a. Identify a working memorial that is not focused on in the chapter materials.
- b. Research the identified memorial and find a minimum of 6 sources (in addition to the chapter materials) to help you to answer the assignment questions below. No more than 2 of the sources can be media-type resources. At least 2 of your sources must be from academic sources (i.e., journal articles and books). The remainder can come from online reports from government and non-governmental organizations (NGOs).
- c. Find 2 or 3 photos of the memorial.
- d. Write a 1000-word essay (give or take 100 words) on the memorial you have identified that answers the questions below (the questions need to be addressed in your paper, but do not need to be answered in
- e. Support the points/arguments you make in your answers with in-text citations that reference the materials you have found in your research, and those that are in the chapter. In-text citations that support your points/arguments are essential and required. Be sure to use a diverse range of materials as opposed to relying heavily on one, or a few sources.
- f. Develop an APA style reference section for all material cited (only material cited in the body of the paper can be included in a reference section).

#### The following must be submitted as part of Option 2 assignments

- i. A proper APA style cover page.
- ii. A written report addressing the questions below.
- iii. A proper APA reference section that contains all the material cited in the assignment.

#### Assignment Questions for Option 2

- 1. What is the name of the memorial?
- 2. Where is the memorial located?
- 3. What/who does it memorialize/commemorate?
- 4. When was it made available for public viewing?
- 5. What makes it a memorial (see Bodner, 2009 and Bruggeman, 2020)?
- 6. Who is the intended audience?
- 7. What message is the memorial meant to convey to its intended audience?

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- 8. Is this an official or grassroots memorial? Explain.
- 9. How does the memorial and its design establish dialogues with, and present questions about, the past, the present, and future (Bodner, 2009)?
- 10. What or who does the memorial leave out?
- 11. Is this memorial for a contested event or is there relative consensus regarding the event being commemorated?
- 12. If there is relative consensus, can you envision a time when that may not have been the case? Explain. If it is contested, has it always been contested? If so, why do you think that is the case?
- 13. If it is contested, has it always been contested? If so, why do you think that is the case? If not, when, why and how did the re-definitional process begin? What changed?
- 14. Is there a consensus over how the event is memorialized (the memorial design, location, etc.) or are there disagreements (i.e., is it design and/or location contested)? Elaborate and explain. Be sure to make use of the Bodnar (2009) and Bruggeman (2020) readings when framing your answer.
- 15. How is this memorial an example of a working memorial? Be sure to make use of the Bodnar (2009) reading when framing your answer.

## 9.10 REFERENCES & MEDIA ATTRIBUTIONS

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Anne Frank Museum. (n.d.). https://www.annefrank.org/nl/

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Barry, C. (October 2021). A world remembers: Memorials honour COVID-19's five million dead. *CTV News*. <a href="https://www.ctvnews.ca/health/coronavirus/a-world-remembers-memorials-honour-covid-19-s-five-million-dead-1.5645209">https://www.ctvnews.ca/health/coronavirus/a-world-remembers-memorials-honour-covid-19-s-five-million-dead-1.5645209</a>

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Bonder, J. (May 19, 2009). On memory, trauma, public space, monuments and memorials. *Places*, 21(1), 62-69. <a href="https://escholarship.org/uc/item/">https://escholarship.org/uc/item/</a>

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Canada. (n.d.-b). *National Aboriginal Veterans Monument*. <a href="https://www.veterans.gc.ca/eng/remembrance/memorials/national-inventory-canadian-memorials/details/7972">https://www.veterans.gc.ca/eng/remembrance/memorials/national-inventory-canadian-memorials/details/7972</a>

- Canada. (n.d.-c). *Nurses' Memorial*. https://www.veterans.gc.ca/eng/remembrance/memorials/national-inventory-canadian-memorials/details/9363
- Canada. (n.d.-d). *Tomb of the unknown soldier*. <a href="https://www.veterans.gc.ca/eng/remembrance/memorials/">https://www.veterans.gc.ca/eng/remembrance/memorials/</a> <a href="mailto:national-inventory-canadian-memorials/details/9367">national-inventory-canadian-memorials/details/9367</a>
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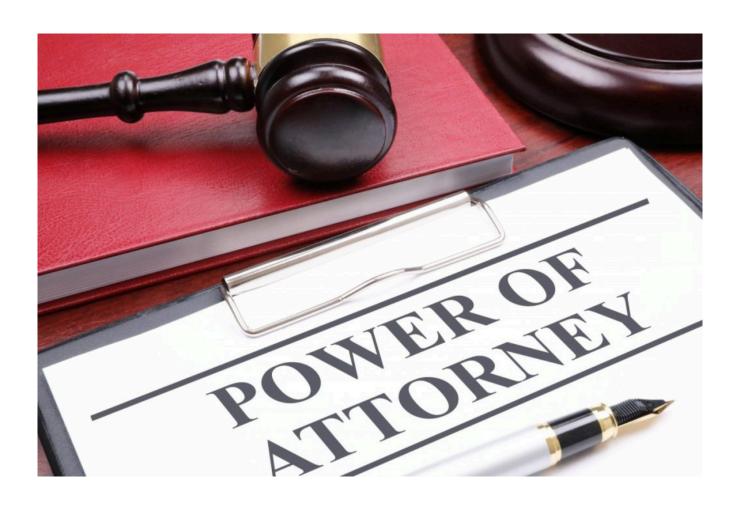
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# CHAPTER 10: ADVANCED DIRECTIVES & PLANNING FOR DEATH



Jacqueline Lewis

## 10.0 INTRODUCTION

#### **Chapter Introduction**

Since the beginning of Chapter 1 (Let's Talk about Death and Dying), the importance of having death-related conversations has been a common theme. Practices tied to being more death positive and the death positivity movement include: having general conversations about death and end-of-life related topics with those around us (hosting or attending a Death Cafe or Death with Dinner event); paying tribute to lives lost through visiting memorials; showing up and being present for people who are grieving the loss of loved one; helping foster compassionate communities though shovelling the walks of an elderly neighbour; sitting down with our loved ones for an open conversation about everyone's values and wishes for end-of-life care. The next step is to actually sit down and make end-of-life care plans including Advanced Care Plans, appointing substitute decision makers, and creating Wills. This chapter explores the development of Advanced Care Plans, Wills, and Powers of Attorney. It also covers choosing substitute decision makers and the importance of having open conversations, so that everyone's end-of-life wishes can be honoured.

## **Chapter Objectives/Learning Outcomes**

After completing the chapter materials, you should have an understanding of:

- 1. Advanced Care Plans, what they are, the steps to developing one, and the importance of having one.
- 2. Appointing a Substitute Decision Maker (SDM), their roles and powers, and things to consider when selecting one.
- 3. The different types of Powers of Attorney, what they are, why they are important, and what powers they give to the person appointed.
- 4. The types of work that must be done when someone dies.
- 5. The importance of having "the conversation" with loved ones (and SDMs) in advance, while we are healthy.

## Questions to Think About When Completing Chapter Materials

- 1. What things would you want in your advanced care plan?
- 2. Who do you think you would select as your substitute decision maker? What are your reasons for selecting this person? How are they best positioned to know your values and wishes and to honour them?
- 3. Think of the assets you may have (e.g., money in the bank, a car, a computer or tablet, a smart watch or phone, jewellery, etc.). Who would you want to leave these things to? How can you make sure that this would occur if something happened to you? Who would make sure that that happened?
- 4. Think of what you would like to ask for or share with your family during a conversation about death and end-of-life wishes. How could you start that conversation?

## 10.1 ADVANCED CARE PLANS

Advanced Care Plans (ACP) are part of being "an empowered patient and caregiver" (Dying with Dignity Canada, 2021).

#### What is Advanced Care Planning?

- It is engaging in the development of an advanced plan for future health and medical decision-making, in preparation for when you may be unable to make those decisions for yourself.
- It is about having incredibly important conversations about your values and wishes about illness and end-of-life care, with your substitute decision maker (SDM) (see next chapter section for details) and other loved ones.
- It is about planning for the future when you may not be able to speak for yourself.
- It addresses the questions of who will make medical decisions on your behalf.
- It is about developing a shared understanding with your SDM of your values and wishes to guide them with possible future health care decisions for you, including the refusal of suggested medical treatments.



Refusal of Treatment Form.

#### What is Involved in Creating an ACP?

Creating an ACP involves 5 things: thinking, learning, deciding, talking, and recording (Advanced Care Planning, n.d.) (See video Advance Care Planning link below for details). Once you have a recorded ACP, it is important to regularly review and update it, to make sure that it continues to accurately reflect your wishes (Advanced Care Planning, n.d.; Dying with Dignity Canada, 2021), and to keep your SDM apprised of any changes. ACPs are part of being "an empowered patient and caregiver" (Dying with Dignity Canada, 2021).

#### What are the Benefits of Having an ACP?

- They help ensure that our health and end-of-life wishes are known and can be honoured.
- They help reduce the stress and anxiety of the person who created the APC.
- They help reduce the stress and anxiety of loved ones and substitute decision makers (SDMs), who are responsible for making decisions for the holder of the ACP. They can also help reduce caregiver stress and anxiety both before and after the death of the person being cared for.

(Advanced Care Planning, n.d.)

Click the links below to learn more about advanced care planning:

#### Other End-of-Life Options

#### Advanced Care Planning: What You Need to Know

#### VIDEO: Advance Care Planning in Canada – Short From Documentary

This video explains what is involved in advanced care planning.



One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddyingvls1/?p=987#oembed-1

# 10.2 SUBSTITUTE DECISION MAKER & POWER OF ATTORNEY FOR PERSONAL CARE

#### VIDEO: Advance Care Planning

This short video provides a quick overview of Advanced Care Planning and choosing a Substitute Decision Maker.



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As part of advanced care planning, it is important to appoint in writing one or more Substitute Decision Maker(s) (SDM) via a Power of Attorney for Personal Care (POAPC). In Ontario, a SDM is referred to as an Attorney for Personal Care (APC) (Dying with Dignity Canada, 2021). A POAPC is a legal document that identifies your substitute decision maker(s) and gives them the legal power to make health and medical decisions on your behalf when you are unable to do so yourself. An SDM/APC is a person (or more than one person) who you authorize through a POAPC to speak for you when you are unable to do so (Advanced Care Planning, n.d.).

As SDMs/APCs have the responsibility to make future health and medical decisions for you, it is important they have a clear understanding of your values and wishes to help guide their decisions (Advanced Care Planning, n.d.). Conversations about end of life and death, as well as your values and wishes around illness and end of life, with your loved ones are essential. These conversations not only help you to assist the people around you to understand the types of care you would/would not want in certain situations., they can also help you identify the person(s) most likely to honour your wishes. The person(s) you choose to be your substitute decision maker(s) should be people "who know you well, will respect your beliefs or values, and who you trust to carry out your wishes" (Dying with Dignity Canada, 2021).



Ontario Power of Attorney for Personal Care Form.

Click the links below to learn more about selecting an SDM. The third link is to a document that helps you to lay out your advanced care directives and select an SDM/APC (The completion of this document is the basis of the assignment for this Chapter):

Engaging in Advanced Care Planning for COVID-19
What is Advance Care Planning?

Make an Advanced Care Plan

## 10.3 WILLS & POWER OF ATTORNEY (FOR PROPERTY)

Wills are important legal documents to have if you have any assets. These documents are meant to provide clear instructions as to how you want your assets to be distributed. They are the only means by which to ensure your wishes about the distribution of your assets are honoured. Although you can write your own Will or use online services to construct one, it is important to make sure your Will is clear. If not, it can become subject to Court scrutiny, which costs time and money (Law Society of Ontario, 2012).

There are two types of Power of Attorney (POA) for financial matters, general and durable. These are legal documents that authorize another person to act on your behalf with regard to the management of your assets (finances/money and property). A General Power of Attorney authorizes a person to act on your behalf for financial (including business) and legal matters. This type of POA, however, ends the moment you become cognitively incapacitated or die. A Durable Power of Attorney gives the same authorization to a person as a General POA, but a Durable POA continues if you become cognitively incapacitated or die (Canada, n.d.-c).

According to the Law Society of Ontario (2012), POAs are legal documents that come into effect the moment you sign them. By creating a Durable POA, you are engaging in advanced planning. The goal is to have a plan in place in case you become incapacitated and can no longer make financial decisions for yourself (temporarily or permanently). The Law Society of Ontario advises choosing the person identified in the POA document carefully. The person should be someone that you trust implicitly to act on your behalf.

#### VIDEO: Your Law – Wills & Estates

In this video members of the Law Society of Ontario explain the importance of Wills and Powers of Attorney (for financial matters).



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## 10.4 AFTER DEATH WORK

As soon as a loved one dies, there is much work to be done. In addition to all the decisions that need to be made about disposal of the body, end of life ceremonies, writing and posting of death notices and obituaries, there are all the things that the government expects the family (or a representative for the family) to complete shortly after the death. This is part of the reason why planning end-of-life wishes in advance (including body disposal arrangements and funeral/memorial plans) is extremely helpful for loved ones. By making as many of these decisions as possible in advance, you ease the burden on your family and provide them more time to mourn, focus on taking care of themselves, and healing.

The Federal, Provincial and Territorial governments provide detailed instructions on their websites of what needs to be done after someone dies. Below are links to relevant Government of Canada and Government of Ontario websites. The Government of



Checklist.

Canada website provides a step-by-step process for you to follow, however, it does require that you be in possession of certain documents pertaining to the deceased: Statement of Death, Death Certificate, Social Insurance Number.

Click the links below to learn more about Government of Canada and Ontario requirements following a death:

Notify the Federal Government of a Death (Government of Canada)
What to do When Someone Dies (Government of Ontario)

## 10.5 TALKING ABOUT END-OF-LIFE CARE



Talking about End-of-Life Care.

The only way we can guarantee that we receive the EOL care we want and ensure that our values and beliefs are honoured is to talk about these things with our loved ones. It is especially important to have these conversations with those individuals who may end up having to make health and EOL decisions on our behalf. Ideally these conversations should occur when we are healthy. It is also important to know your rights as a patient. Remember that "knowledge is power" (Dying with Dignity Canada, n.d.-b).

#### Click the link below to learn more about your rights as a patient:

Protect Yourself: Your Rights As a Patient

#### VIDEO: Practice Makes Perfect

This short video illustrates ways you can start "the conversation."



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#### VIDEO: Advance Care Planning – Conversations

This short video reminds us of the importance of talking about death and the importance of having "the conversation" about what you want in advance with your loved ones and  $\ensuremath{\mathrm{SDM}}(s)$ .



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### **10.6 CHAPTER SUMMARY**

### **Key Summary Points**

- 1. Advanced Care Plans (APC) detail our values and wishes for end-of-life care.
- 2. Substitute Decision Makers (SDM) are people we appoint through a Power of Attorney for Personal Care to make health and medical decisions on our behalf, when we are unable to do so for ourselves.
- 3. Having a Will detailing our wishes for the distribution of our assets and appointing a durable Power of Attorney (for property), is an important part of any end-of-life planning activities.
- 4. Having "the conversation" with loved ones is essential for end-of-life planning and for making sure our values and wishes are honoured.
- 5. Opening up a dialogue about death and engaging in end-of-life planning (including planning for the disposal of our body and our end of life ceremony) can ease the burden of the work that has to occur after we die.

### **Additional Resources**

#### Additional Viewings

The Conversation Project (n.d.-b). Videos. https://theconversationproject.org/videos

#### **Additional Readings**

Canada. (n.d.-a). *Benefits of estate planning*. <a href="https://www.canada.ca/en/financial-consumer-agency/services/financial-toolkit/financial-planning/financial-planning-4/2.html">https://www.canada.ca/en/financial-consumer-agency/services/financial-planning-financial-planning-4/2.html</a>

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#### Websites

Death with Dignity Canada. (n.d.). https://www.dyingwithdignity.ca/ Hospice Palliative Care Ontario. (n.d.). https://www.hpco.ca/ The Conversation Project. (n.d.) https://theconversationproject.org/

### 10.7 REQUIRED COURSE MATERIALS

Jacqueline Lewis

In addition to the videos and reading links embedded into the chapter, you are required to complete the following course material:

### **Required Course Viewings**

The Conversation Project. (October 7, 2020b). Who will speak for you? [Video]. YouTube. <a href="https://youtu.be/0TFyfwWziPM">https://youtu.be/0TFyfwWziPM</a>

The Guardian. (November 28, 2019). *Death cafes and planning your own death – Death Land #4* [Video]. YouTube. <a href="https://youtu.be/YsgGqnWJu80">https://youtu.be/YsgGqnWJu80</a> (Watch to 5:26 mark).

### Required Course Readings

Grant, L. & Khan, F. (January 31, 2022). The precariousness of balancing life and death. *The Lancet*. https://doi.org/10.1016/S0140-6736(22)00162-3

### 10.8 CHAPTER ASSIGNMENT

## Advanced Directive & Planning for Illness & Death Assignment

This chapter focused on the importance of advanced planning for illness and death. You have 2 options for this chapter's assignment. Option 1 involves completing your Advanced Care Plan (ACP) and Power of Attorney for Personal Care via a downloadable and fillable PDF document. Option 2 involves writing a reflection paper. It is important to complete all chapter materials (chapter content, including all embedded links to readings and videos, and the required course materials) prior to starting either Option 1 or 2 for the assignment.

### Options for assignment #10

### Option 1

After downloading a document containing the necessary forms, this assignment option requires you to do three things: (1) complete your Advanced Care Plan (ACP)/ Advanced Directives (including signature); (2) appoint your Substitute Decision-Maker (SDM)/Attorney for Personal Care (APC) via the creation of a Power of Attorney for Personal Care (including signatures); and (3) submit the PDF document to demonstrate completion of the assignment.

### Steps to Completing Option 1 Assignment

- a. Click on the following link to download a PDF of the ACP for Ontario to your computer <u>Advance Care Planning Kit Website for Ontario</u>
- b. Read the document in its entirety so you understand what it is you are completing.
- c. Fill in your Advance Care Directives (ACP) form, carefully following the directions (especially #1 and #2 of the instructions on page 2 of the document). Be sure to take some time to carefully reflect on the questions that are asked and the answers you choose.
- d. Sign, date and print your name at the bottom of the form. You must actually sign the document. To add your signature you can: print and sign; sign with your finger or digital pencil on an iPad or similar device; or create a digital signature, through one of the many free digital signature sites on the web, which you can then add to the document.

- e. Fill out your Power of Attorney for Personal Care form.
- f. Sign and date where indicated on the form, in the presence of 2 witnesses (as noted in #1 of the instructions for this document, witnesses cannot be: people under 18 years of age; the person/people you are appointing to act as your Attorney for Personal Care; your spouse or child). You must put your actual signature on the document (see D above for details).
- g. Have your 2 witnesses sign, date and print their names on the form (they too must put their actual signature on the document, following the same directions provided in D above).
- h. Save the entire PDF document (beginning with the Death with Dignity Logo and Advanced Care Directive/Wishes instructions to the end of your Power of Attorney for Personal care form) in PDF format to your computer.
- i. Give the document a name that clearly indicates whose document it is and what it is (e.g., Smyth, Jasmine, Advanced Directives & Power of Attorney Assignment).
- j. Submit the properly labelled (as per I) entire PDF document (beginning with the Death with Dignity Logo and Advanced Care Directive/Wishes instructions to the end of your Power of Attorney for Personal care form) to demonstrate completion of the assignment.

#### Option 2

Write a reflection paper that details/explains/explores: what you learned from or got out of this course; how this course impacted you; if and how what you learned and/or your experiences taking the course altered your views of how you approach death, dying, grief, etc.; why you chose not to complete Option 1 for this assignment, and what steps will it take for you to get to a place where you can and will complete those documents.

### Assignment Formatting & Style for Written Report

- Assignments formatting requirements: Arial 12-point font; 1 inch/2.54 centimeter margins; single spaced; APA in-text citation style, reference section and cover page.
- Use proper essay/paragraph style.
- Paraphrase as opposed to relying on direct quotes.
- Proofread your submission to make sure it is clear, well written and intelligible.

### Steps to Completing Option 2 Assignment

- a. Click on the following link to download a PDF of the ACP for Ontario to your computer <u>Advance Care Planning Kit Website for Ontario</u>
- b. Read the document in its entirety.
- c. Write a 1000-word reflection paper (give or take 100 words) that addresses what is outlined under

Option 2 above.

### The following must be submitted as part of Option 2 assignments

- 1. A proper APA style cover page.
- 2. A written reflection paper, as per text under Option 2 above.
- 3. A proper APA reference section that contains any/all the material cited in the reflection paper.

### 10.9 REFERENCES & MEDIA ATTRIBUTIONS

### References

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Grant, L. & Khan, F. (January 31, 2022). The precariousness of balancing life and death. *The Lancet*. https://doi.org/10.1016/S0140-6736(22)00162-3

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**Cover Photo:** Youngson, N. (n.d.). *Power of attorney* [Photograph]. Pix4Free. <a href="https://pix4free.org/photo/">https://pix4free.org/photo/</a> <a href="https://pix4free.org/photo/">10475/power-of-attorney.html</a>

### **CHAPTER REVIEWS**

Current University of Windsor students and recent graduates reviewed and provided feedback on the chapters in this eCampus Pressbook. The following are the brief overall feedback summaries provided for each chapter.

#### **Chapter 1 Review**

"An enlightening introduction to the very 'taboo' topic of death and dying; from this chapter, students will definitely take-away lots of very applicable and healthy information" (Alyssa Woodbridge).

#### **Chapter 2 Review**

"Chapter 2 is an insightful chapter on historical beliefs and death-related practices. Students can expect to expand their knowledge on fascinating rituals across the globe, and in their own communities" (Alyssa Woodbridge)

### **Chapter 3 Review**

"This chapter is an intriguing chapter that provides students with an awareness of a variety of cultural rituals and practices that they may not be familiar with; students will be able to appreciate diverse practices from all around the world" (Alyssa Woodbridge).

### **Chapter 4 Review**

"This chapter does a great job of highlighting some important topics regarding the disposal of bodies after death; the chapter assignment is a very unique and healthy way of facilitating students to explore these topics as they relate to their own end-of-life plans" (Alyssa Woodbridge).

### **Chapter 5 Review**

"With the occurrence of the COVID-19 pandemic, Chapter 5 covers very relevant material for students to compare and construct past plagues, pandemics, and mass death events" (Alyssa Woodbridge).

#### **Chapter 6 Review**

"This chapter helps students understand genocide through both the U.N. definition and the stories of individuals who have been directly impacted by these atrocities" (Chantelle Dagley).

#### **Chapter 7 Review**

"All in all, this chapter enlightens one on the reality of what is to come when someone is near death. It discusses the different options/routes one may take when they are known to essentially lose their battle in due time. This chapter really draws on one's own experience and own opinion regarding end-of-life possibilities and ensures to emphasize on the opinion of the person with lived experience" (Olivia Mirisola).

#### **Chapter 8 Review**

"Chapter 8: Grief, Loss & Bereavement allows readers to better understand the definition of grief and how to properly support someone who recently went through a loss. Grief is something very personal, that most people feel as if they are going through it a lone and feel as if no one can understand how they are feeling. The chapter helps readers know how to support the bereaved in a way that does not excuse the emotions they are feeling, and that does not make them feel as if they need to move on right away. It has engaging videos from speakers who define and explain grief in their own ways and includes engaging and easy-to-read articles that can help readers understand grief on their own" (Yara El-Houssami).

### **Chapter 9 Review**

"This chapter is an enlightening chapter that highlights the types of memorials, commemoration, and remembrance rituals, in the past and present, all around the world" (Alyssa Woodbridge).

### **Chapter 10 Review**

"Critically engages students in discussions surrounding advanced care plans, substitute decision makers, Wills and how to discuss end of life care and planning with family members. Students gain knowledge surrounding the processes involved in death and dying, and the benefits of early planning and open conversations" (Holly Deckert).

# APPENDIX – MATERIALS USED WITH PERMISSION

| Subchapter | Reference and Attribution   |
|------------|---|
| 1.2        | Speak Up Ontario. (n.d.). <i>Logo</i> [Photograph]. Speak Up Ontario. https://www.speakupontario.ca/<br>©Speak Up Ontario (n.d.). All rights reserved. Image used with permission.  |
| 1.3        | The Groundswell Project Australia. (2020). <i>Talking about death is a part of Life!</i> [Photograph]. <a href="https://www.thegroundswellproject.com/dying-to-know-day">https://www.thegroundswellproject.com/dying-to-know-day</a> Talking about death is a part of life! ©The Groundswell Project Australia (2020). All rights reserved. Image used with permission.   |
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| 2.2        | Scwordie. (June 23, 2017). Backyard Cemetery [Photograph]. Flickr.  https://tinyurl.com/58xbpar7  Backyard Cemetery ©Scwordie. All rights reserved. Image used with permission.   |
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The 519. (June 2018). *AIDS Memorial* [Photograph]. Facebook. <a href="https://www.facebook.com/The519/photos/a.10156417352244801/10156417369749801">https://www.facebook.com/The519/photos/a.10156417352244801/10156417369749801</a> AIDS Memorial. ©The 519. All rights reserved. Image used with permission. 10.5

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Jacqueline Lewis, PhD (She/Her) is an Associate Professor in the Department of Sociology, Anthropology & Criminology at the University of Windsor. She received her doctorate in sociology from the University of Toronto in 1994. Over the course of her career, her teaching and research has focused on: the impact of public policy on the health and well-being; identity and stigma management; drugs, drug use and drug policy; illness, death and dying; sex work,

sexual labour and sex work policy; and research ethics.