On Death & Dying (2nd Edition)

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University of Windsor

Windsor, ON





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Contents

- Land Acknowledgement
- On Death & Dying (2nd Edition)
- Adopting or Adapting the Book
- Instructor Materials
- Acknowledgements
- · Accessibility Statement
- Nature of Course & Support Resources
- Course & e-Book Introduction
- Chapter 1: Let's Talk about Death & Dying
- 1.0 Introduction
- 1.1 Death & Daily Life
- 1.2 Talking About Death
- 1.3 Death Positivity & Listening to the Dying
- 1.4 The Death Positive Movement
- 1.5 Chapter Summary
- 1.6 Required Chapter Materials
- 1.7 Chapter Assignment
- 1.8 References & Media Attributions
- Chapter 2: Historical Beliefs & Death-Related Practices
- 2.0 Introduction
- 2.1 Death Related Customs & Rituals in History

- 2.2 Death in North America, Late-18th to late-19th Century
- 2.3 Death in North America, Late-19th to Early-20th Century
- 2.4 Indigenous Death-Related Beliefs & Practices
- 2.5 Chapter Summary
- 2.6 Required Chapter Materials
- 2.7 Chapter Assignment
- 2.8 References & Media Attributions
- Chapter 3: Cultural & Religious Beliefs & Death-Related Practices
- 3.0 Introduction
- 3.1 Culture, Rituals & Death
- 3.2 Death Rituals & Ceremonies
- 3.3 Death & Dying: Current Customs & Rituals
- 3.4 Chapter Summary
- 3.5 Required Chapter Materials
- 3.6 Chapter Assignment
- 3.7 References & Media Attributions
- Chapter 4: Dealing with Bodies after Death
- 4.0 Introduction
- 4.1 Traditional Disposal Methods: Embalming, Burial & Cremation
- 4.2 Environmental Impact of Embalming, Burial & Cremation
- 4.3 Burial Capacity & Space Limits
- 4.4 Grave Recycling
- 4.5 Environmentally Sustainable Solutions
- 4.6 The Impact of the COVID-19 Pandemic on Death-Related Practices
- <u>4.7 Chapter Summary</u>
- 4.8 Required Chapter Materials
- 4.9 Chapter Assignment
- 4.10 References & Media Attributions
- Chapter 5: Plagues, Pandemics & Mass Death Events
- 5.0 Introduction
- 5.1 What is a Pandemic?
- 5.2 History of Pandemics
- 5.3 The Black Plague
- 5.4 The Spanish Flu
- 5.5 HIV/AIDS
- 5.6 COVID-19
- 5.7 Human Responses to Pandemics
- 5.8 Chapter Summary
- 5.9 Required Chapter Materials
- 5.10 Chapter Assignment
- 5.11 References & Media Attributions
- Chapter 6: Genocide
- 6.0 Introduction
- 6.1 Learn About Genocides
- 6.2 The Armenian Genocide
- 6.3 The Holocaust
- 6.4 The Rwandan Genocide
- 6.5 The Genocide of Indigenous Peoples in Canada
- 6.6 Chapter Summary

- <u>6.7 Required Chapter Materials</u>
- <u>6.8 Chapter Assignment</u>
- 6.9 References & Media Attributions
- Chapter 7: End-of-Life Care: Hospice, Palliative Care & Medical Assistance in Dying
- 7.0 Introduction
- 7.1 What is Dying with Dignity?
- 7.2 Palliative Care
- 7.3 What is Hospice Care?
- 7.4 Palliative Care in Canada
- 7.5 Medical Assistance in Dying (MAiD) in Canada
- 7.6 Dying with Dignity Advocacy Organizations
- 7.7 Assisted Dying Around the World
- 7.8 Chapter Summary
- 7.9 Required Chapter Materials
- 7.10 Chapter Assignment
- 7.11 References & Media Attributions
- Chapter 8: Grief, Loss & Bereavement
- 8.0 Introduction
- 8.1 Defining Loss, Grief, & Bereavement
- <u>8.2 Understanding Grief</u>
- 8.3 Supporting the Bereaved
- 8.4 Grief & Social Media
- 8.5 Healing from COVID-19
- <u>8.6 Chapter Summary</u>
- <u>8.7 Required Chapter Materials</u>
- 8.8 Chapter Assignment
- 8.9 References & Media Attributions
- Chapter 9 Obituaries & Eulogies
- 9.1 Introduction
- 9.2 Death Notices & Obituaries
- 9.3 Bias in Death Notices & Obituaries
- 9.4 Obituary Writing
- 9.5 Elegies & Eulogies
- 9.6 Eulogy Writing
- 9.7 How will you be remembered?
- 9.8 Chapter Summary
- 9.9 Required Chapter Materials
- 9.10 Chapter Assignment
- 9.11 References & Media Attributions
- Chapter 10: Memorials, Commemoration & Remembrance
- 10.0 Introduction
- 10.1 Defining Memorials & Commemoration
- 10.2 Memorials & Memorialization
- 10.3 Official Monuments & Canadian War Memorials
- 10.4 Genocide Memorials, Commemoration & Remembrance
- 10.5 Indigenous Memorials, Commemoration & Remembrance in Canada
- 10.6 Pandemic Memorials, Commemoration, & Remembrance
- 10.7 Chapter Summary
- 10.8 Required Chapter Materials

- 10.9 Chapter Assignment
- 10.10 References & Media Attributions
- Chapter 11: Advanced Directives & Planning for Death
- 11.0 Introduction
- 11.1 Advanced Care Plans
- 11.2 Substitute Decision Maker & Power of Attorney for Personal Care
- 11.3 Wills & Power of Attorney (for property)
- 11.4 After Death Work
- 11.5 Talking About End-of-Life Care
- 11.6 Chapter Summary
- 11.7 Required Chapter Materials
- 11.8 Chapter Assignment
- 11.9 References & Media Attributions
- Appendix A Chapter Reviews
- APPENDIX B Materials used with permission
- About the Author

1

Land Acknowledgement

The University of Windsor sits on the traditional territory of the Three Fires Confederacy of First Nations, which includes the Ojibwa, the Odawa, and the Potawatomie. As a settler, I acknowledge and thank the traditional custodians of this place.

2

On Death & Dying (2nd Edition)

This is the 2nd edition of *On Death & Dying* by Jacqueline Lewis (<u>link to original eBook</u>). The 2nd edition is updated and enhanced. There are a number of changes, additions and updates including:

- One new Chapter: Chapter 9 Obituaries & Eulogies.
- An H5P on memorials added to Chapter 10.2.
- An easier to navigate Resource List made in Canva (see Course Resources page).
- An illustration of a narrated PowerPoint assignment for Chapter 5, contributed by a previous student in the course (see Chapter 5.10).
- An updated syllabus.
- An updated assignment rubric.
- Updated chapter content includes materials from over 50 resources from 2022-2023.

Adopting or Adapting the Book

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Instructor Materials

Course Syllabus

On Death & Dying Syllabus

Grading Rubric

On Death & Dying Assignment Evaluation Rubric

5

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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.

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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.

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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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- Alt text has been provided for images that are not decorative.
- Videos developed for this project contain closed captioning and also offer downloadable transcripts.

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7

Nature of Course & Support 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, in consultation with the professor, students may also opt to not fully participate in certain course sessions or not consume particular course content.

For students who decide to take this course, a variety of support resources are available if needed via this link: <u>Support ResourcesList</u>. They can also be download by clicking on this link: <u>Support Resources List (PDF File)</u>.

8

Course & e-Book Introduction

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 eBook 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 and materials. 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.

^① 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.

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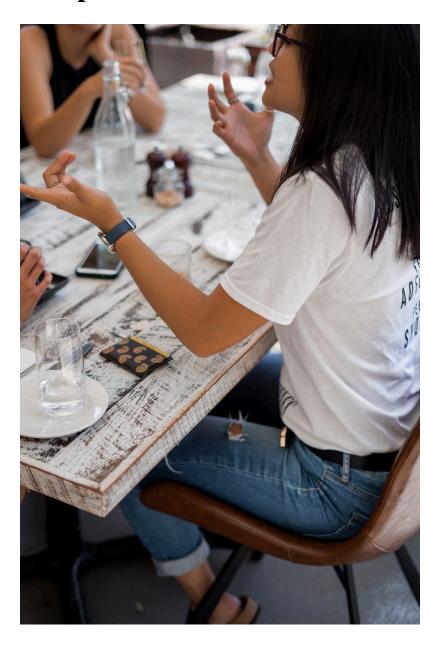
MEANING

Content warnings
Required reading and/or video course content.
Instructions for students

Required reading and/or video course content.

Supplementary information (hyperlinks or definitions). Not required course content.

Chapter 1: Let's Talk about Death & Dying



Jacqueline Lewis

1

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 about 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.)?

2

1.1 Death & Daily Life



Chat bubbles.

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 famous persons, 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 Read" series. Some examples of books 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

3

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/prognosis.
- 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 Care), 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 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 with 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).

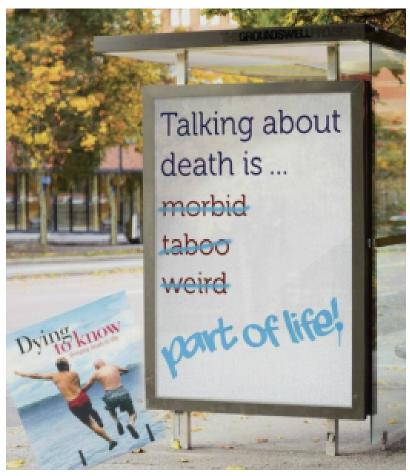
VIDEO: Learning How to Think About Death Changed How I live

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: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=36#oembed-1

4

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 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). It is also 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



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

A good way to start a course on death and dying is to listening to the voices of people who are nearing the end of life, to hear their experiences, their struggles, and the wisdom only they can share. Many heart wrenching stories are tied to 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. (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).

VIDEO: This Nova Scotia Woman is Dying Earlier than She Wanted because of Assisted Dying Law

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5

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

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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:

Compassionate Communities

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.

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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/deathanddying2nded/?p=42#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.

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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: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=42#oembed-5

6

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 Cafés, Death over Dinner, and the

Additional Resources

Below are a list of supplementary resources for students interested in learning more about the chapter topics. <u>These resources are NOT required course materials</u>. A list of required course materials, beyond those found throughout this chapter, are provided on the following page.

Additional Viewings

Talks at Google. (June 14, 2018). *Inviting the wisdom of death into life — Frank Ostaseski* [Video]. YouTube. https://youtu.be/wBraurRo_bg

7

1.6 Required Chapter Materials

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

Required Chapter Viewings

TEDx Talks. (May 9, 2017). *Let's talk about death – Isabel Merrin* [Video]. YouTube. https://youtu.be/R2HextBCK-o

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

Required Chapter Readings

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

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. *TheConversation.com*. https://theconversation.com/death-isnt-taboo-were-just-not-encouraged-to-talk-about-it-25001

Wilhelm, T. (May 3, 2018). Windsor's first Death Café gives life to uncomfortable conversation. *Windsor Star*. https://windsorstar.com/news/local-news/windsors-first-death-cafe-gives-life-to-uncomfortable-conversation

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: (1) complete all chapter materials (chapter content, including all embedded links to readings and videos, and the required course materials) prior to starting the assignment; and (2) cite relevant course material throughout your assignment to support your points, credit sources of concepts/ideas, and demonstrate completion of assigned course materials.

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.
- Use APA in-text citation style to support points, credit sources of concepts/ideas, and demonstrate completion of assigned course materials.
- Use APA style appendices to organize assignment.
- Proofread your submission to make sure it is clear, well written and intelligible.

Options for Chapter #1 Assignment

Option 1

Attend a Death Café (in person or virtual). Find a local or virtual death café 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. Use APA in-text citation style to support points, credit sources of concepts/ideas, and demonstrate completion of assigned course materials. 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.

The following must be submitted as part of Option 1 assignments

- 1. A proper APA style cover page.
- 2. A properly sourced written report.
- 3. A proper APA style reference section.
- 4. A proper APA style appendix containing the details on the death café attended (date, time, location, photo of event ad).

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 assignment

- Watch 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. Use APA in-text citation style to support points, credit sources of concepts/ideas, and demonstrate completion of assigned course materials. <u>In-text citations to support your points/arguments are essential and required</u>.

The following must be submitted as part of Option 2 assignments

- 1. A proper APA style cover page.
- 2. Your properly sourced written report (in addition to the written components required for the appendices detailed in #4 below).
- 3. A proper APA style reference section.
- 4. Proper APA style appendices containing:
 - A copy of your death over dinner plan sent to you from the Death over Dinner website.
 - A brief explanation of your choices for your dinner plan (the choices you made on the website).
 - Your guest list, with a brief explanation of your guest choices and the number you plan to invite.
 - Your invitation that you will send out to guests.
 - Your dinner menu, with a brief explanation of your meal choices.

Variation on Option 2: Once you have planned your Death over Dinner, 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 assignment 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. The Death over Dinner website asks people who host dinners to write "your story" pieces to post on their website. Your written submission must follow that format. Whether or not you submit "your story" to the website is up to you. "Your story" must be 350-600 words in length and would replace the written report detailed above for Option 2 (non-variation version). You are still required to complete all of #1, 3 & 4 for Option 2 above. Be sure to clearly indicate in your submission that you have chosen to complete the "Variation on Option 2". In your write-up be sure to use APA in-text citation style to support points, credit sources of concepts/ideas, and demonstrate completion of assigned course materials.

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. Use APA in-text citation style to support points, credit sources of concepts/ideas, and demonstrate completion of assigned course materials. <u>In-text citations to support your points/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.

The following must be submitted as part of Option 3 assignments

- 1. A proper APA style cover page.
- 2. A copy of your 500-600 word, properly sourced, report on what the experience was like thinking about and filling in your guide.
- 3. A proper APA style reference section.
- 4. A proper APA style appendix containing the completed/filled in copy of your Conversation Starter 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 anywhere from 600-1000 words in length. You must also complete #1, 3 & 4 for Option 3 above. Be sure to clearly indicate in your submission that you have chosen to complete the "Variation on Option 3". In your write-up be sure to use APA in-text citation style to support points, credit sources of concepts/ideas, and demonstrate completion of assigned course materials.

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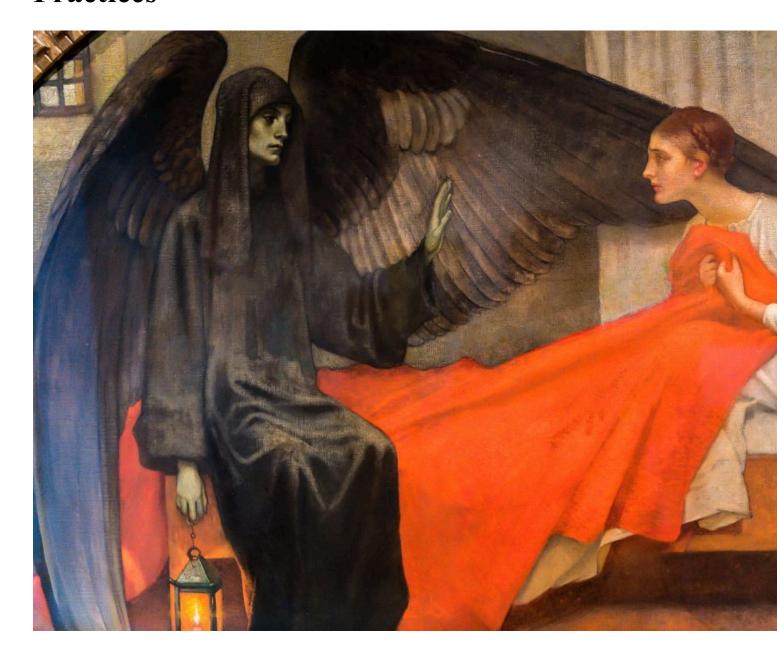
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Cover Photo: Da Rosa, J. (March 2019). Women sitting on the chair photo [Photograph]. Unsplash.

II

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 surrounding 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 death-related 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?

11

2.1 Death Related Customs & Rituals in History

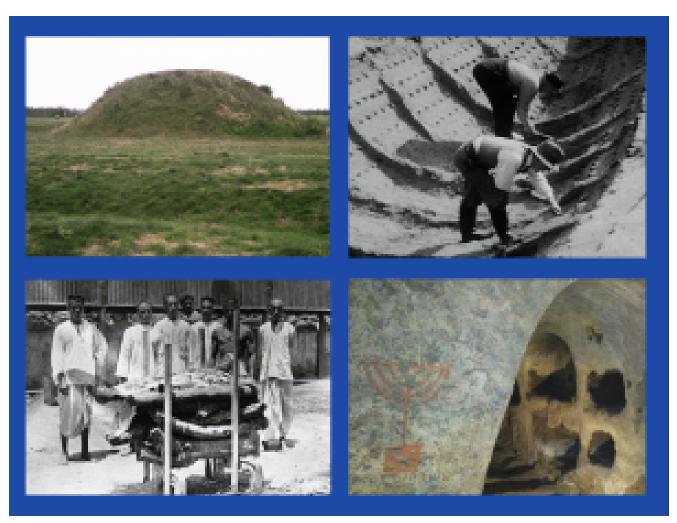
There are an abundance of death-related beliefs and practices (e.g., customs and rituals) that we as

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:

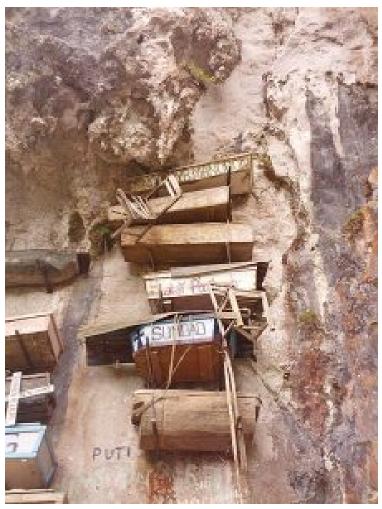
Why I Wore Black After He Died: Lessons from Victorian Mourning Culture

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

12

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 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/deathanddying2nded/?p=63#oembed-1

13

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 20th 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: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=65#oembed-1

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 – transitioning 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 at 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 helps to 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/deathanddying2nded/?p=65#oembed-2

14

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). <u>Oral traditions</u> 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.

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=68#oembed-2



Medicine Wheel.

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., 2015).

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).

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=68#oembed-1

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 embracing 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.

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=68#oembed-3

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.

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=68#oembed-4

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: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=68#oembed-5

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/deathanddying2nded/?p=68#oembed-6

15

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

Below are a list of supplementary resources for students interested in learning more about the chapter topics. <u>These resources are NOT required course materials</u>. A list of required course materials, beyond those found throughout this chapter, are provided on the following page.

Additional Readings

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=2ahUKEwjjwvnEi8v2AhVNWs0KHWbwCHUOFnoECAgO.

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2.6 Required Chapter Materials

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

Required Chapter 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*. https://theconversation.com/what-we-can-learn-from-death-rites-of-the-past-will-help-us-treat-the-dead-and-grieving-better-today-74718

Dugdale, L. (February 8, 2012). The art of dying well. *Hastings Center Report*, 40(6), 22-23. https://doi.org/10.1002/j.1552-146X.2010.tb00073.x

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Kinch, A. (October 29, 2017). How the dead danced with the living in medieval society. *TheConversation.com*. https://theconversation.com/how-the-dead-danced-with-the-living-in-medieval-society-85881

Reagan, R. (May 28, 2020). *Dancing with death: A short history of funeral feasts & merry wakes*. Blackthorn&Stone.com. https://blackthornandstone.com/2020/05/28/dancing-with-death-a-short-history-of-funeral-feasts-merry-wakes/

San Filippo, D. (January 2006). Historical perspective on attitudes concerning death and dying. *Faculty Publications*, 29. https://digitalcommons.nl.edu/faculty_publications/29/

17

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: (1) complete all chapter materials (chapter content, including all embedded links to readings and videos, and the required course materials) prior to starting the assignment; and (2) cite relevant course material (from current and previous chapters) throughout your assignment to support your points, credit sources of concepts/ideas, and demonstrate completion of assigned course materials.

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.
- Use APA in-text citation style to support points, credit sources of concepts/ideas, demonstrate research completed for assignment and completion of assigned course material.
- Use APA style appendices to organize assignment.
- Proofread your submission to make sure it is clear, well written, and intelligible.

Steps to Completing the Assignment

- a. Visit one or more Canadian cemeteries in person or virtually (in order to visit a cemetery virtually, you will need to find one or more cemeteries that has/have all their headstones catalogued on their website) (the larger and older the cemetary, the less likely you will have to go to more than one, physically or virtually) 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. If planning to go to a cemetery, 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/save the image of 3 grave markers/headstones within a 10-year period for people who died between 1910 and 1933.
 - II. Find and photograph/save the image of 3 grave makers/headstones within a 10-year period for people who died between 2000 and 2023.
- b. Go online and search for Canadian statistics for the 2 decades from which you drew your sample markers/stones to find out: the 8 leading causes of death; and the average life-expectancy for those 2 periods of time.
- c. Write a properly sourced, 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 (in-person or online).
- d. Organize photos/images, statistical data collected into appendices. For each photo, indicate where and when it was taken. For images borrowed from the internet, be sure to properly credit their source and provide the website address at which they were found. Clearly indicate which cemetery or cemeteries you went to and include their address(es)/web address(es).
- e. Use APA in-text citation style to support points, credit sources of concepts/ideas, demonstrate research completed (i.e., statistical data sources) for assignment and completion of assigned course materials. <u>In-text citations to support your points/arguments are essential and required.</u>
 Be sure to use a diverse range of materials (from current and previous chapters) as opposed to relying heavily on one, or a few sources.

As explained in this chapter's materials, cemeteries are interesting historic sites, and many are places where you can commune with nature.

However: Due to the often isolated nature of cemeteries, it is highly recommended that you DO NOT visit a cemetery on your own. Instead ask a friend, family member, or classmate to join you OR do your research online and base your assignment a cemetery or cemeteries that have all their headstones catalogued on their website.

Assignment Submissions Must Include

- 1. A proper APA style cover page.
- 2. A short, properly sourced, essay as detailed above.
- 3. A proper APA reference section that contains all the material cited in the assignment. If basing the assignment on online cemetery catalogues or data bases, provide a citation for each image borrowed (including web address links).
- 4. Proper APA style appendices containing: photographs of the 6 grave markers; cemetery information; and statistical data used in the assignment.

18

2.8 References & Media Attributions

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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?
- 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 commonalities 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,

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, p. 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



A weeping woman sitting on a chair at a funeral.

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, 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).

Click the link below to read about how the mourning rituals for a victim of the Maui fires in 2023, helped friends and family to express their collective loss, to provide and receive support, and to honour the life of their loved one.

After the Maui Fires Took Carole, Her People Honored Her on the Water

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.

Teenager Breaks Down in Tears During Memorial Māori Haka

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/deathanddying2nded/?p=87#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 prefuneral event 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 some professional mourner services:

Paid for Their Tears: The Peculiar Profession of Professional Mourners

VIDEO: This British Woman Got a Dance Group to Perform Queen's "Another one bites the dust" at Her Funeral

The following video illustrates another form of professional mourning service, one that sets the mood and tone the deceased wanted for her own end-of-life ceremonial 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/deathanddying2nded/?p=87#oembed-2

22

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: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=96#oembed-1

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.

<u>Islamic Funeral Customs and Service Rituals</u>



Mosque in Abu Dhabi.

Jewish Funeral Service Rituals



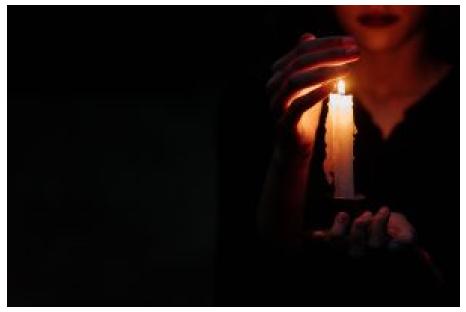
Star of David Symbol.

<u>Sikh Funeral Service Rituals</u>



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).

23

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

Below are a list of supplementary resources for students interested in learning more about the chapter topics. <u>These resources are NOT required course materials</u>. A list of required course materials, beyond those found throughout this chapter, are provided on the following page.

Additional Readings

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

3.5 Required Chapter Materials

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

Required Chapter 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*. https://australian.museum/about/history/exhibitions/death-the-last-taboo/

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

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

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25

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 poetry, 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: (1) complete all chapter materials (chapter content, including all embedded links to readings and videos, and the required course materials) prior to starting the assignment; and (2) cite relevant course material (from current and previous chapters) throughout your assignment to support your points, credit sources of concepts/ideas, and demonstrate completion of assigned course materials.

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.

- Use APA in-text citation style to support points, credit sources of concepts/ideas, demonstrate research completed for assignment and completion of assigned course material.
- Paraphrase as opposed to relying on direct quotes.
- Use APA style appendices to organize assignment.
- 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. These CANNOT be pieces of art or poetry included in this eBook or any required course materials.
- b. If you have chosen works of art, find photos of each. If you have chosen poetry, find the full text of the poem. Be sure to gather the information from the source where you found the images or text to allow you to provide proper APA 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 and 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 and interpretations of 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 into appendices. 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. Cite materials, via in-text citations and reference section, to credit sources used in assignment.

 <u>In-text citations to support your points/arguments are essential and required</u>. Be sure to use a diverse range of materials (from current and previous chapters) as opposed to relying heavily on one, or a few sources.
- g. 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, information from internet searches on the pieces, and course materials.

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 poems you chose for the assignment.
- 3. A properly sourced reflection paper.
- 4. A proper APA reference section.
- 5. Proper APA style appendices.

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.
- 2. 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



Image of a man's body in an open casket that is made to look like he is sleeping.

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 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/deathanddying2nded/?p=114#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



An example of a concrete burial vault.

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, <u>burial vaults andgrave liners</u>. 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.).

Cremation

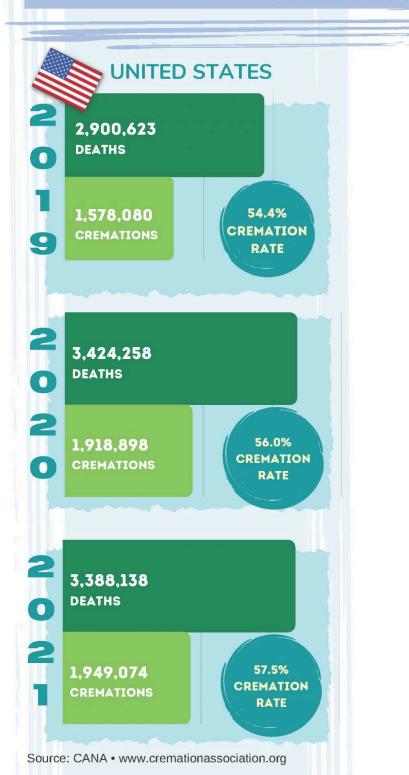


A willow coffin decorated with flowers is moved into a cremator.

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 2022 statistics report, 74.8% of the body disposals in Canada in 2021 were via cremation (CANA, 2022) (See infographic below). That number was more than double the cremation rate two decades earlier (CANA, 2021).

CA 2022 ANNUAL STATISTICS REPORT

TWO YEARS OF UNPRECEDENTED CREMATION NUMBERS AND CONTINUED PREDICTABLE GROWTH RATE





© 2022 Cremation Association of North A

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

THE ENVIRONMENT OF FUNER

ALL CEMETERIES IN THE UNITED STATE AN ESTIMATED 1 MILLION ACRES O

BURIED WITHIN TH

OVER 800,000 GAL OF FORMALDEHYD

Access the Word file containing text for the infographic

30

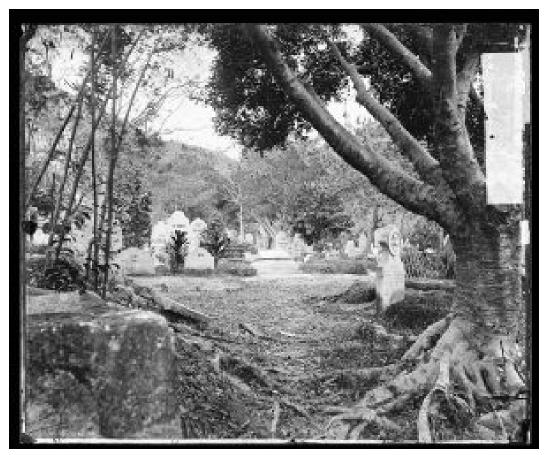
4.3 Burial Capacity & Space Limits



Image of crowded cemetery with limited room between plots.

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 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 <u>Catacombs of Paris</u> (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 almost 7 million COVID-19 related deaths worldwide (as of December 2023), the issue has become even more dire in various parts of the world. For example, during the pandemic, efforts to empty old graves had to be sped up in Sao Paulo Brazil 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/deathanddying2nded/?p=122#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., <u>Japan</u>, 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 reintroduced 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 small size these tombs 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 link below to learn more about burial plot recycling:

Losing the Plot: Death is Permanent, But Your Grave Isn't

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: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=126#oembed-1

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: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=128#oembed-1

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.

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=128#oembed-2

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: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=128#oembed-3

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/deathanddying2nded/?p=128#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



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

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 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 have become a normalized option for many funerals in order 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:

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

Coronavirus Is Changing Funerals And How We Deal With The Dead

34

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

Below are a list of supplementary resources for students interested in learning more about the chapter topics. <u>These resources are NOT required course materials</u>. A list of required course materials, beyond those found throughout this chapter, are provided on the following page.

Additional Viewings

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

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

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. https://doi.org/10.1016/j.proeng.2015.08.419

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

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-in-canada/#.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. https://thetowerinfo.com/vertical-cemetery-high-rise/

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

35

4.8 Required Chapter Materials

In addition to the videos and reading links embedded into the chapter, studentsare required to complete the following:

Required Chapter Viewings

Doughty, C. (April 3, 2017). A burial practice that nourishes the planet [Video]. TEDMED. https://www.ted.com/talks/caitlin doughty a burial practice that nourishes the planet

Required Chapter 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

36

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: (1) complete all chapter materials (chapter content, including all embedded links to readings and videos, and the required course materials) prior to starting the assignment; and (2) cite relevant course material (from current and previous chapters) throughout your assignment to support your points, credit sources of concepts/ideas, and demonstrate completion of assigned course materials.

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 (below the reflection part of the assignment).
- Use bullet points for parts A and B next to the corresponding roman numerals. Each of these parts of the assignment (A and B below) must be placed in an appendices (see #4 below).
- Use APA in-text citation style to support points, credit sources of concepts/ideas, and demonstrate completion of assigned course materials.
- Use APA style appendices to organize 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 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 400-600 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. <u>In-text citations to support your points/arguments are essential and required</u>. Be sure to use a diverse range of materials (from current and previous chapters) as opposed to relying heavily on one, or a few sources.

Assignment Submissions must Include

- 1. A proper APA style cover page.
- 2. A properly sourced reflection paper as per C above.
- 3. A proper APA reference section that contains all the material cited in the assignment.
- 4. Proper APA style appendices containing: Plan for body disposal and Plan for after death event(s) as per A and B above.

37

4.10 References & Media Attributions

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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?
- 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



White ceramic sculpture with black mask.

- 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 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:

Visualizing the History of Pandemics

Pandemics That Changed History

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

41

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:

How Medieval Writers Struggled to Make Sense of the Black Death

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/deathanddying2nded/?p=152#oembed-1

42

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:

Stories of the 1918 Flu Pandemic (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.

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=155#oembed-1

5.5 HIV/AIDS



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

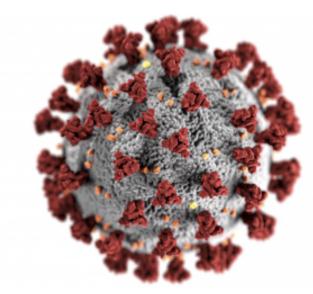
VIDEO: HIV/AIDS Video from Columbia Public Health

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/deathanddying2nded/?p=158#oembed-1

44

5.6 COVID-19



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 December 2023, almost 7 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:

Research Insights: A Look at Canada's Economy and Society Three Years After the Start of the COVID-19 Pandemic

Reports Says Long COVID Could Impact Economy and be 'Mass Disabling' Event in Canada

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 (September 21, 2021), 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/deathanddying2nded/?p=161#oembed-1

45

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). Anti-masking 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). Parallels were found during the COVID-19 pandemic with less than half of the people in the U.S. following 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 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).

Click the link below to learn more about the spread of misinformation with regard to the AIDS and COVID pandemics:

<u>Misinformation is a Common Thread Between the COVID-19 and HIV/AIDS Pandemics — With Deadly Consequences</u>

46

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, HIV/AIDS, and COVID-19.
- 2. 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

Below are a list of supplementary resources for students interested in learning more about the chapter topics. <u>These resources are NOT required course materials</u>. A list of required course materials, beyond those found throughout this chapter, are provided on the following page.

Additional Readings

Canada. (December 2022). *Post-COVID condition in Canada: What we know, what we don't know and a framework for action*. Office of the Chief Science Advisor of Canada. https://science.gc.ca/site/science.gc.ca/site/science/en/office-chief-science-advisor/initiatives-covid-19/post-covid-19-condition-canada-what-we-know-what-we-dont-know-and-framework-action

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

and-moralistic-images-of-1980s-still-haunt-our-view-of-hiv-that-must-change-106580

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

Jarus, O. (November 15, 2021). *The worst epidemics and pandemics in history*. Live Science. https://www.livescience.com/worst-epidemics-and-pandemics-in-history.html

Landau, M. (July 22, 2021). Vaccines are highly unlikely to cause side effects long after getting the shot. *National Geographic*. https://www.nationalgeographic.com/science/article/vaccines-are-highly-unlikely-to-cause-side-effects-long-after-getting-the-shot-

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

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

47

5.9 Required Chapter Materials

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

Required Chapter 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*. https://theconversation.com/coronavirus-and-the-black-death-spread-of-misinformation-and-xenophobia-shows-we-havent-learned-from-our-past-132802

De Witte, M. (April 30, 2020). *Past pandemics redistributed income between the rich and poor, according to Stanford historian*. Stanford News. https://news.stanford.edu/2020/04/30/pandemics-catalyze-social-economic-change/

McMullan, L., Blight, G., Gutierrez, P. & Levett, C. (April 29, 2020). How humans have reacted to pandemics throughout history – A visual guide. *The Guardian*. https://www.theguardian.com/society/ng-interactive/2020/apr/29/how-humans-have-reacted-to-pandemics-through-history-a-visual-guide

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. https://www.frontiersin.org/articles/10.3389/fpubh.2021.630449/full

Varlik, N. (October 26, 2021). From Black Death to COVID-19, pandemics have always pushed people to honor death and celebrate life. *TheConversation.com*. https://theconversation.com/from-black-death-to-covid-19-pandemics-have-always-pushed-people-to-honor-death-and-celebrate-life-170517

48

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, conduct research on it, and create a narrated slideshow presentation using PowerPoint (all University of Windsor students have access to the MS Software Suite) that provides information and a detailed background on your chosen pandemic, as per the questions below (an example of a narrated slideshow MP4, created by Jessica Popescu in 2022, is provided at bottom of this page). The pandemic chosen for the assignment CANNOT be among the four pandemics focused on in this chapter or SARS. It is important to: (1) complete all chapter materials (chapter content, including all embedded links to readings and videos, and the required course materials) prior to starting the assignment; and (2) cite relevant course material (from current and previous chapters) and material from your research on your chosen pandemic throughout your assignment to support your points, credit sources of concepts/ideas, and demonstrate completion of assigned course materials.

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.
- Presentation must be 3-5 minutes in length (no longer than 5 minutes).
- PowerPoint presentations should have between 6 and 8 content slides (10 slides maximum including a title page slide and a reference slide). Be sure to build in slide transitions and slide animations to make the slide show more engaging.
- The final slide must be a reference slide (APA format). Narration is not part of this slide.
- Be sure to include images and photographs (these must be properly sourced).
- Videos CANNOT be incorporated in the narrated presentation.
- Use proper APA in-text citation style to support points, credit sources of concepts/ideas, demonstrate research completed for assignment, and completion of assigned course materials on slides AND in the speaker notes for each slide. One citation at the bottom of the slide or after the last bullet point is not sufficient.

- Avoid putting too much text on a slide. If you are making the font smaller on some slides, then there is too much content. Remember that slide content is typically in point form and the narration allows for elaboration. Recording yourself simply reading the slide content is NOT the same as slide narration. Slide narration expands/provides more details on slide content.
- For slide content, paraphrase and use point form as opposed to relying on full sentences and direct quotes.
- Proofread slides for typographical errors and to make sure slide content is clear, well written, and intelligible.
- Create speaker notes for each slide within Power point. This helps guide you during the recording of your slide narrations. Be sure to expand on slide content (not simply read slide content) and provide sourcing/citations (on both slides and in speaker notes).
- When recording narrations, speak slowly and clearly. If you are rushing through your speaker notes then you have too much content. It is usually best to record your narration one slide at time. This enables you to check how you sound, make adjustments, and re-record smaller amounts of your presentation.
- Proof slide narrations. Check to make sure your voice level is consistent and that you do not stumble over your words. Re-record any individual slides where there is a problem.
- Setup narrated slide show and narration to automatically play (no clicks required after the one to start the MP4) from the first slide through to the final slide.
- When your document is complete, "save as" an MP4 format (use "export to" to convert to MP4 format or do a Google search for instructions). Click the link to learn more about converting narrated PowerPoint presentations to MP4 format https://support.microsoft.com/en-gb/office/save-a-presentation-as-a-movie-file-or-mp4-4e1ebcc1-f46b-47b6-922a-bac76c4a5691
- Convert your PowerPoint speaker notes used for your narration to PDF and submit as part of your assignment (i.e., you are required to submit BOTH the MP4 of your narrated video slideshow AND a PDF of your speaker notes). Click here to see how to prepare slides with speaker notes to print or save as PDF (instructions for PC, MAC and Web are available under the video). https://support.microsoft.com/en-us/office/print-speaker-notes-c7231a54-4ac8-4479-9199-6005a40efa2a. To save as PDF, for a PC be sure to change your printer to "PDF". For a Mac make sure the bottom left box indicates "PDF" or "save as PDF" rather than printing.

Steps to Completing the Assignment

- 1. Identify a pandemic that is not among the four focused on in the chapter materials, nor SARS.
- 2. Research the identified pandemic and find a <u>minimum</u> 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), including slides with narration. There are several ways to add narrations to your slideshow (there is an option to add a video of you speaking, but this is not necessary). Click this link to learn more about creating narrated PowerPoint slideshows https://support.microsoft.com/en-us/office/record-a-slide-show-with-narration-and-slide-timings-0b9502c6-5f6c-40ae-ble7-e47d8741161c. There are instructions on this page for PC, MAC and Web versions of PowerPoint.
- 4. In the slides, address the questions below. Questions do not need to be answered in order. Given the number of questions that must be answered, some questions should be addressed on the

- same slide as others. Combine those that logically go together.
- 5. Support the points/arguments on slides and speaker notes with APA in-text citations that reference the materials you have found in your research, and those that are in the chapter and eBook. <u>In-text citations to support your points/arguments are essential and required</u>. Be sure to use a diverse range of materials (from current and previous chapters) as opposed to relying heavily on one, or a few sources.
- 6. 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, and any submitted speaker notes, can be included in a reference section. This slide should contain no voice over.

The following must be submitted for the assignment

- A MP4 version of the slideshow presentation as detailed above. Please note: When uploading to the course website, it may take up to 10 minutes after hitting submit for the file to upload. Please be patient. Be sure to record the submission confirmation number.
- A PDF of your slides with speaker notes. See above for further instructions.

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?
- 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.

Narrated Slideshow MP4 Example

The following narrated slideshow MP4, created by Jessica Popescu (2022), provides an excellent illustration of a narrated slideshow MP4. Please note that the topic used for this slideshow, SARs, is NOT a permitted topic for this chapter's assignment.

One or more interactive elements has been excluded from this version of the text. You can view them

5.11 References & Media Attributions

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VI

Chapter 6: Genocide



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.

^① 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.
- 3. 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.

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=179#oembed-1

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 has only been ratified by 153 States (United Nations, n.d.-a), 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.

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=179#oembed-2

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>. <u>Genocide Convention Fact-Sheet. UN.org.</u>)

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/deathanddying2nded/?p=179#oembed-3

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 between 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 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.

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52

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 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 state-sanctioned 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: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=182#oembed-1

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; confiscation of belongings and assets; forced to live in 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).



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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54

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 contracting 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). (Click "Watch on YouTube" below to access the video).

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=189#oembed-1

55

6.5 The Genocide of Indigenous Peoples in Canada

From the actions of European settlers during <u>colonization</u>to Canadian Government policies, such as the <u>Residential School</u> (IRS) system and the <u>Sixties Scoop</u>, 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 <u>Truth and Reconciliation Commission</u> (TRC) as <u>cultural genocide</u> (ATPN, 2015; Canada, n.d.; NCCIH, 2014; Staniforth, 2015). The findings of the <u>National Inquiry into Missing and Murdered Indigenous Women and Girls</u> (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 number 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 murdered and missing Indigenous women 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:

No Longer 'The Disappeared': Mourning the 215 Children Found in Graves at Kamloops....Residential School (Warning: Article contains use of some not up-to-date language illustrative of the language used when developing the RS school plan)

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

VIDEO: Is it Really Genocide? In Canada?

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: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=193#oembed-1

56

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

Below are a list of supplementary resources for students interested in learning more about the chapter topics. <u>These resources are NOT required course materials</u>. A list of required course materials, beyond those found throughout this chapter, are provided on the following page.

Additional Viewings

CBC. (2012). We were children [Video]. CBC Gem. https://gem.cbc.ca/media/we-were-children/s175

CBC News. (June 22, 2018). *Separating children from parents: The Sixties Scoop in Canada* [Video]. YouTube. https://youtu.be/ nmd6HXKXYU

Clod, L. (2015). *Genocide worse than war full length documentary PBS* [Video]. YouTube. https://youtu.be/vsMe7QvqpaU (Warning: This is a very difficult documentary to view).

Fairfax Network – Fairfax Country Public Schools. (January 28, 2016). *Surviving the Holocaust: Full show* [Video]. YouTube. https://youtu.be/ayN-IhDYBBQ

LADbible TV. (October 24, 2021). *I saw people being beheaded and eaten by dogs* [Video]. YouTube. https://youtu.be/owNlSNNd7tw (Warning: A survivor's story that is very difficult and distressing to listen to).

United States Holocaust Memorial Museum. (January 13, 2014). *The path to Nazi genocide* [Video]. Youtube. https://www.youtube.com/watch?v=sRcNq4OYTyE&t=8s (Warning: The content of this video may be difficult to watch).

United Nations. (September 5, 2019). *The Genocide Convention: A Call for Action* [Video]. Kaltura. https://cdnapisec.kaltura.com/index.php/extwidget/preview/partner_id/2503451/uiconf_id/43914941/entry_id/1_et29yipm/embed/dynamic

Additional Readings

Deer, K. (September 29, 2021). Why it's difficult to put a number on how many children died at residential schools. *CBC News*. https://www.cbc.ca/news/indigenous/residential-school-children-deaths-numbers-1.6182456

National Inquiry into Missing and Murdered Indigenous Women and Girls (MMIWG). (2019). *A legal analysis of Genocide: Supplementary report*. https://www.mmiwg-ffada.ca/wp-content/uploads/2019/06/Supplementary-Report Genocide.pdf

Staniforth, J. (June 10, 2015). 'Cultural genocide'? No, Canada committed regular genocide. *Toronto Star.* https://www.thestar.com/opinion/commentary/2015/06/10/cultural-genocide-no-canada-committed-regular-genocide.html

Taylor, A. (October 16, 2011). World War II: The Holocaust. *The Atlantic*. https://www.theatlantic.com/photo/2011/10/world-war-ii-the-holocaust/100170/ (Warning: Very difficult images to view).

Wiesel, E. (1972). *Night*. New York: Hill & Wang. https://us.macmillan.com/books/9780374500016/ night (Warning: This book is a difficult read).

57

6.7 Required Chapter Materials

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

Required Chapter 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*. https://www.utm.utoronto.ca/communications/media/240/download?inline (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 a series of questions about that genocide. It is important to: (1) complete all chapter materials (chapter content, including all embedded links to readings and videos, and the required course materials) prior to starting the assignment; and (2) cite relevant course material (from current and previous chapters) throughout your assignment to support your points, credit sources of concepts/ideas, and demonstrate completion of assigned course materials.

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.
- Use APA in-text citation style to support points, credit sources of concepts/ideas, demonstrate research completed for assignment and completion of assigned course materials.
- 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. Properly sourced, essay style 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 5 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 1 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 (ALL questions need to be addressed in your essay).
- 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 and eBook. <u>In-text citations to support your points/arguments are essential and required</u>. Be sure to use a diverse range of course materials (from current and previous chapters) 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? Be sure to use the material from Ch.6.1, especially the required viewing *International Law in Action II 1.3 Core Crimes Genocide* to help answer this question.

59

6.9 References & Media Attributions

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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, and 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.

61

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



Person in blue medical scrubs holding the hand of a patient in a hospital bed.

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 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 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, something that 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 providing 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).

62

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: 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/deathanddying2nded/?p=210#oembed-2

Click the link below to learn more about palliative care:

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/deathanddying2nded/?p=210#oembed-1

63

7.3 What is Hospice Care?

Hospice Care



Two people holding hands.

The modern-day concept of hospice as a place for end-of-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 of 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).

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.

Click the link below to learn about a new hospice that opened in Windsor ON in November 2022 to serve the needs of people experiencing housing insecurity:

Windsor's only hospice for people experiencing homelessness says needs are high

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)

64

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 national guiding principles that are fundamental to the provision of high-quality palliative care (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).

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/deathanddying2nded/?p=216#oembed-1

65

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

In a Nutshell: The Special Joint Committee on MAiD and Advanced Requests

Medical Assistance in Dying

Click the following link to learn about challenges to/alternative perspectives on Canadian MAiD legislation:

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

7.6 Dying with Dignity Advocacy Organizations

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



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

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 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.

Click the following link to learn about the history of Dying with Dignity Canada:

Dying wth Dignity Canada: How far we have come. Dying with Dignity Canada.

Dying with Dignity Canada (n.d.-b) is also fighting for the rights of people to receive MAiD in the location of their choice. 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 about the challenges that people seeking MAiD can face:

When a hospital denies MAiD: A forced transfer story.

7.7 Assisted Dying Around the World



Elderly couple holding hands in hospital.

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, Portugal, 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; Sodha, May 12, 2023). There is also a range of terms used to refer to the various processes tied to assisted dying.

Assisted Dying Terminology

Current 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)

Outdated and inaccurate 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"



<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.

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).

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 USA & 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, March 8, 2023). "Since the law was passed in 1997, a total of 3,712 people have received prescriptions under the DWDA and 2,454 people (66%) have died from ingesting the medications" (Oregon Health Authority, March 8, 2023, p. 6). 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/deathanddying2nded/?p=226#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 Additional Resources section of this Chapter) (Click "Watch on YouTube" below to access the video).

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=226#oembed-2

68

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.
- 2. 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

Below are a list of supplementary resources for students interested in learning more about the chapter topics. <u>These resources are NOT required course materials</u>. A list of required course materials, beyond those found throughout this chapter, are provided on the following page.

Additional Viewings

Dying with Dignity Canada. (April 15, 2024). *In my own time* [Video]. YouTube. https://youtu.be/aTLMJ6PSyWo?si=10ULvMVuizjrDEZ7

Shared Wisdom Network. (October 12, 2022). *Living & dying: A love story* (Full documentary) [Video]. YouTube.com. https://youtu.be/K7WYimyuvE8?si=uNRnw7PYFxnmcHv7

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

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

Additional Readings

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

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

Websites

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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/hc-sc/documents/services/health-care-system/reports-publications/palliative-care/framework-palliative-care-canada.pdf

MAiDHouse. (n.d.). https://www.maidhouse.ca/

Ontario. (June 28, 2024). *Palliative and end-of-life care*. Ministry of Health. https://www.ontario.ca/page/palliative-and-end-life-care

7.9 Required Chapter Materials

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

Required Chapter Viewings

Canadian Virtual Hospice. (January 21, 2008). *Canadian Virtual Hospice palliative care video* [Video]. YouTube. https://youtu.be/ZWLoQkJD0WA

Covenant Health Canada (October 3, 2019). *What is palliative care* [Video]. YouTube. https://youtu.be/Mc5ImaOciR4

Required Chapter Readings

Aleccia, J. (May 15, 2019). *'Living their values': Palliative care power couple faces cancer at home*. KHN. https://khn.org/news/living-their-values-palliative-care-power-couple-faces-cancer-at-home/

Canada. (March 14, 2023). *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

Final days. (n.d.) Cancer Research UK. https://www.cancerresearchuk.org/about-cancer/coping/dying-with-cancer/last-few-weeks-and-days/final-days

Grant, M., Collins, A. & Philip, J. (October 29, 2017). What is palliative care? A patient's journal through the system. *TheConversation.com*. https://theconversation.com/what-is-palliative-care-a-patients-journey-through-the-system-82246

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*. https://theconversation.com/dying-virtually-pandemic-drives-medically-assisted-deaths-online-139093

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-assisted-deaths-1.6224353

Moura, C. (January 25, 2021). Dear Grandma. Canadian Medical Association Journal, 193(4).

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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-their-exits#:~: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. *TheConversation.com*. https://theconversation.com/end-of-life-care-people-should-have-the-option-of-general-anaesthesia-as-they-die-159653

70

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 (ideally within the Windsor/Essex region, but can also be a municipal or regional organization within the province of Ontario) that provides palliative (at home or in a dedicated health care facility), hospice, and/or MAiD-related services. It is important to: (1) complete all chapter materials (chapter content, including all embedded links to readings and videos, and the required course materials) prior to starting the assignment; and (2) cite relevant course material (from current and previous chapters) throughout your assignment to support your points, credit sources of concepts/ideas, and demonstrate completion of assigned course materials.

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.
- Use APA in-text citation style to support points, credit sources of concepts/ideas, demonstrate research completed for assignment and completion of assigned course materials.
- 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 (see above for details on what constitutes local for this 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 and eBook. <u>In-text citations that source/support your information/points are essential and required</u>. Be sure to use a diverse range of materials (from current and previous chapters) 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. A properly sourced 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.
- 4. Optional: Any supplementary materials you wish to include must be placed in proper APA style appendices.

71

7.11 References & Media Attributions

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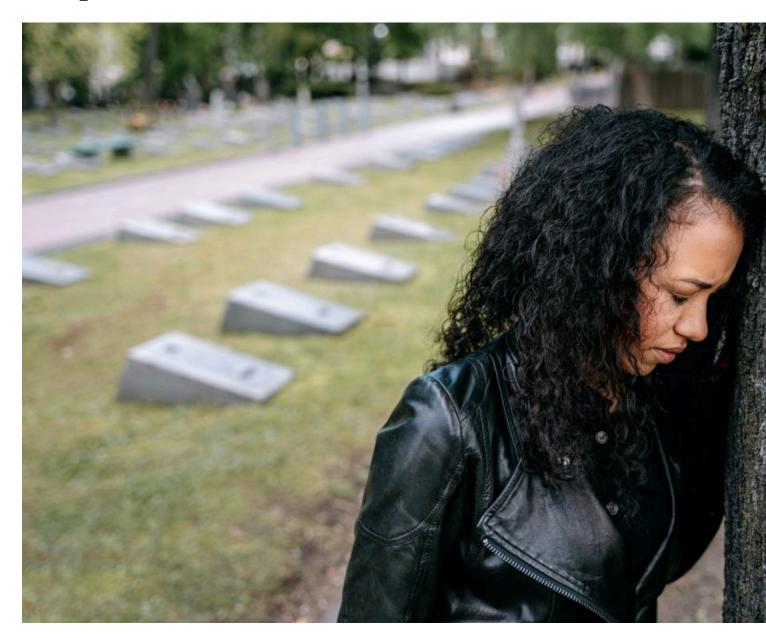
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Chapter 8: Grief, Loss & Bereavement



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?
- 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?

73

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.). According to the Canadian Centre for Addiction and Mental Health (CAMH, n.d., para. 4), some common reactions associated with grief include: "shock, disbelief

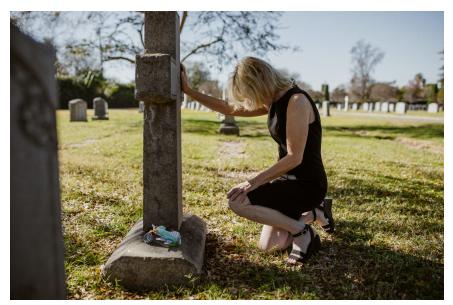
and confusion; anger; trouble concentrating and focusing on tasks; altered patterns of eating and sleeping; physical changes such as dizziness, headaches or upset stomach; sadness and yearning; memories and thoughts about who or what has been lost; and withdrawing from usual activities".



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 life 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 processes 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.
- 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 people who 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: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=246#oembed-1

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/deathanddying2nded/?p=249#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



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

COVID-19 Related Loss

Much of the media coverage on the COVID-19 pandemic and the resulting Public Health Emergency of International Concern (PHEIC) (March 11, 2020-May 5, 2023) (WHO, n.d.) focused on the number of people who were gravely ill and who had died from the virus. Although we saw and heard the daily hospitalization and death statistics, we rarely heard about all of those people, families and communities experiencing mourning and grief. According to Cadell (2021, para. 11), however, "it is estimated that for every one person who… [died from COVID-19], there… [were] five left grieving those loses."

As noted in the previous sections of this chapter, grief is not just a reaction to losses tied to death, it can be associated with other forms of loss. During the PHEIC tied to the COVID-19 pandemic, many people experienced loss on multiple levels. There were the losses tied to physical, economic, and housing security. There was 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 also lost 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 were the losses associated with the pandemic's impact on healthcare, education, and world economic stability and peace (Weir, 2020). Not only did postponing, curtailing, or eliminating end-of-life rituals impact both how we mourned the dead and grieved (see Chapter on Cultural & Religious Beliefs & Death-Related Practices), it impacted how we grieved all of these other types of losses (Cadell, 2021; Phillips, 2021).

The Need for a National Grief Strategy

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). Since the Canadian Grief Alliance (CGA) was formed by the Canadian Virtual Hospice in 2020, it has called for government funding of a national grief strategy (Cadell, 2021). The importance of this initiative has grown exponentially due to COVID-19, shedding light on the importance and necessity of a government implemented 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 grief (Cadell, 2021, p.). In November 2023, the Canadian Government announced one million dollars in funding to the CGA, marking the first step towards providing support for grieving Canadians (CGA, November 16, 2023).

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

78

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

Below are a list of supplementary resources for students interested in learning more about the chapter topics. <u>These resources are NOT required course materials</u>. A list of required course materials, beyond those found throughout this chapter, are provided on the following page.

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/education-2021/community-resource-sheets/grieving-resources-pdf.pdf

Pierce, J. (2014). *The last walk: Reflections on our pets at the end of their lives*. University of Chicago Press. https://press.uchicago.edu/ucp/books/book/chicago/L/bo11097201.html

Websites

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

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

79

8.7 Required Chapter Materials

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

Required Chapter Viewings

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

TEDx Talks (September 9, 2020). *The journey of grieving, feeling and healing* | *Dr. Edith Eva Eger* [Video]. YouTube. https://youtu.be/Cwdo8_gwjog (Watch to 11 minute mark).

Required Chapter Readings

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

Conrad, M. (June 17, 2021). Anticipatory grief: What it is and how to cope. *Forbes Health*. https://www.forbes.com/health/mind/what-is-anticipatory-grief/

Hickey, H., & Dell, H. (August 24, 2017). Singing death: why music and grief go hand in hand. *TheConversation.com*. https://theconversation.com/singing-death-why-music-and-grief-go-hand-in-hand-81679

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

80

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: (1) complete all chapter materials (chapter content, including all embedded links to readings and videos, and the required course materials) prior to starting the assignment; and (2) cite relevant course material (from current and previous chapters) throughout your assignment to support your points, credit sources of concepts/ideas, and demonstrate completion of assigned course materials.

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

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.
- Use APA in-text citation style to support points, credit sources of concepts/ideas, demonstrate research completed for assignment and completion of assigned course materials.
- Paraphrase as opposed to relying on direct quotes.
- Use an APA style appendix to organize assignment.
- Proofread your submission to make sure it is clear, well written and intelligible.

Steps to Completing the Assignment

- a. Watch the video above (Craftspace. (n.d.). *Craft in Common with artist Alinah Azadeh* [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. Support information/points you make in your essay with in-text citations that reference course materials. In-text citations that source/support your information/points are essential and required. Be sure to use a diverse range of materials (from current and previous chapters) as opposed to relying heavily on one, or a few sources.

Assignment Submissions must Include

- 1. A proper APA style cover page.
- 2. A properly sourced reflection paper.
- 3. An APA style reference section.
- 4. An APA style appendix containing 2 to 3 images of your memory object.

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

81

8.9 References & Media Attributions

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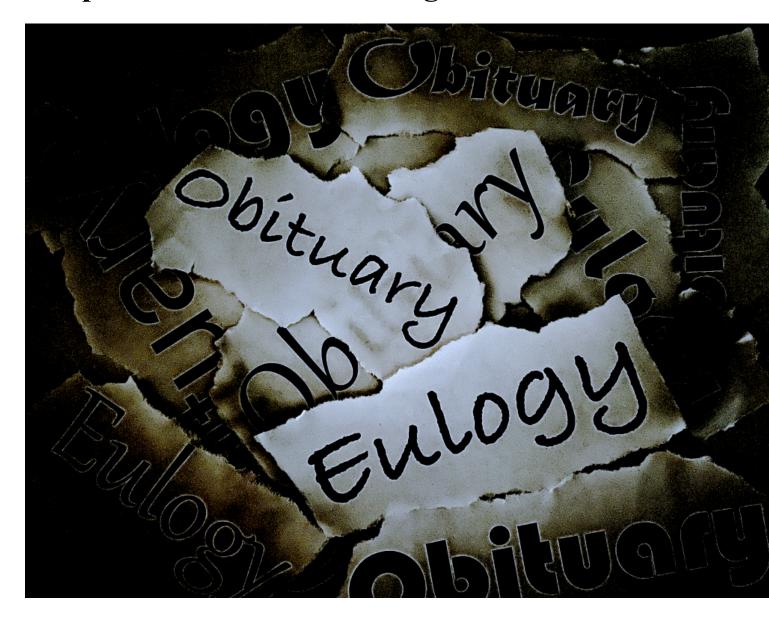
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Chapter 9 Obituaries & Eulogies



Jacqueline Lewis

82

9.1 Introduction

Chapter Introduction

What happens in the social world when people die. Typically, deaths are announced, lives lived are

acknowledged, people are memorialized, celebrated, grieved and remembered. The process via which these things occur involves various forms of death-related communication, such as death notices, obituaries, eulogies, funeral home memorial programs, gravestone inscriptions, and memorial websites. The forms of communication occur shortly after death, prior to and after body disposal, and/or as part of events held post-death, including funerals, celebrations of life, and religious ceremonies. Although often left until after a death, the planning and writing of each can occur prior to death, and can involve the person for whom they are created. This chapter explores common death-related communications in North American society, focusing primarily on obituaries and eulogies.

Chapter Objectives/Learning Outcomes

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

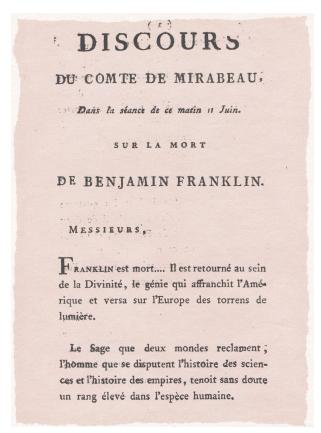
- 1. The functions and purposes of death notices and obituaries
- 2. The functions and purposes of elegies and eulogies.
- 3. Strategies for obituary writing.
- 4. Strategies for writing and giving a eulogy.

Questions to Think About When Completing Chapter Materials

- 1. What are the similarities and differences between death notices and obituaries?
- 2. What are the similarities and differences between elegies and eulogies?
- 3. What are the similarities and differences between obituaries and eulogies?
- 4. How do you want to be remembered at the end of your life?
- 5. What would you want included in your obituary and eulogy?

9.2 Death Notices & Obituaries

What are Death Notices?



Benjamin Franklin's Death Notice (1790).

Death Notices are announcements that someone has died. They are typically published in newspapers (print or online), posted in social common areas for public consumption (see Queen Elizabeth II death notice below), and increasingly are appearing in online spaces. Beyond containing the name of the individual who has died and when they died, death notices provide a limited amount of information, such as details on any post-death event to honour the deceased (e.g., funeral, memorial service, or celebration of life — if the event is open to the public — links to virtual broadcasts) and information on the family's and/or deceased individual's preferences for flowers or charitable donations.

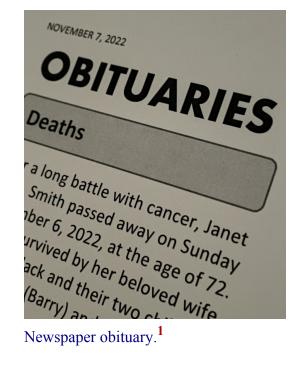


Queen Elizabeth II Death Notice, Holyroodhouse Palace, Edinburgh, Scotland (2022).

The posting and/or distributing of hand written death notices date back to the Roman <u>Acta Diurna</u> (meaning "Daily Acts" or "Daily Public Record") (The history, February 9, 2017) of around 59 BCE (Roos, December 3, 2019; The Origins, October 6, 2020). Printed death notices first appeared in the places colonized by Britain in the 1500s. The evolution of the printing press from the 14th century in Europe, through to the 20th century, made it increasingly easier and less costly to produce longer announcements. This allowed short death notices to transition into longer obituaries and provided more families access to this mode of death announcement (History of obituaries, n.d.; Roos, December 3, 2019).

What are Obituaries?

The term obituary is derived from the Latin word "obitarius" or "record of death" (Szczesniak, n.d.). Its use can be traced back to the early 18th century (Eulogy vs obituary, July 5, 2022). Obituaries are expanded forms of death notices that are published typically in newspapers (print or online), funeral home memorial programs and websites, and dedicated obituary/memorial websites (e.g., everloved.com, forevermissed.com, legacy.com). In addition to providing the details found in a basic death announcement, obituaries include a short biographical sketch of the deceased (Campbell, March 4, 2019). Other details included: date and place of birth (including parent's names) and death, full name, date and place of marriage, education, career, achievements, accomplishments, contributions, passions and hobbies, and sometimes cause of death (Spector, September 21, 2019).



Both surviving and predeceased family members are also acknowledged, starting with the closest relation (usually the spouse). Obituaries typically conclude with information on any post-death event for the deceased (including web links/addresses if the event will be broadcast online and/or will be available to view after the fact) (How to write, June 23, 2022; Lastly.com., n.d.-b) and special messages, such as notes of thanks (e.g., to hospice or hospital staff), requests for donations and sometimes short communications (e.g., "Mum, you are always in our hearts", "gone but not forgotten", or part of poem, song lyric or prayer) (How to write, June 23, 2022).

As they are meant to capture the essence of and pay tribute to the deceased (Writing an obituary, December 13, 2019), the tone of obituaries vary depending upon who the deceased was. They can be formal and traditional, somber and respectful, emotional and touching, light-hearted and humorous (see Kay Heggestad's and Joe Heller's obituaries below), or some combination of these. Even more somber or touching obituaries may contain a humorous anecdote about the deceased. According to Spector (September 12, 2019), except in the case of tragic deaths, people are increasingly moving away from more traditional style obituaries towards those that include "humor, flair, wit, [and] personality" (para. 6).

Writing an obituary is a task we all will likely have to undertake in our lives. It is something that has to be produced rather quickly, but requires thought, research and effort. Although not an easy task, the experience of researching (e.g., interviewing bereaved family and close friends about the deceased) and writing an obituary can have the apeutic benefits, for both the person writing the obituary and the grieving family and friends (How to write, June 23, 2022).

Obituary Examples

Click the following links to read a few longer online obituaries:

Jonathan Cooper (2021)

Joe Heller (2019)

Lee Maracle (2021)

¹ © Warning: Language around cancer that uses wartime rhetoric (e.g., battle, fight, warrior, beat, etc.) can be experienced differently by different people. For some, it may be viewed as acceptable or even helpful, while for others, typically those who are unlikely to or will not "win their battle", this language can be isolating, uncomfortable and frustrating. To learn more watch the NFB documentary *Pink Ribbons Inc*.

84

9.3 Bias in Death Notices & Obituaries



Susan Maxwell's (1923) obituary is a rare example of an obituary for a racialized woman in the early 1900s in Canada.

What is interesting when looking at the history of death notices and obituaries, is who is honoured and acknowledged and who is not. Historically there has been a tendency for obituaries to predominately acknowledge the deaths of white men, particularly affluent men (Starck, 2008). What began with the early Roman death notices that honoured only notable male citizens (The Origin, October 6, 2020), continued through the centuries. The result is that many people and their loved ones have been denied

public recognition of their deaths and tributes to their lives.

In 2018, The New York Times (NYT) publicly acknowledged their history of biased obituary publishing practices. As noted by Padnanni and Bennett (March 8, 2018), the NYT admitted that from 1851 to 2018 their obituary section has been dominated by men, predominately white men. In an effort to correct this injustice, it began publishing an online website entitled "Overlooked" (2018), that features obituaries/ stories of "other remarkable people" who have died over the years. The "Overlooked" project continues to grow as more people are regularly added to the website.

Click the following link to read more about the NYT "Overlooked" project:

'The New York Times' is publishing obituaries of previously 'overlooked' women like Charlotte Bronte and Ida B. Wells

Click the links below to view the NYT's "Overlooked" webpages:

Overlooked

Obituaries: Overlooked



Viola Desmond on Canadian \$10 bill.

Click the following link to read about the life of Viola Desmond. Although not a traditional obituary, it is an "overlooked" and long awaited Canadian tribute to Viola Desmond, honouring her life and her civil rights activism that began in Nova Scotia in the 1940s. The 2017 tribute was published online the year prior to the release of the Canadian \$10 note featuring her image (see image to right).

Viola Desmond (1965)

9.4 Obituary Writing



Essential Elements of Obituaries

- Announce the death.
- Provide a short biography that illuminates who the deceased person was.
- Identify the bereaved family members.
- Provide details for events to honour the deceased and support the family members.
- Include "special messages" (e.g., donations, thank/recognition, message to the deceased, a lyric from a song, a stanza from a poem, a short prayer, etc.).
- A photograph of the deceased.
- Choose where to publish (e.g., newspaper, funeral home memorial program, funeral home website, dedicated memorial website).

(How to write, June 23, 2022; Lastly, n.d.-a; Writing an Obituary, December 12, 2019).

Click the following links to learn more about the essential elements of obituaries, and how to write an engaging and meaningful one:

How to write an obituary

How to write the perfect obituary, according to professional writers

VIDEO: How do I write an obituary?

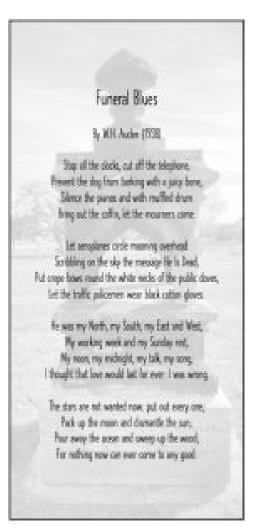
In the following video, Eric from "The Obituary App", explains how to write an obituary, elaborating on and covering some important material in the two previous readings.

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=280#oembed-1

9.5 Elegies & Eulogies



What is an Elegy?



"Funeral Blues" over cemetery stone.

Elegies are expressions of loss and mourning (Elegy, April 14, 2022). The word elegy is derived from the Greek word élegos, or funeral lament (Hirschi, 2014). "The poetry of lamentation, which arose in oral literature..., seems to exist in all languages and poetries" (e.g., ancient Egyptian, ancient Greek, Hebrew, Chinese, Sanskrit, Zulu) (Lament, n.d. para. 1). Elegies or lamentations can take various forms, ranging from meditative poems (sometimes accompanied by a flute, violin or piano) (Hirschi, 2014) to mournful songs (with or without lyrics). Although traditional elegies are outpourings of grief tied to death, in more recent times the use of elegies has expanded to include lamentations for someone or something that is gone or inaccessible, including lost loves tied to the ending of relationships, or as a personal reflection on loss and/or death (Buja, August 20, 2015).

Elegies

Funeral Blues (see poem, above right) is a famous elegy by W.H. Auden (1938). As with many funeral elegies, it is often read along with a quiet, somber musical accompaniment.

Below are three videos that provide illustrations of the various forms that elegies can take.

VIDEO: In Memoriam A.H.H. (Canto 27) By Lord Tenneyson — Poetry Reading #19

In the following video Peter Brown performs an excerpt from the elegy *In Memoriam*, penned by a devastated Lord Tennyson following the sudden death of his dear friend, Arthur Henry Hallam (In Memoriam AHH, n.d.).

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VIDEO: Neil Gow's 'Lament for the Death of His Second Wife'

In the following video, recorded at the Highwayman pub in Kidlington, Oxforshire UK, Jed Mugford, Kate McCullough and Mike Gardiner perform Neil Gow's haunting lament.

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MUSICAL PERFORMANCE: Condor's Lament

In the following musical recording, Painted Raven performs "Condor's Lament" from their 2004 CD *Spirit Journey*.

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What is a Eulogy?

A eulogy is a written speech to memorialize, honour, and pay tribute to the deceased (Campbell, March 4, 2019). The term eulogy comes from the Greek word "eulogia", meaning "praise" or "good" or "true

words" (Johnson, August 11, 2022; Szczesniak, n.d.). The giving of a eulogy "is the last formal, public testament to a dead person's life" (Mends, June 10, 2019). It is an opportunity to reflect on the person, what made them special or unique, the impact they had on other's lives, their accomplishments, their lifetime social contributions — in other words, how they will be remembered (Campbell, March 4, 2019). The goal being to capture "the essence of the person" (Prepare, n.d.).



President Obama giving eulogy for Reverend Clementa Pickney, killed during mass shooting at a church in Charleston SC.



Woman reading eulogy next to decorated cardboard coffin.

The tone of eulogies vary from somber, to light, with even some comical elements, depending on the person who is giving the eulogy, who is being eulogized, and how they died (Campbell, March 4, 2019) (see for example the eulogy given by John Cleese found via the link at the bottom of this page). The goal of a eulogy is to capture "the essence of the person", through sharing stories that illustrate who they were. Including humour in parts of the story(ies) shared can make people laugh or wistfully smile, easing anxiety and temporarily lighten the mood (Isaacs, September 18, 2012). However, humour may not be appropriate in eulogies for people who died young or tragically.

Once written, eulogies are typically delivered to audiences in attendance at funerals, graveside during burials or interments, wakes, and during celebrations of life (Meade, n.d). Eulogies are usually between 5 and 15 minutes in length. During COVID-19, we saw many of these tributes either being broadcast or

given online, increasing access and audience size.

Historically, eulogies were reserved for public figures. However, as familial/community proximity to death increased with the emergence and professionalization of the funeral industry in North America during the late 1800s (Lundgren & Houseman, 2010) (see Chapter on Historical Beliefs & Death-Related Practices), eulogies have become popularized as a way to honour our loved ones (Campbell, March 4, 2019).

Eulogy Videos

The first two eulogies are somber, heart-felt remembrances, delivered by family members of two Canadian police officers killed in the line of duty in 2022.

Click the link below to watch a CTV recording of Constable Shaelyn Yang's Eulogy:

'Shaelyn Yang was always a hero': Fallen RCMP officer's family pays tribute at her funeral

VIDEO: Daughter of Slain Toronto Const. Andrew Hong speaks at this funeral

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=287#oembed-4

The third eulogy is a tribute in honour of Albert Brenner Glickman, philanthropist and business leader, by a group of his grandchildren. It is a touching tribute of love and laughter. Glickman was a leader in the Michael J. Fox foundation for Parkinson's Research and was further eulogized at the same funeral service by Michael J. Fox.

VIDEO: Eulogy: The grandchildren

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=287#oembed-5

Click the following link to access an online document containing six eulogy videos. The videos illustrate a variety of approaches one can take to preparing a eulogy. The final eulogy, given by comedic actor John Cleese at Graham Chapman's Memorial service, provides some "light relief", part of which involves the use of the F___ word:

6 inspiring eulogy examples to draw from.

9.6 Eulogy Writing



Steps to Preparing a Eulogy

- Gather information and memories.
 - Talk to people who were close to the person.
 - Go through old photographs, letters/emails, videos, etc.
 - Do some research to learn more about things the person was passionate about or involved in (e.g., hobbies, favourite music, etc.).
- Organize your thoughts, write in stages (e.g., creating an outline and draft notes).
- Use storytelling as opposed to a list of details of the person's life.
- Decide on a theme.
- Decide on tone (e.g., somber, reflective, loving, humorous, etc.).
- Carefully choose the memories you will focus on.
- Be respectful. Do not talk about private or embarrassing things, or negative things that are out of character for the person.
- Think of and try to connect with your audience, do not make it all about your relationship with the deceased.
- Include moments meant to lighten the mood (i.e., through laughter).
- Close the eulogy (e.g., with a message to the deceased, a line from their favourite poem or song, their favourite quote, etc.).
- Write the eulogy out full.
- Seek feedback of the final product.

(7 Simple Tips, June 21, 2020; Eulogies & Obituaries, n.d.; Meade, n.d.; Lastly.com, n.d.-c)



Preparing to Deliver a Eulogy

- Practice and time your eulogy several times. Tape and listen to yourself to make sure you are projecting your voice and speaking slowly and clearly.
- Know your time limit.
- Know where your eulogy fits in the order of speakers.
- Know who your audience will be (e.g., family only or a larger more diverse group, in person and/or online).
- Know the context for the eulogy. Where will the eulogy take place. Will there be a podium for your notes? Will there be a microphone?
- Arrive early on the day you are giving the eulogy.
- Know that it is alright to show how you are feeling (i.e., choked up, tears).
- Make sure to bring a bottle of water and tissues.
- Remember to introduce yourself, to inform the audience how you know the deceased.
- Make eye contact with the audience during your delivery.

(Meade, n.d.; *How to write*, September 22, 2021).

How to Write a Eulogy

Click the following links to learn more about the essential components of a eulogy and how to go about writing and preparing to give an engaging and meaningful one:

How to give a eulogy that truly celebrates the person you're honoring

How to write a good eulogy for a funeral

VIDEO: How to Write a Eulogy

In this TEDx Talk, Bret Simner talks about how to give a eulogy and explains how "delivering a eulogy is an opportunity to share something beautiful".

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=291#oembed-1

88

9.7 How will you be remembered?

We all have some degree of control over how we will be remembered after our death. The way we live our lives and the daily choices that we make, impact how and for what we will be remembered.

According to the Academy of Ideas (January 31, 2018, 4:08), the problem is that too many of us waste time on things that are inconsequential, "of little...positive value" to our lives or the lives of others (e.g., bad/self-destructive habits, unhealthy relationships, dead-end jobs). We often move through life distracted, neither living in nor appreciating the present (Abramson, November 13, 2019), and failing to recognize that what we do, how we live our lives and treat others today, is a reflection of who we are, that will ultimately impact how we are remembered.

VIDEO: Rascal Flatts – How they remember you

The following lyric video of the Rascal Flatts song "How they will remember you" asks some important questions about how the choices we make and how we live our lives will impact how we are remembered after our 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/deathanddying2nded/?p=293#oembed-2

Although the notion of leaving a legacy is often associated with the future and the need to strive for some ideal of who we should be and what we should achieve during our lifetime, it is actually more about understanding ourselves and being true to that person (Bland, 2020). This involves knowing what a rewarding and satisfying life means to us, and how to achieve it (Bland, 2020; Payne et al., 2022). Taking the time to reflect on our lives (and deaths), through writing our own obituary and/or eulogy, can be a pathway toward self-understanding and a happier more fulfilling life (Abramson, November 12, 2019; Wong, 2017).

The idea of opening ourselves (and those around us) to honest, matter-of-fact conversations about life and death is part of the death positivity movement (see Chapter on Let's Talk About Death & Dying) (Walker, February 15, 2020). According to Bland (2020), the experience of reflecting on and writing our end-of-life narratives (i.e., obituaries and eulogies) can be transformative, particularly for young adults. It can lead to a "shift in...direction...a greater sense of acceptance, appreciation, and awe toward the possibilities of living the life" we envision (Bland, 2020, p. 1). Such exercises can be eye opening, serving as a wake-up call or "an aspirational guide" for our lives (Evans, 2017, para. 11).

What We Can Learn From Obituaries

VIDEO: What I learned from 2,000 obituaries

In this video Lux Narayan, co-founder and CEO of analytics firm Unmetric, talks about his team's research on New York Times obituaries and their findings regarding how "people make a positive dent in the social fabric of life."

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=293#oembed-3

Writing Your Own Obituary

Click the links below to learn about writing your own obituary:

'He was the greatest person ever': What would you write in your own obituary?

VIDEO: How to write your own obituary

In the following video, novelist Brad Meltzer talks about his experience with reading his own obituary and his struggle to answer the question of "how will you be remembered?"

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=293#oembed-4

Writing Your Own Eulogy

Click the following link to learn more about how to write your own eulogy:

A note from my dead self. Be Yourself

How to write a eulogy for yourself: Step-by-step

VIDEO: Imagine Your Own Funeral?

In this video, Kevin Shen asks a group of people to think about how they want to be remembered at their funeral, to write and share their own eulogy, and to talk about what they learned from this personal reflection exercise

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=293#oembed-1

89

9.8 Chapter Summary

Key Summary Points

- 1. There are various forms of death-related communications (e.g., death notices, obituaries, elegies, eulogies).
- 2. Death notices and obituaries are public notices of death. They differ in the amount of information they provide, with the former being much shorter (i.e., no biographical sketch, information on the family, or special messages).
- 3. Elegies and eulogies are similar in that they are given before an audience of attendees (i.e., at funerals, graveside, celebrations of life, etc.). The former is an expression of grief in the form of a mournful poem or song and the latter is a speech honouring and paying tribute to the deceased.
- 4. There are a number of elements that need to be included in an obituary. It is important to do research and make sure the information contained is accurate.
- 5. There are a series of steps involved in writing and preparing to give a eulogy. Although it can be a challenging task, it can also be a therapeutic exercise.

6. Writing one's own obituary and/or eulogy can be a powerful personal exercise and/or wake-up-call for the writer. Leaving a pre-written obituary and/or eulogy is also helpful for surviving family and friends, who then have one less thing to take care of while dealing with their grief and loss.

Additional Resources

Below are a list of supplementary resources for students interested in learning more about the chapter topics. <u>These resources are NOT required course materials</u>. A list of required course materials, beyond those found throughout this chapter, are provided on the following page.

Additional Viewings

TED. (March 23, 2017). What I learned from 2,000 obituaries – Lux Narayan [Video]. YouTube. https://youtu.be/JlbwchclCBo

TED. (February 20, 2019). *Millennials try writing their own eulogy* [Video]. YouTube. https://youtu.be/zl4DZtspowY

TED. (February 2, 2020). Eulogies for the living – Andrea Driessen [Video]. YouTube. https://youtu.be/6N0U6iri2As

Additional Readings

Barnett, R. (June 9, 2017). *What 2,000 deaths can teach us about living a good life*. Ideas.TED.com. https://ideas.ted.com/what-2000-deaths-can-teach-us-about-living-a-good-life/

Meade, L. (n.d.). Eulogy-Good Words. In *Advanced Public Speaking*. https://uark.pressbooks.pub/speaking/chapter/eulogy/

Tetrault, S. (August 22, 2022). *Guide to obituary etiquette: Predeceased family & more*. Joincake.com. https://www.joincake.com/blog/obituary-etiquette-predeceased/

Thompson, R. (April 8, 2017). *A guide to Facebook etiquette after someone has died*. Mashable.com. https://mashable.com/article/facebook-etiquette-grief

Williams, J. (2003). Obituaries. In C. Bryant & D. Peck (Eds.), *Handbook of death and dying* (pp. 694-702). SAGE Publications Inc. https://dx.doi.org/10.4135/9781412914291

Elegies & Eulogies by & for Famous People

ABC News. (June 10, 2016). *Muhammad Ali Funeral – Billy Crystal Eulogy* [Video]. YouTube. https://www.youtube.com/watch?v=7XB3sD9QJCI

Carlson, M. (January 2, 2022). Betty White obituary. TheGuardian.com. https://www.theguardian.com/tv-and-radio/2022/jan/02/betty-white-obituary

CNN. (June 6, 2015). *Obama delivers Beau Biden's eulogy* [Video]. YouTube. https://youtu.be/SEe6Bnw1w3I

Paiz, K. (May 11, 2018). *Billy Crystal's Robin Williams Eulogy* [Video]. YouTube. https://youtu.be/wgNgwFcLy90

Schultz, P. (November 3, 2008). *Big bird at Jim Henson's memorial* [Video]. YouTube. https://youtu.be/lrzyMptC2eQ

Waterstones. (October 13, 2022). *Emma Thompson's moving tribute to Alan Rickman* [Video]. YouTube. https://youtu.be/bo9b0rLQYUc

WX11 12 News. (June 7, 2014). Full remarks: First Lady Michelle Obama [Video]. YouTube. https://youtu.be/fTrqFE1nbIc

90

9.9 Required Chapter Materials

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

Required Chapter Viewings

TED. (August 15, 2022). *The profound power of gratitude and "living eulogies" – Andrea Driessen* [Video]. YouTube. https://youtu.be/CaqaMwfYk 4

Required Chapter Readings

Abramson, A. (November 3, 2019). Why you should spend time thinking about your own death. Forge. https://forge.medium.com/why-you-should-spend-time-thinking-about-your-own-death-6b4c122e1fa0

Before I Die Project. (n.d.). *The story: Artist Candy Chang shares the story of how the Before I Die Project came to be.* https://beforeidieproject.com/story/

Death & social media: 10 dos and don'ts for social platforms. (n.d.). FuneralBasics. https://www.funeralbasics.org/death-social-media-10-dos-and-donts-for-social-platforms/

Ganger, B. (June 11, 2021). *How to announce a death on social media*. Beyond the Dash. https://beyondthedash.com/blog/etiquette-and-advice/how-to-announce-a-death-on-social-media/4951

Walker, R. (February 15, 2020). *Dearly beloved, we are gathered here today ... to write our obituaries*. The Guardian. https://www.theguardian.com/society/2020/feb/15/dearly-beloved-we-are-gathered-here-today-to-write-our-own-obituaries

9.10 Chapter Assignment

Obituaries & Eulogies Assignment

This chapter's assignment is about writing obituaries and eulogies. There are two options to select from for this assignment: writing your own obituary or writing your own eulogy. There are three parts to completing the assignment (for either option), the first two parts require you to write different versions of your obituary or eulogy, and the third part involves reflecting on your experience writing your obituary or eulogy. It is important to: (1) complete all chapter materials (chapter content, including all embedded links to readings and videos, and the required course materials) prior to starting the assignment; and (2) cite relevant course material (from current and previous chapters) throughout your assignment to support your points, credit sources of concepts/ideas, and demonstrate completion of assigned course materials.

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 in obituaries/eulogies and the short reflection paper.
- Use APA in-text citation style to support points, credit sources of concepts/ideas, and demonstrate completion of assigned course materials.
- Proofread your submission to make sure it is clear, well written and intelligible.

Options for Chapter #9 Assignment

Option 1

Write two personal obituaries (obituaries for yourself), one for if you were to die tomorrow and the other for if you died at your normal life expectancy, and a reflection paper based on the obituary writing exercise. Be sure to use and cite the resources on obituary writing from the chapter to help you outline and frame your obituaries and reflection paper. If you use an obituary template to help construct your assignment, you must also note this and cite the source.

Steps to completing the Option 1 assignment

- 1. Be clear in your assignment which option you have chosen for the assignment.
- 2. Write your obituary for if you were to die tomorrow (200-300 words) and indicate where it would appear.
- 3. Write your obituary for if you were to die at your normal life expectancy (200-300 words) and indicated where it would appear.
- 4. Write a properly sourced, short essay (500-750 words) where you address/reflect upon:
 - Why you wrote what you did?
 - Why is this how you think you should be remembered in your obituary for the two different time periods?

- What will you need to do to in your life in order to have the obituary you wrote for a normal life expectancy? What do you need to change?
- What was it like writing your own obituaries?
- What did you learn completing this assignment?
- 5. Use APA in-text citation style to support points, credit sources of concepts/ideas, and demonstrate completion of assigned course materials (current and previous chapters). <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.

The following must be submitted as part of Option 1 assignments

- 1. A proper APA style cover page.
- 2. A properly sourced 500-750 word reflection essay.
- 3. A proper APA reference section that contains all the material cited and/or relied on in the assignment.
- 4. Proper APA format appendices containing:
 - An obituary for if you died tomorrow (200-300 word).
 - An obituary for if you died at your normal life expectancy (200-300 word).

Option 2

Write two personal eulogies (eulogies for yourself), one for if you were to die tomorrow and the other for if you died at your normal life expectancy, and a reflection paper based on the eulogy writing exercise. Be sure to use and cite the resources on eulogy writing from the chapter to help you outline and frame your eulogies and reflection paper. If you use any additional materials to help in framing your eulogy, you are required to make note of this and cite them.

Steps to completing the Option 2 assignment

- 1. Be clear in your assignment which option you have chosen for the assignment.
- 2. Write a 3-5 minute eulogy for yourself for if you were to die tomorrow (the average reader reads 300 words per minute).
- 3. Write a 3-5 minute eulogy for yourself for if you were to die at your normal life expectancy (the average reader reads 300 words per minute).
- 4. Write a properly sourced, short essay (500-750 words) where you address/reflect upon:
 - Why you wrote what you did?
 - Why is this how you think you should be eulogized for the two different time periods?
 - What will you need to do to in your life in order to have the eulogy you wrote for a normal life expectancy? What do you need to change?
 - What was it like writing your own eulogies?
 - What did you learn completing this assignment?
- 5. Use APA in-text citation style to support points, credit sources of concepts/ideas, and demonstrate completion of assigned course materials (current and previous chapters). <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.

The following must be submitted as part of Option 2 assignments

- 1. A proper APA style cover page.
- 2. A properly sourced 500-750 word reflection essay.
- 3. A proper APA reference section that contains all the material cited and/or relied on in the assignment.
- 4. Proper APA format appendices containing:
 - A eulogy for if you died tomorrow (3-5 minute).
 - A eulogy for if you died at your normal life expectancy (3-5 minute).

Note: If you like what you have produced, consider sharing it with family and friends and including it with your end-of-life documents (see Chapters on "Advanced Directives & Planning for Death" and "Dealing with Bodies at the End of Life").

92

9.11 References & Media Attributions

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Cover Photo: Lewis, J. (August 6, 2022). *Obituary & Eulogy* [Photograph].

Chapter 10: Memorials, Commemoration & Remembrance



Jacqueline Lewis, Jillian Holland-Penney & Jackie Durocher

10.0 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?

10.1 Defining Memorials & Commemoration



World Trade Center Memorial, NYC.

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 may be the subject of contestation and debate (Lewis & Fraser, 1996).



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

95

10.2 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 in the understanding of 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).

View the following slideshow to see various memorials located in the Windsor-Essex ON Region (mouse over images for description):

An interactive H5P element has been excluded from this version of the text. You can view it online here:

https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=311#h5p-1

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 (Kasabayo, 2008), who, what, and in what format someone or something is memorialized is subject to re-evaluation, reexamination, re-interpretation, 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...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).

96

10.3 Official Monuments & Canadian War Memorials



Poppy on Canadian soldier's epaulette.

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 warrelated sacrifices (NSLA, n.d.). It is celebrated through national ceremonies, the wearing of poppies, and the reading of the dirge "In Flander's Fields" by Lieutenant-Colonel John McCrae (NSLA, n.d.).

<u>War memorials</u> 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 <u>Arlington National Cemetery</u> 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., <u>The National Aboriginal Veterans Monument</u>, <u>The Nurses' Memorial</u>).

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: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=313

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 that 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 Canadians) and to move 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, Peter Mansbridge provides some historical information 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/deathanddying2nded/?p=313#oembed-1

10.4 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).



Image of one part of the Dutch Homomonument, a

memorial to members of the LGBTQ+ community killed by the Nazis during WWII.

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 Auschwitz-Birkenau); 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). 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

Berlin Holocaust Memorials

(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).

10.5 Indigenous Memorials, Commemoration & Remembrance in Canada

"Every Child Matters"



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

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 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 remember the MMIWG.



Interactive image of the BC Memorial Quilt honouring the lives of the MMIWG in Canada. See Courage/MMIWG below.

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

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:

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).

<u>Courage | MMIWG</u> (Instructions: click view full project, scroll through images, and read stories).

10.6 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.



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

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 AIDS-related illnesses are represented on the 50,000 individual three-by-sixfoot 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 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 Ouilts size, and the fact that each individual panel is the size of a grave, the Ouilt 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/deathanddying2nded/?p=329#oembed-1

COVID-19 Pandemic



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

Beginning in late 2020, grassroots memorials began 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 Chapters on Plagues & Pandemics and Grief, Loss & Bereavement). Since losses of life due to COVID-19 are 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 (Over 1.1 million US deaths as of December 2023), covered the National Mall in Washington DC (See photo above) (Barry, October 2021). In London UK, the National COVID Memorial Wall 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:

How Do You Mourn a Pandemic?

Why We Need COVID Memorials Now – And For The Future

Memorialising COVID-19

100

10.7 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

Below are a list of supplementary resources for students interested in learning more about the chapter topics. <u>These resources are NOT required course materials</u>. A list of required course materials, beyond those found throughout this chapter, are provided on the following page.

Additional Readings

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

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. https://doi.org/10.1016/j.sbspro.2013.06.361

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

Manitoba. (n.d.). *A brief history of war memorial design*. https://www.gov.mb.ca/chc/hrb/internal reports/pdfs/war memorials brief history.pdf

Platero, M. (December 10, 2021). Global memorial to the pandemic. *ReVista Harvard Review of Latin America*. https://revista.drclas.harvard.edu/global-memorial-to-the-pandemic/

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

101

10.8 Required Chapter Materials

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

Required Chapter Viewings

The Tragically Hip. (December 6, 2021). *The Tragically Hip — Montréal (Live from Molson Centre, Montreal, 2000)* [Video]. YouTube. https://youtu.be/PaLb52ILCgw

Required Chapter 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*. https://theconversation.com/in-rwanda-genocide-commemorations-are-infused-with-political-and-diplomatic-agendas-160283

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

The importance of remembrance. (n.d.). The Remembrance Process. https://www.remembranceprocess.com/why-remembrance/

10.9 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) that is NOTfocused on within the course materials and conduct research on it that will help you addresses a series of questions. 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). The working memorial can be one associated with the topic you chose for the genocide chapter assignment, or it can memorialize something altogether different.

It is important to: (1) complete all chapter materials (chapter content, including all embedded links to readings and videos, and the required course materials) prior to starting the assignment; and (2) cite relevant research AND course material (from current and previous chapters) throughout your assignment to support your points, credit sources of concepts/ideas, and demonstrate completion of assigned course materials.

Options for Chapter #10 Assignment

Option 1

Select a working memorial (see above) and conduct research on it. Then, create a narrated slideshow presentation using PowerPoint that addresses the series of questions outlined below. An excellent example of a narrated slideshow MP4, is <u>Jessica Popescu's (2022) video at the bottom of Chapter 5.10</u>.

Assignment Formatting, Style & Length for Option 1

- Presentation must be 3-5 minutes in length (no longer than 5 minutes).
- PowerPoint presentations must include between 6 and 8 content slides (10 slides maximum including a title page slide and a reference slide). Be sure to build in slide transitions and slide animations to make the slide show more engaging.
- Presentations must include a cover slide that identifies the topic of the presentation (including the working memorial chosen), whose presentation it is, and the course number.
- The final slide must be a reference slide (APA format). Narration is not part of this slide.
- Be sure to include images and photographs (these must be properly cited sourced in the reference section).
- Videos CANNOT be incorporated into the narrated presentation.
- Use proper APA in-text citation style to support points, credit sources of concepts/ideas, demonstrate research completed for assignment, and completion of assigned course materials on slides AND in the speaker notes for each slide. One citation at the bottom of the slide or after the last bullet point is not sufficient.
- Avoid putting too much text on a slide. If you are making the font smaller on some slides, then there is too much content. Remember that slide content is typically in point form and the

- narration allows for elaboration. Recording yourself simply reading the slide content is NOT the same as slide narration. Slide narration expands/provides more details on slide content.
- For slide content, paraphrase and use point form as opposed to relying on full sentences and direct quotes.
- Proofread slides for typographical errors and to make sure slide content is clear, well written, and intelligible.
- Create speaker notes within PowerPoint for each slide. This helps guide you during the recording of your slide narrations. Be sure to expand on slide content (not simply read slide content) and provide sourcing/citations (on both slides and in speaker notes).
- When recording narrations, speak slowly and clearly. If you are rushing through your speaker notes then you have too much content. It is usually best to record your narration one slide at time. This enables you to check how you sound, make adjustments, and re-record smaller amounts of your presentation.
- Proof slide narrations. Check to make sure your voice level is consistent and that you do not stumble over your words. Re-record any individual slides where there is a problem.
- Setup narrative slide show and narration to automatically play (no clicks required after the one to start the MP4) from the first slide through to the final slide.
- When your document is complete, "save as" an MP4 format (use "export to" to convert to MP4 format or do a Google search for instructions). Click the link to learn more about converting narrated PowerPoint presentations to MP4 format https://support.microsoft.com/en-gb/office/save-a-presentation-as-a-movie-file-or-mp4-4e1ebcc1-f46b-47b6-922a-bac76c4a5691
- Convert your PowerPoint speaker notes used for your narration to PDF and submit as part of your assignment (i.e., you are required to submit BOTH the MP4 of your narrated video slideshow AND a PDF of your speaker notes). Click here to see how to prepare slides with speaker notes to print or save as PDF (instructions for PC, MAC and Web are available under the video). https://support.microsoft.com/en-us/office/print-speaker-notes-c7231a54-4ac8-4479-9199-6005a40efa2a. To save as PDF, for a PC be sure to change your printer to "PDF". For a Mac make sure the bottom left box indicates "PDF" or "save as PDF" rather than printing.

Steps to Completing Option 1 Assignment

- a. Identify a "working memorial" (Bodner, 2009) that is not among those focused on in the chapter materials. The link to Bonder's (2009) work is found at the bottom of Ch.10.4. See "On memory, trauma, public space, monuments and memorials".
- b. Research the identified working memorial and find a <u>minimum</u> 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. Find 2 or 3 photos of the memorial.
- d. Prepare a 3-5 minute presentation (see *Assignment Formatting, Style & Length* above for limits on number of slides for presentation submissions), including slides with narration. Three are several ways to add narrations to your slideshow (there is an option to add a video of you speaking, but this is not necessary). Click this link to learn more about creating narrated PowerPoint slideshows https://support.microsoft.com/en-us/office/record-a-slide-show-with-narration-and-slide-timings-0b9502c6-5f6c-40ae-ble7-e47d8741161c. There are instructions on this page for PC, MAC and Web versions of PowerPoint.
- e. In the slides, address the questions below. Questions do not need to be answered in order. Given the number of questions that must be answered, some questions should be addressed on the

- same slide as others. Combine those that logically go together.
- f. 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 and eBook. <u>In-text citations to support your points/arguments are essential and required</u>. Be sure to use a diverse range of materials (from current and previous chapters) as opposed to relying heavily on one, or a few sources.
- g. 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, and any submitted speaker notes, can be included in a reference section. This slide should contain no voice over.

The following must be submitted for Option 1 assignments

- A MP4 version of the slideshow presentation as detailed above.
- A PDF of your speaker notes. See above for further instructions.

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 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 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/person/people are memorialized (the memorial design, location, etc.) or are there disagreements (i.e., is its design and/or location contested)? Elaborate and explain. Be sure to make use of the Bodner (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 Bodner (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, give or take 100 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.
- Use APA in-text citation style to support points, credit sources of concepts/ideas, demonstrate research completed for assignment and completion of assigned course materials (from current and previous chapters).
- 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" (Bodner, 2009) that is not focused on in the chapter materials. The link to Bonder's (2009) work is found at the bottom of Ch.10.4. See "On memory, trauma, public space, monuments and memorials".
- b. Research the identified working memorial and find a <u>minimum</u> 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 order).
- e. Support the points/arguments you make with APA in-text citations that reference the materials you have found in your research, AND those that are in the chapter and eBook. <u>In-text citations to support your points/arguments are essential and required</u>. Be sure to use a diverse range of materials (from current and previous chapters) 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 properly sourced, essay format written report addressing the questions below.
- iii. A proper APA reference section that contains all the material cited in the assignment.
- iv. An APA style appendix containing properly sourced photos of the memorial.

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?
- 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.
- 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 its design and/or location contested)? Elaborate and explain. Be sure to make use of the Bodner (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 Bodner (2009) reading when framing your answer.

103

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Chapter 11: Advanced Directives & Planning for Death



Jacqueline Lewis

11.0 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 through 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?

11.1 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 Form 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/deathanddying2nded/?p=344#oembed-1

106

11.2 Substitute Decision Maker & Power of Attorney for Personal Care

VIDEO: Advance Care Planning

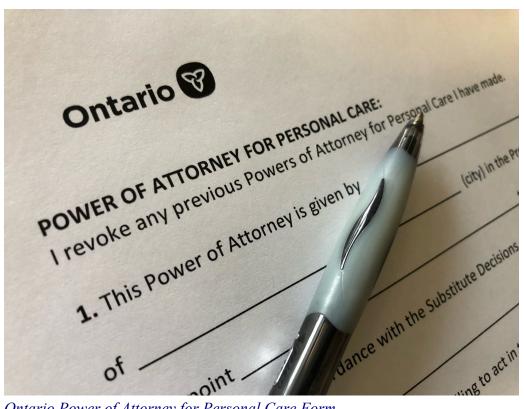
This short video provides a quick overview of Advanced Care Planning and choosing a Substitute Decision Maker.

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=347#oembed-1

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 link below to download the Advanced Care Planning Kit referred to in the video at the top of this page. This document provides important information on ACPs and SDMs and is essential reading prior to working on the assignment for this chapter.

Advanced Care Planning Kit

11.3 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).

VIDEO: Wills and Estate Planning Canada

In this video members of the Law Society of Ontario explain why we all need a Will and Power of Attorney and some of the implications of not having them at time of 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/deathanddying2nded/?p=349#oembed-2

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: Ontario Wills & Estates — What is a Power of Attorney?

In this video a Law Clerk with Russell Alexander Family Lawyers explains the importance of appointing a Power of Attorney (for financial matters).

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=349#oembed-1

11.4 After Death Work



Checklist.

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, funeral/memorial plans, obituary and/or eulogy writing) 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 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, and 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)

11.5 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."

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddying2nded/?p=355#oembed-1

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 SDM(s).

One or more interactive elements has been excluded from this version of the text. You can view them online here: https://ecampusontario.pressbooks.pub/deathanddving2nded/?p=355#oembed-2

11.6 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 (POAPC) 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

Below are a list of supplementary resources for students interested in learning more about the chapter topics. <u>These resources are NOT required course materials</u>. A list of required course materials, beyond those found throughout this chapter, are provided on the following page.

Additional Viewings

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

Jacky Kuk. (November 17, 2020). *Canada Estate Planning 101 (6 things you must consider!)* [Video]. YouTube. https://youtu.be/I1XFUQ fss4

Jacky Kuk. (January 25, 2022). *Best ways to get your will/POA done in Canada?* [Video]. YouTube. https://youtu.be/Jl5qdFXSI_I

Additional Readings

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

Canada. (n.d.-b). What every older Canadian should know about: Having a will and making funeral plans. https://www.canada.ca/en/financial-consumer-agency/services/estate-planning.html

Canada. (n.d.-c). What every older Canadian should know about Powers of attorney (for financial matters and property) and joint bank accounts. https://www.canada.ca/en/employment-social-development/corporate/seniors/forum/power-attorney-financial.html

Milestones in hospice palliative care. (n.d.). Canadian Hospice Palliative Care Association.

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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/

111

11.7 Required Chapter Materials

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

Required Chapter Viewings

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

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

Required Chapter 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

112

11.8 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: (A) completing your Power of Attorney for Personal Care and Advance Care Directive via a downloadable and fillable PDF document; AND (B) writing a short reflection piece. Option 2 involves writing a reflection paper. Regardless of which option is chosen

for the assignment, 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. Both options require the citing of relevant course material (from current and previous chapters) throughout your assignment to support your points, credit sources of concepts/ideas, and demonstrate completion of assigned course materials.

Options for Chapter #11 Assignment

Option 1

After downloading the Advance Care Directive for Ontario document containing the necessary forms (see A below), this assignment option requires you to do four things: (1) complete your Advanced Care Directive/Advanced Care Plan (ACP), including signature; (2) appoint your Substitute Decision-Maker(s) (SDM) via the creation of a Power of Attorney for Personal Care (APC) (including signatures); (3) write a 500-600 word reflection piece based on your experience of completing the document; and (4) submit 2 properly labelled PDF documents: your completed and signed Advanced Care Directive document (which includes the appointment of your SDM/APC) **AND** your reflection piece.

Students may choose to submit 2 properly labelled PDF versions of their completed ACP, one of which is marked up with notes and citations. Anyone choosing this option will be submitting 3 PDF documents: Completed and signed ACP and APC; completed ACP and APC marked up with notes and citations; and a reflection piece (as per 3 above).

Steps to Completing Option 1 Assignment

- 1. Click on the following link to download a PDF of the Advance Care Directive for Ontario to your computer Power of Attorney for Personal Care and Advance Care Directive.
- 2. Read the downloaded document in its entirety so you understand what it is you are completing. It is also extremely important to read the document "Advance care planning kit" assigned earlier in this chapter.
- 3. Fill out Section C of the document appointing your Power of Attorney for Personal Care (APC).
- 4. Fill out Section D of the document detailing your Advance Care Directives (ACP). It is important to carefully read and following the directions in the document. For this assignment, students choosing Option #1 are required to complete sections B, C, D and E and to read the remaining sections of the document, paying particular attention to sections A and H. As noted above, it is also essential to complete the "Advance care planning kit" reading assigned earlier in the chapter. Be sure to take some time to carefully reflect on your options in section D prior to making your choices or detailing additional directives for D6 and D7.
- 5. Initial, sign, print your name and date where indicated in the document. For this assignment Option, you are required to actually initial and sign your Advanced Care Directive and appointment of ACP(s). To add your initials and signature you can either print and initial/sign or initial/sign with your finger or digital pencil on an iPad or similar device. A digital signature can also be created through one of the many free digital signature sites on the web, which you can then add to the signature lines of the document.
- 6. When signing and dating the documents, be sure to have your signature properly witnessed. As per Section E, you are required to sign and date the document where indicated in the presence of 2 witnesses. Be sure to read Section A8 for information on who can legally act as a witness.
- 7. 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 E above).
- 8. Save the entire PDF document (beginning with the Death with Dignity Logo and Advanced Care Directive/Wishes instructions through to the end of Section H) in PDF format to your computer.
- 9. Write a 500-600 word short essay in which you reflect on your experience of completing the Advanced Care Directive document. (i.e., choosing the options you did in the document, choosing the person to act as your APC, etc.). Be sure to incorporate and properly source relevant course material into your reflection piece and include an APA style reference section. In-text citations to support your points/arguments/choices are essential and required. Be sure to use a diverse range of materials from this eBook (not just this chapter) as opposed to relying heavily on one, or a few sources.
- 10. See Option 2 below for Formatting & Style requirements for the written reflection piece part of the assignment.
- 11. Give all submitted documents (the Advanced Care Directive form[s] and the short reflection piece) a name that clearly indicates whose documents they are and what the document is that is being submitted.
- 12. Submit BOTH properly labelled PDF documents: (1) the Advanced Directive document (beginning with the Death with Dignity Logo through to the end of Section H); and (2) your short reflection essay. Students may also choose to submit a third document a completed Advanced Care Directive document marked up with notes and citations. This too must be properly labelled.

The following must be submitted as part of Option 1 assignments

- 1. A proper APA style cover page.
- 2. A properly sourced, essay style written reflection paper based on your experience of completing the document as per i above.
- 3. A proper APA reference section that contains all the material cited in the assignment submission.
- 4. Proper APA style appendices containing your Power of Attorney for Personal Care and Advance Care Directive form[s]. Appendices can either be appended to the end of the reflection piece or submitted as properly labelled separate PDF documents (each of which must have a proper APA style appendix cover page).

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 it will take for you to get to a place where you can and will complete those documents (something that is highly recommended).

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.
- Use APA in-text citation style to support points, credit sources of concepts/ideas, and demonstrate completion of assigned course materials.

- 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

- 1. Click on the following link to download a PDF of the Advance Care Directive for Ontario to your computer Power of Attorney for Personal Care and Advance Care Directive.
- 2. Read the document in its entirety.
- 3. Write a properly sourced 1000-word reflection paper (give or take 100 words) that addresses what is outlined in the text under Option 2 above.
- 4. Support your points/arguments with APA in-text citations that reference course materials. Intext citations to support your points/arguments are essential and required. Be sure to use a diverse range of materials from this eBook (not just this chapter) as opposed to relying heavily on one, or a few sources.

The following must be submitted as part of Option 2 assignments

- 1. A proper APA style cover page.
- 2. A properly sourced, essay style 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.

113

11.9 References & Media Attributions

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

Appendix A – Chapter Reviews

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 alone 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 a feast of ideas and perspectives on death-related communications. The author does a wonderful job of setting the table for the learner to think deeply about life and death, including their own" (Bridget Nicholls).

Chapter 10 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 11 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).

2

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Subchapter Reference and Attribution

Speak Up Ontario. (n.d.). *Logo* [Photograph]. Speak Up Ontario. https://www.speakupontario.cg/

1.2 https://www.speakupontario.ca/

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1.3	The Groundswell Project Australia. (2020). <i>Talking about death is a part of Life!</i> [Photograph]. https://www.thegroundswellproject.com/dying-to-know-day Talking about death is a part of life! ©The Groundswell Project Australia (2020). All rights reserved. Image used with permission.
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4.1	Cremation Association of North America (CANA). (2022). CANA 2022 annual statistics report. https://www.cremationassociation.org/resource/resmgr/members_statistics/StatsInfographicMay2022.pdf CANA annual statistics report.©All rights reserved. Image used with permission.
6.5	Monkman, K. (2017). <i>The Scream</i> [Acrylic on Canvas]. Collection of the Denver Art Museum. 84" x 126". https://www.kentmonkman.com/painting/2017/1/20/the-scream The Scream ©Kent Monkman. All rights reserved. Image used with permission.
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About the Author



Jacqueline Lewis, PhD (She/Her) is an Associate Professor in the Department of Sociology & 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 of marginalized populations; 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.