

# Handout on Death and Dying

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Do you feel comfortable with the topic of death and dying? It's my impression that few people really do.<sup>1</sup> Do you have questions on these topics? In recent years, I have taken classes on the subject that proved to be thought provoking. In fact, they made me want to summarize for you some of the points that were raised. The coronavirus health threat also provides an impetus for delving into these issues. The material that follows will prompt you to think about your relationship to your own mortality. It may also lead you to think about deaths of loved ones. Although this handout is relatively short and simple, at moments, the content may be distressing. Take your time and take breaks in reading if needed. I hope that you will find something useful here, and feel free to leave the rest behind.

**The First Paradox:** From the moment we are born, with every passing minute, each of us is getting closer to death; yet, each of us is alive until we take our last breath.

**The Taboo:** In our society, death is often treated as a topic too upsetting to think about privately or talk about openly with others. For many of us, the topic of death evokes a great deal of unease. The term *death anxiety* refers to “a feeling of unsafety, anxiety, or fear related to death or near death.” What is most feared may vary from person to person. For some it is the idea of ceasing to exist that is most troubling, while others say they are most bothered by the idea of becoming insignificant or losing connection with the people they love. Some people are especially troubled by uncertainty about whether there will be an afterlife or what it will be like. Others have anxiety about the possibility of suffering during the dying process, or needing to depend heavily on others during this process, or dying alone. Research studies suggest that when physical health is taken into account, death anxiety decreases across the adult life-span.

From a biological perspective, a certain amount of death phobia—which involves avoidance of the topics of death and dying—makes sense; staying alive requires having an interest in survival that outweighs an interest in death. Death phobia also makes sense from a sociological perspective. For most of human history, death happened with little time for preparation. This has changed. Nowadays, the journey towards dying is often prolonged and often takes place in institutions that provide a medical context for the process. While cultural and religious practices provide some guidance, society has not developed a script for what to say and how to behave under these new conditions. The *Death Positive Movement* encourages individuals to overcome their aversion to dealing with the topics of death and dying so that they can develop an approach which can be helpful to themselves and their loved ones.

Take a deep breath .....



**Rethinking Our Relationship to Death and Dying:** What if we approached these topics with curiosity rather than fearfulness? What if we engaged in a dialogue about death and dying with ourselves and with loved ones rather than avoiding the topics? The differences between the assumptions underlying *death phobic* and *death positive* stances are summarized below.

STANCE	Death Phobic	Death Positive
Emotional response to death and dying	<b>Anxiety and dread</b>	<b>Curiosity and interest</b> , as well as anxiety and other emotions
Relation of death to life	<b>Death is the opposite of life</b>	<b>Death is a meaningful part of life</b>
Meaning	<b>Death represents the failure of attempts to stay alive</b>	<b>Death represents the successful completion of worldly life</b>
Processes involved in death and dying	<b>Dying is a medical process</b>	<b>Dying involves psychological, spiritual, and social</b> , as well as medical processes
	<b>A succession of losses</b>	<b>Involves growth</b> as well as loss
Agency of the dying person	<b>The dying person is passive in the dying process</b>	<b>The dying person is actively engaged in the dying process</b>

### Death Literacy

A new concept that is receiving attention, death literacy refers to knowledge, skills, and experiences that enable individuals to make informed choices about arrangements for their own death and dying processes or to be helpful to others in their dying process.



**The Second Paradox:** Although all of us know that we will die eventually, most of us do not know exactly when death will occur or under what circumstances. This can make it challenging to know how and when to prepare.

If we look at results from clinical studies, there are four distinct “paths” to dying and then death. These are formally known as *illness trajectories*, and we all know vaguely what they are.

- **Sudden death of a healthy person.** This may be due to a medical event (such as a stroke, heart attack, or severe case of the coronavirus), accident (such as a fall), or another cause. The person may have been functioning at a high level and may not have been thinking about mortality at all. There is little or no time for preparation. In premodern life, this was the most common manner of death.

- **Terminal illness.** This may be due to a serious medical condition such as pancreatic cancer. Due to advances in medical care, many people with terminal illnesses maintain a high level of function, often for extended periods of time, but they are aware that they have a life-limiting condition. There is time to prepare emotionally, spiritually, and practically for the dying process and death.

- **Chronic and progressive disease.** This category includes conditions such as chronic obstructive pulmonary disease, congestive heart failure, and kidney failure. A gradual overall decline in health and function occurs over many years, with periodic accelerations. There is time to prepare, yet the person may not think of herself or himself as being involved in the dying process.

- **Frailty.** This gradual decline sometimes occurs in the final stages of dementia, as well as in very advanced age. The person may function at a reduced level for many years. Although there is much time to prepare, the extended duration of decline may dampen awareness of death and dying.

What distinguishes the different illness trajectories is how much the person and their loved ones are aware of declines in function. It may be apparent to you that individuals and their loved ones often feel unprepared for a dying process.

Change in Function with Time in Four Illness Trajectories

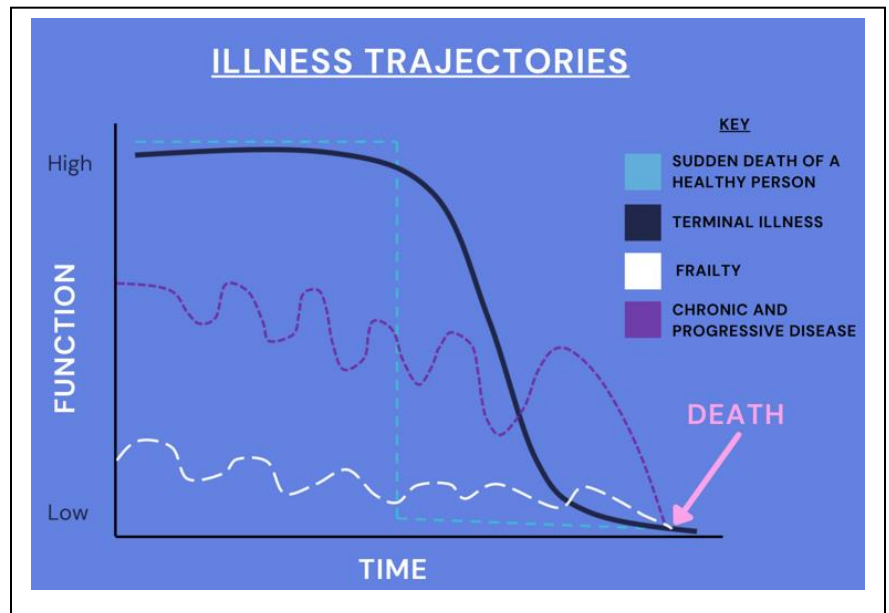


Illustration by Alexis Aberman. Adapted from: Palliative Care Network of Wisconsin. Fast Facts #325.

**Living While Keeping Death and Dying in Mind.** If there is uncertainty about when dying and death will happen, then how can we prepare? When do we start preparing? The choice of how to prepare is very personal. Stock answers are not helpful. There are no right or wrong answers. Here, however, are some considerations highlighted by people who have devoted much effort to thinking about these questions. Under each of the seven points below, I have listed some questions that may help if you wish to work on that particular point.

### *1. Living Fully*

- What do you value most in life? Are you living your life according to these values? If not, are you interested in exploring what is holding you back?
- What makes for a good day? Are pleasure, accomplishment, and connection present? If not, are you interested in trying to change this?
- If you had died last week, would there have been something important left undone? If so, would you like to think about how you can begin doing that *now*?

### *2. Taking Practical Steps to Deal with Worldly Affairs*

Have you:

- completed paperwork for a healthcare proxy, advanced directives, and power of attorney?
- written a legally binding will?
- made a plan for how, over time, you will let go of material belongings?

If not, are these things you would be willing to put thought and effort into now? Attending to these details may provide peace of mind for you and for those who are close to you.

### *3. Educating Yourself About Death and Dying*

Take stock of your level of 'death literacy':

- What do you already know about death and dying? What questions do you have?
- What do you consider a "good death" to be?
- Do you have specific beliefs or ideas about what happens after death?
- What have been your experiences of the death and dying of family members or others? How do these experiences influence your thinking and preferences?
- What family or cultural traditions have you inherited regarding death and dying?
- For further exploration, see the death literacy index on page 10 of this handout.

Are you interested in:

- reading books about death and dying, including books about practices in other cultures?
- attending lectures on these topics?
- participating in death cafes (gatherings where people talk about death and dying)?
- consulting reliable online resources?

#### *4. Attending to Relationships with Family, Friends, and Community*

Are you interested in:

- making a deliberate effort to spend time with and enjoy the people in your life?
- initiating meaningful conversations with loved ones about death and dying?
- thinking about how you will say goodbye to people in your extended circle and people in your intimate circle--and preparing for that?
- speaking with a counselor about unfinished business in relationships, e.g., things that you wish to ask forgiveness for, and thinking through whether and how to address this?

#### *5. Developing Your Relationship with Yourself*

A great deal of psychological growth has to do with an evolving relationship with oneself that comes with awareness of death and dying. Are you interested in:

- writing or recording the story of the life that you have lived?
- reflecting on what you want your legacy to be? There may be things you wish to write down or create in order to pass on.
- talking with a counselor about unfinished business—such as regrets or disappointments or memories that continue to be emotionally painful—in order to work these through?
- reflecting on what you see as the bigger picture of meaning in life?
- doing meditation practices that foster being at ease with the transience of life?

#### *6. Making Arrangements for Funeral and Burial*

Throughout much of premodern and modern history, funeral and burial were handled by families in the home. In the 18<sup>th</sup> century several forces prompted changes. One change was an increase in concern about communicable diseases. Another, 19<sup>th</sup> century change was the catalyst of the Civil War, which presented communities with the challenge of preserving bodies of soldiers until they could be brought home. The practice of embalming and the role of the funeral home were established.

Many people still wish to arrange a traditional funeral taking place at a funeral home with casket burial or cremation. However, you may be interested to know that there are new alternatives. For example, “green burials” involve interring the body in a way in that allows for reintegration with the Earth.

Home funerals are also becoming more popular. In these, loved ones and family members are being encouraged to have a greater level of participation in the handling of the deceased’s body and the funeral itself. For example, some loved ones choose to wash the body in preparation for its movement to a site for a funeral, or they choose to design rituals for each point in the body’s transition to its resting place. Funeral director Amy Cunningham is of the view that active participation in the funeral and burial process is helpful to the grieving process. She encourages people to take emotional risks by including movement in any ceremonies, finding roles for children, and rehearsing eulogies. Even though this has been very challenging during the coronavirus pandemic because of the need to maintain social distancing, people have found creative ways to connect and grieve.



Some helpful questions may be:

- Have you made arrangements for funeral and burial and shared these details with loved ones?
- Are you interested in taking some time to picture your own funeral or memorial service?
  - Where would you ideally want it to take place?
  - Who would you wish to be there?
  - Do you have specific wishes for the handling of your body (such as how it would be clothed)?

## 7. Preparing for the Dying Process

Some, but not all of us, will experience a period of dying. “*Pre-active Dying*” is a term that refers to a phase of dying that lasts a few days to a few weeks prior to death. Meanwhile, “*Active Dying*” is a term that refers to a phase of dying that lasts hours to days. In both of these phases, the body is breaking down in ways that are observable. That is, there are predictable changes in appetite, breathing, temperature and more. Are you interested in learning more about the physical processes involved in dying? (For an overview of these signs and processes, see the CBC podcast referenced in online resources). You may also be interested to reflect on what your wishes are for the dying process. Under ideal circumstances:

- Where would you want to be?
- Who would you want to be with you?
- Are there experiences that would be particularly meaningful to have, such as a particular kind of music, or objects that you would want to have around you, such as photographs?
- How important would it be to have sedation versus being alert for the last moments of life?
- Would you want to have palliative and/or hospice care? Have you spoken with your primary care physician about how to access these services, if needed?
- Would you want to work with an end-of-life doula? End-of-life doulas are trained professionals who serve as guides for a dying person and their loved ones in the transition between life and death. They often begin working with individuals for some time prior to dying, are present for a vigil during the dying process, and stay after death to help loved ones deal with grieving. End-of-life doulas often work with hospices. They also work on a private (fee-for-service) or volunteer basis with individuals and their loved ones.

**An Important Caveat:** In a small number of cases, thoughts of death and dying may be a sign of a treatable psychiatric condition such as depression, anxiety, or obsessive-compulsive disorder rather than a helpful exploration of these topics. If thoughts are recurrent and distressing, especially if they are interfering with doing everyday activities, the most important step to take is to speak with a trusted person, physician, or counselor. Thoughts of suicide can affect anyone and are a sign that a person is under too much stress. This is best addressed by speaking with a trusted physician or counselor. Suicide hotlines, such as the National Suicide Hotline 1-800-273-8255, are available to provide support 24/7.

**The Choice Is Yours to Make:** The Death Positive Movement suggests that engaging with death and dying can be personally meaningful and also ease the experience of loved ones. However, there are no musts.

There is very little research data at this time to show what the impact of such an approach is or who most benefits from this kind of stance. One example is the online course, “Dying2Learn,” which provided an online platform for learning about and sharing perspectives on death and dying. Several thousand people enrolled and participated. Those who completed the course and responded to surveys strongly agreed that: the course was enjoyable (96.5%), they would recommend the course to others (94.6%), and that it deepened their knowledge of death (91.2%). However, the respondents represented less than one quarter (23.0%) of those who began the course. On average, course participants completed a limited portion of the material (37.4%). One interpretation of these findings is that the approach may work well for some people, but others may need something different.

Whatever you choose to take away from this handout is up to you. The act of reading through this handout, reflecting on some of its points and questions, and tolerating whatever uncomfortable internal experiences arose already represents a significant step in countering the avoidance that many of us engage in when it comes to the topics of death and dying

## Footnotes

1. Update 10/6/2021. However, in a 2018 AARP survey of 1003 adults, 80% reported being comfortable with death and dying, wanting to know if a serious health issue, and are likely to prepare relevant legal documents. See AARP. (2019). End of life survey: thought and attitudes on death and dying. Downloaded from: <https://www.aarp.org/research/topics/life/info-2019/death-dying-survey.html>

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## Disclaimer

The opinions expressed in this handout are my own and not those of any institution with which I am affiliated. The purpose of this handout is to provide general information. It is not intended as medical advice and is not a substitute for individualized feedback from a trained medical or mental health professional.

## Feedback

Feedback on any errors or inaccuracies can be emailed to Nimali Jayasinghe at: [nij2001@med.cornell.edu](mailto:nij2001@med.cornell.edu).

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## Online Resources:

### *Shows/Talks/Podcasts*

- Atul Gawande – PBS Frontline Show with Atul Gawande  
<https://www.pbs.org/wgbh/frontline/film/being-mortal/>
- CBC/Radio Canada – What to expect at the end of life  
<https://www.youtube.com/watch?v=KxzI0EMHgSk>
- TED Radio Hour – Dying Well  
<https://www.npr.org/programs/ted-radio-hour/645334275/dying-well>

### *Websites:*

- The Art of Dying Well (written from a Catholic perspective)  
<https://www.artofdyingwell.org/>
- The Bevival  
<https://www.bevival.com/>
- D2KD Workbook  
<https://www.d2kdusa.com/workbook-2017/>
- The Green Burial Council  
<https://www.greenburialcouncil.org/>
- The Order of the Good Death.  
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# DEATH LITERACY INDEX

The development of the Death Literacy Index (DLI) serves two purposes: to gauge the current death literacy of specific groups and to assess the effectiveness of a variety of interventions. Below, we have included the 29 items that make up the Death Literacy Index for your reference, divided by its four subscales.



## PRACTICAL KNOWLEDGE

### TALKING SUPPORT

Please rate how difficult or easy you would find the following talking support (on a scale of 1-5 between *Not at all able* to *Very able*)

1. Talk about death, dying or grieving to a close friend
2. Talk about death, dying or grieving to a child
3. Talk to a newly bereaved person about their loss
4. Talk to a GP about support at home or in their place of care for a dying person

### DOING HANDS-ON CARE

Please rate how difficult or easy you would find the following hands on support (on a scale of 1-5 between *Not at all able* to *Very able*)

5. Feeding a person or assisting them to eat
6. Bathing a person
7. Lifting a person or assisting to transfer them
8. Administering injections



## EXPERIENTIAL KNOWLEDGE

Please rate how much each of the below statements sound like you. My previous experience of grief, loss or other significant life events has (on a scale of 1-5 between *Very untrue of me* to *Very true of me*)

9. Increased my emotional strength to help others with death and dying processes
10. Led me to re-evaluate what is important and not important in life
11. Developed my wisdom and understanding
12. Made me more compassionate toward myself
13. Provided me with skills and strategies when facing similar challenges in the future



## FACTUAL KNOWLEDGE

Please rate how much each of the below statements sound like you. My previous experience of grief, loss or other significant life events has (on a scale of 1-5 between *Very untrue of me* to *Very true of me*)

14. I know the law regarding dying at home
15. I feel confident in knowing what documents you need to complete in planning for death
16. I know how to navigate the health care system to support a dying person to receive care
17. I know how to navigate funeral services and options
18. I know how to access palliative care in my area
19. I have sufficient understanding of illness trajectories to make informed decisions around medical treatments available and how that will shape quality of end of life
20. I know about the contribution the cemetery staff can make at end of life



## COMMUNITY KNOWLEDGE

### OTHERS CAN HELP ME PROVIDE END OF LIFE CARE

Please rate your level of agreement with the following statements. If I were to provide end of life care for someone, I know people who could help me (on a scale of 1-5 between *Strongly disagree* to *Strongly agree*)

21. Access community support
22. Provide day to day care for the dying person
23. Access equipment required for care
24. Access culturally appropriate support
25. Access emotional support for myself

### SUPPORT GROUPS IN MY COMMUNITY

Please rate your level of agreement with the following statements. If I were to provide end of life care for someone, I know people who could help me (on a scale of 1-5 between *Strongly disagree* to *Strongly agree*)

26. People with life threatening illnesses
27. People who are dying
28. Carers for people who are dying
29. People who are grieving

LEONARD, R., NOONAN, K., HORSFALL, D., PSYCHOGIOS, H., KELLY, M., ROSENBERG, J. P., ... RAHN, A. (2020). DEATH LITERACY INDEX: A REPORT ON ITS DEVELOPMENT AND IMPLEMENTATION. [HTTPS://DOI.ORG/10.26183/5EB8D3ADB20B0](https://doi.org/10.26183/5EB8D3ADB20B0)

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