

Unity Death, Dying, and Health Care Directive (HCD) Project Participant Handout (version 5, 2-16-16)

Goal: To enable deep and meaningful conversations regarding issues of death and dying that prepare participants to contemplate, discuss with their loved ones, and complete a Health Care Directive (HCD) that expresses your views and values.

Health Care Directives are important at all stages of life, not just in old age. You will need to revisit and revise your HCD as your stage of life and life circumstances change.

Overall Plan: There will be two facilitated sessions of two hours each with about 6 participants. These sessions will be about two months apart.

Session 1: You will take part in confidential discussions of

- a series of questions regarding their experiences, views, and beliefs about death and dying;
- the of basics of a Minnesota Health Care Directive Form;
- next steps as well as emotional and practical obstacles that might arise in completing your personal Health Care Directive.

Session 2: You will reconvene to discuss

- evolution of your thoughts and feelings regarding death, dying, and end of life planning
- your experiences in talking with their loved ones or personal community about these issues
- your specific experiences in developing your Health Care Directive, including how they have expressed your wishes about end of life care, as well as uncertainties, confusions, or concerns, and shared ideas about next steps in the process.

Unity Death, Dying, and Health Care Directive (HCD) Project Agenda

1. Opening Reading and Chalice Lighting (2 minutes)
2. Review Goal, the 2- Session Plan, and Agenda- see Page 1 (3 minutes)
3. Discussion of Ground Rules and Facilitator Role (5 minutes)
4. Introductions (5 minutes)
5. Discussion of Death and Dying Questions (35 minutes)
6. Important Concepts in health care decisions (5 minutes)
7. Information about Health Care Directives (HCD) (25 minutes)
8. Discussion Questions for HCD and Further Actions (20 minutes)
9. Writing Down Your Plan of Action For the Next Two Months (10 minutes)
10. Plan for Next Meeting (3 minutes)
11. Closing Reading (2 minutes)

Note: These sessions specifically address the Health Care Directive. There will be a plan to provide other information regarding other planning issues such as

- A Will (your way to apportion your estate and belongings when you die)
- An Ethical Will (your way to discuss and devise what you hope your legacy will be to those you care about)
- Other delegation of powers such as Power of Attorney (which in Minnesota does not give power to make health care decisions)

Session 1 Discussion Guide with Suggested Timings

1. **Opening reading and chalice lighting (2 minutes)**
2. **Review goal, the 2- session plan, and agenda- see Page 1 (3 minutes)**
3. **Discuss ground rules and the role of your facilitator Role (5 minutes) :**

Recognizing we will discuss deep, emotional and important issues:

 - a. Please remember your facilitator is not an expert in health care or HCD- he or she will lead the group in raising questions for you to think about and then talk about with your loved ones and your personal doctor and health care providers.
 - b. Confidentiality – Conversation held in group should not be discussed or shared outside of the group; you can talk about what you said or thought, but not about what others said in the group.
 - c. Group members can meet outside the group with other if they both wish to.
 - d. Group ownership – This is your group, and we empower you to decide where to direct conversation and also to assert yourself when you see fit.
 - e. Please shut off media (cell phones) that are not being used for emergency purposes, and if you feel need to keep a device on, please let the group know ahead of time so they are prepared for interruption.
 - f. Do your best to avoid interrupting others and having side conversations. There may be times when re-direction by fellow group members or facilitators is necessary in order to maintain a respectful and facilitative environment, please accept that gracefully.
 - g. Be conscious of the equity of talking time amongst group members to ensure all have the opportunity to add to conversation adequately; the facilitator may intervene to give quieter members a chance to speak.
 - h. A non-judgmental approach by all involved will promote conversation quality and depth.
 - i. These are discussion groups, not debate groups; embrace the possibility for multiple truths.
 - j. We have some specific goals and a limited amount of time; each of you brings your own health care and loss experience to the group, and unfortunately there is not time to talk about all of them.
 - k. Your facilitator is the timekeeper- we have a packed agenda with specific goals. This will mean not everyone gets to share everything they wish to share, but is necessary to achieve our goal of helping each other to talk with our loved ones or personal circle.

- l. If deep emotional reactions remain unsettled, talk to the facilitator about contact with church support persons for further discussion.
4. **Introductions (5 minutes maximum)**
 - a. Name, current age, who lives in their home, their relationship to Unity
 5. **Discussion of Death and Dying Questions (35 minutes)**
 - a. Each of you will have a chance to describe a positive or negative experience in facing death, dying or loss that you carry with you or that influences your current thinking and views; please aim at no more than 3 minutes (if there are six people in the group). You might start by giving a first name or relationship and approximate year; think of what you carry with you from that experience.
 - b. How do you imagine your own end of life scenario- what do you want and what you fear
 6. **Important Concepts in Health Care Decisions (5 minutes)**
 - a. We each decide for ourselves what health care goals are and generally what treatments we want.
 - b. All medical treatments are optional and should be used if they help us but don't have to be used if they don't help achieve our goals.
 - c. A treatment once started can be stopped if it is not helping achieve the person's goals. Withdrawing treatment and withholding treatment are generally considered morally equivalent.
 - d. Withdrawing treatment is often emotionally more difficult for decision-makers.
 - e. Withholding and withdrawing medical nutrition and hydration is sometimes especially difficult. Because these procedures are tied to our feelings about the basic human act of feeding each other, withholding them is sometimes controversial and hard to discuss.
 - f. When agreed upon limits are placed on life-sustaining treatment at the end of life the focus of care becomes maintaining a patient's comfort.
 - g. If you have questions or concerns or wonder what is the right thing to do you should always raise the question- it is your right to have those discussions with your health care providers.
 - h. A health care directive or a decision to proceed with hospice/comfort- care- only can also be altered or revoked.
 7. **Information about Health Care Directives (HCD) (25 minutes)**
 - a. HCD based on discussions in advance is helpful because your agent will likely be dealing with possible anxiety, grief, or loss at the time.

- b. Who can and should do an HCD?
 - i. You must be 18 and of sound mind.
 - ii. If you ever ride in a car it is a good idea to have an HCD.
 - iii. If you have chronic health conditions it is an especially good idea.
 - iv. Hospitals are required to ask each person admitted if they have an HCD.
- c. HCD is the official term for this legal document that
 - i. Helps you appoint person or persons to make decisions for you and describe your wishes when you can't communicate for yourself.
 - ii. Express your wishes for your health care, especially but not exclusively in end of life situation.
 - iii. Health Care Directives can be used to limit treatments you don't want or request treatments you do want.
- d. HCDs go into effect when you can no longer communicate for yourself regarding your health care wishes; as long as you can indicate your wishes your providers will generally follow what you request.
- e. You can change or revoke your HCD at any time; if you change it, be sure to change all the copies people have; always date your revised copies.
- f. Keep a list of who has your HCD. Also keep a card in your wallet stating that you have an HCD.
- g. Other terms used in other states or in the past include "Living Will," "Advanced Directive," "Health Care Power of Attorney."
- h. Medicare now covers an advance care planning visit separately or as part of an annual physical; some other insurers may cover this as well. Talk to your provider about their specific mechanism.
- i. Other terms or concepts you will encounter that are related but are not HCD:
 - i. DNR (Do Not Resuscitate) or DNAR (Do Not Attempt Resuscitation)- this is a medical order signed by your provider (with your authorization) to withhold Cardiopulmonary Resuscitation (CPR) if your breathing or heart were to stop; generally used in the hospital.
 - ii. POLST (Provider Order for Life-sustaining Treatment) – this is a medical provider order for home or outpatient settings and is generally accepted by EMTs for a DNR or to withhold certain other treatments at home or other places not in the hospital.
- j. The Minnesota law requires that a valid HCD include the following elements
 - i. It must be in writing, must state your name, and be dated
 - ii. It must be signed by you when you have "capacity" (are legally competent) to understand what you are saying and signing.
 - iii. It must include your health care instruction, your naming of one or more agents, or both (and it is good to do both, but you don't have to)
 - iv. Contain verification of the person's signature either by notary public or by two witnesses
- k. We are recommending the use of the HCD Form that is included in your materials, but other forms such as Five Wishes or other forms can be used if you have one you like or if you have already completed another form.

- l.** Each state has its own law and requirements regarding HCD. If you are in another state for long periods of time you should check on their requirements to see if you Minnesota form would be recognized there.
- m.** The recommended form

 - i. Part I:** Has a place to name a number of agents- its good to name one or more alternate agents who can step in if your primary agent is unavailable or unable to function as your agent one (especially if you ever ride in a car with your primary agent)

 1. Talk to the people you wish to name as your primary agent and secondary agent(s) to be sure they will accept the job and follow your wishes. You should of course choose people whom you trust to carry out your wishes.
 2. Consider whether your primary agent should act alone or together with your alternates (It is generally better to act alone and use the primary and alternates in order specified in the form).
 3. Consider the “Additional Powers” and the “Limiting the Powers” sections.
 4. You must tell people if you appoint them as agents!
 5. Be sure they agree to follow your wishes
 6. If there are other people who may think they should speak for you, be sure to tell them you have appointed an agent and that is the person who will speak on your behalf.
 - ii. Part II:** Has a place for a verbal description of your overall wishes, and the “Part B Worksheet” which can help you think through things and articulate your specific wishes about treatment questions that come up:

 1. Your verbal description can be as long as you like and can be attached on a separate sheet if you need more space (which you probably will!).
 2. We have provided an example of a verbal description of one person’s wishes- it is only an example.
 3. It can be helpful to work through the Part B Worksheet first as a way of thinking about the issues that frequently come up, then write you your verbal description after that.
 4. The Part B Worksheet can be attached to be part of your HCD, but it doesn’t have to be attached.
 5. It is good to specify your thoughts on “nutrition and hydration support” by medical means because this is a controversial area in society and sometimes a source of strife for hospitals and families.

6. It can be a good idea to discuss how your wishes should be taken into account if you develop dementia.
- iii. **Part III:** This is how you make the document official:
 1. Sign in presence of a notary public or two witnesses.
 2. Two witnesses are fine; the witnesses can't be your health care agent, and only one of them can be a direct care provider.
 3. Some doctors and nurses believe the official stamp of a notary public will carry more weight in the hospital (even though it shouldn't).
 4. Give a copy to your doctor or health care provider; talk with them about whether they and the hospital they use will follow your wishes.
 - iv. Additional Ideas:
 1. It's not required but we recommend that you give copies to the people who are most likely to be present or be called if you are so sick or injured that you can't speak for yourself.
 2. You should keep at least one copy at home and be sure people know where to find it (refrigerator, your special file cabinet, etc.).
 3. You should review it every few years or when your condition changes; always date your revised HCD.

8. Discussion Questions for HCD and Further Actions (20 minutes)

- a. Do you have any personal beliefs that make the task of preparing your HCD more difficult?
- b. How are you going to make decisions about who to talk to? (If you don't know whom to talk with discuss it with the ministerial team.)
- c. Do you have any immediate concerns that might affect your ability to have conversations with your chosen person/people? What if some of your chosen people disagree with you about important issues?
- d. Who do you want to speak for you when you might not be able to speak for yourself? Is there anyone you don't want to speak for you?
- e. What do you want these people to know?
- f. What does your vision of your death and dying communicate about your personal beliefs and how you want to be remembered?
- g. Do you have a way to share these thoughts with your chosen person/people?

9. Writing Down Your Plan of Action For the Next Two Months (10 minutes)

- a. When will you think about your personal preferences in death and dying?
- b. Who do you want to talk to?
- c. Who do you want to name as agents?
- d. When will you have these discussions?

10. Plan for Next Meeting (3 minutes)

We will coordinate another meeting of our group in about 2 months to discuss:

- evolution of your thoughts and feelings regarding death, dying, and end of life planning
- your experiences in talking with their loved ones or personal community about these issues
- your specific experiences in developing their Health Care Directive, including how you have expressed your wishes about end of life care; uncertainties, confusions, or concerns; and shared ideas about next steps in the process.
- Let's talk date and time!

11. Closing Reading (2 minutes)