



THE DARTMOUTH DEMENTIA DIRECTIVE

An advance care document for dementia care planning

PART I – GENERAL INFORMATION:

What is Dementia?

Dementia is a general term for a significant decline in mental abilities. The decline is severe enough to interfere with daily life. Dementia is one of the most common medical conditions of late life.

There are numerous types of dementia. The most common, by far, is Alzheimer’s disease. Some of the other common forms of dementia are vascular dementia; mixed dementia; Lewy body dementia; dementia associated with Parkinson’s disease, and frontotemporal dementia. The clinical features and the course of illness differ in each type of dementia. Usually, dementia progresses (worsens) over time. It usually causes impairments in memory, rational thinking, daily functioning, judgment, and decision-making.

Persons with dementia often require help from others in order to function well. Family members or friends who provide this help do not always know what kind of care a person with dementia would want.

Dementia and Decision-Making (“Decisional Capacity”)

It is crucial to determine if the person with dementia continues to be able to make his or her own choices for care – to possess “decisional capacity”. Four basic abilities must be present: (1) The ability to **understand the choices** being presented. This includes understanding the potential risks and benefits of each choice. (2) The ability to **appreciate** the present condition. (3) The ability to clearly and consistently state one’s **choice for care** from among the options presented; and (4) The ability to communicate one’s **reason(s)** for the choice made.

A physician or nurse practitioner must determine if someone is able to make decisions. If the clinician determines that the person no longer can make decisions, he or she must indicate that in the person’s medical record. Without such a notation from the clinician, it is assumed that an individual continues to possess decisional capacity.

Because of the changing and generally progressive nature of dementia, decisional capacity should be re-assessed at regular intervals. We recommend revisiting this issue yearly, or whenever significant clinical changes occur. You may learn more about decisional capacity on our website, at <https://sites.dartmouth.edu/dementiadirective/determining-decisional-capacity/>.

Advance Directives

An advance directive is a written document that states a person’s wishes regarding medical treatment in the event he or she is no longer able to make medical decisions for him/herself. An advance directive, together with periodic conversations with your health care provider and family, can help ensure your wishes are heard and respected. It can also reduce the suffering of your loved ones. You should involve family and other potential caregivers in this planning.

If you have not already done so, please complete a standard advance directive.

STATEMENT OF TREATMENT PREFERENCE

NAME: _____

PLEASE NOTE: THIS IS A SUPPLEMENT TO THE STANDARD ADVANCE DIRECTIVE. IT DOES NOT REPLACE THE STANDARD ADVANCE DIRECTIVE

DATE OF BIRTH: _____

The Dartmouth Dementia Directive is a Supplement to your Standard Advance Directive

It is *not* meant to replace a standard advance directive. It is designed to address the gradual loss of decision-making ability which typically occurs in dementia, which may not be specifically addressed in a standard advance directive. There may be some preferences that are addressed in both the standard advance directive and the Dartmouth Dementia Directive. It will be important to ensure that your preferences, as expressed in your standard advance directive, agree with those expressed in the Dartmouth Dementia Directive.

Durable Power of Attorney for Health Care (DPOA–HC)

If you are no longer able to make your own healthcare decisions, it becomes the responsibility of the Durable Power of Attorney for Healthcare (DPOA-HC) to communicate with your physician or nurse practitioner and to ensure your wishes are followed. You should name a single Durable Power of Attorney for Healthcare. However, you may also name at least one additional individual to serve as an alternate. This can be useful if your Durable Power of Attorney for Healthcare is unavailable when needed. Selecting your Durable Power of Attorney for Health Care and an alternate are extremely important decisions. You should make these decisions after considerable thought and discussion with your loved ones. The individual(s) you select need to be aware you have chosen them and must agree to serve in this important role. They must be more than 18 years of age. The names and contact information of individuals you select for your Durable Power of Attorney for Health Care, and any alternate, should be given on the standard advance directive, and will be the same for the Dartmouth Dementia Directive.

Stages of Dementia

Dementia is often described as being in the mild, moderate or severe stage. Nearly all dementias progress from mild to severe, although the duration of each stage is quite variable. In addition, the symptoms people may have in each stage can vary greatly. Individuals with dementia gradually have less ability to make healthcare decisions as the illness progresses. However, there can be much individual variation. Each person’s primary doctor or nurse practitioner should regularly assess decision-making capacity.

Mild Dementia. People with mild dementia usually have difficulty with short term memory. They may not know the correct time or date and can become confused in new places. They may forget words or use incorrect ones. They have occasional trouble expressing their thoughts or answering questions. People with mild dementia often need help with certain tasks. They may have difficulty managing money. This might include making change, calculating a tip, or paying bills, for example. People with mild dementia may occasionally forget to wash, shave or comb their hair, but generally can manage their own grooming. They may have difficulty with driving and have minor accidents or become lost. This is more likely to happen on less familiar roads. People with mild dementia can enjoy activities if they are not too complex. However, they can become very frustrated with activities which they are unable to master because of their cognitive impairment. Many people with mild dementia make their own decisions regarding their health care. However, they may rely on a family member or friend to assist with these decisions.

Moderate Dementia. People with moderate dementia usually show more significant memory problems. They are often unaware of the date or even the month. Persons with moderate dementia may not know where they are. If they are at home, they may or may not recognize it. They may be unable to recall their own address or phone number. Speech may be confused or may not make sense. People with moderate dementia may forget the name of their high school or college. They usually need assistance with many activities of daily life. This includes managing finances, cooking, and shopping, for example. They may also need help choosing proper clothing for the season or for a specific occasion. Persons with moderate dementia may still enjoy certain activities if these are not demanding. Decision-making in persons with moderate dementia is often impaired. This is particularly true for complex matters such as healthcare choices.

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Severe Dementia. People with severe dementia are unable to remember even very basic information. They have no ability to recall any events. People with severe dementia are disoriented to time and place, even when at home. They may not speak at all. If they do speak, it may not be understandable. They are often unable to recognize people who should be very familiar. This can even include the spouse. People with severe dementia are usually unresponsive to those around them. They are not able to actively participate in any activities. They may enjoy passive activities such as listening to music although this is not always the case. People with severe dementia are completely dependent on others for all aspects of personal care. They may lose the ability to walk independently. If able to walk independently, they may be unable to find their way around the house. They are generally unable to make medical or other important decisions on their own.

Another common staging system divides cognitive decline into seven, rather than three, stages. In that system, mild dementia corresponds to Stage 4. Moderate dementia corresponds to Stages 5 and 6. Severe dementia corresponds to Stage 7.

You can find more detailed information about the stages of dementia on our website:
<https://sites.dartmouth.edu/dementiadirective/stages-of-dementia/>.

Wishes for Care Depending on the Stage of Dementia

The Dartmouth Dementia Directive gives you the opportunity to express different wishes for care depending on the **stage of dementia** – mild, moderate, or severe. For each stage of illness, the Dartmouth Dementia Directive addresses three main areas of care: **(1) Medical Care; (2) Nutrition and Fluids; and (3) Location of Care.** For example, you may wish to have more aggressive medical care if you are in the stage of mild dementia. In a later stage of dementia, however, you may wish to have comfort care only, and not receive interventions which would prolong your life. Likewise, if you have mild dementia, you may be willing to be hospitalized and/or to receive intravenous fluids if these are needed. However, you may prefer to not to be hospitalized or receive intravenous fluids if you are in a more advanced stage of illness. There is no “right or wrong” option; the choice is yours.

Standard Advance Directives, The Dartmouth Dementia Directive and the POLST (Physician’s Order for Life-Sustaining Treatment)

Your physician or nurse practitioner may complete a POLST (sometimes referred to as a COLST, Clinician’s Order for Life-Sustaining Treatment) depending on your clinical situation. The POLST expresses your wishes in the form of medical orders. You or your durable power of attorney for health care should ensure that the clinician follows your wishes, as expressed in your standard advance directive and in the Dartmouth Dementia Directive when he or she completes the POLST. A POLST form does **not** replace a standard advance directive or the Dartmouth Dementia Directive.

PART II – CHOICES FOR CARE

On the following pages you will indicate your preferences for the care you would wish to receive if you were suffering from mild, moderate or severe dementia. This directive only goes into effect if your doctor or nurse practitioner determines that you lack the capacity to make health care decisions. Your durable power of attorney for health care will then make healthcare decisions on your behalf. But your DPOA-HC should follow the wishes for care you have indicated below.

Specify your preferences, below, by initialing the box next to your choice. If a box is initialed, it indicates that you agree with the statement. If a box is left blank, it indicates that you do not agree with the statement. There is a space to write additional comments for each stage. If you wish, you may also add additional comments on Page 9.

CHOICES FOR CARE IF I HAVE MILD DEMENTIA AND LACK DECISIONAL CAPACITY:

CHOICE	MEDICAL CARE (MILD DEMENTIA)
	<p>FULL TREATMENT: I want to remain alive for as long as possible, and I want to undergo all medical treatments and other interventions in order to prolong my life, including the use of CPR or a ventilator, if necessary.</p>
	<p>LIMITED TREATMENT: I want to receive treatment to prolong life, or to see if I get better, but if my heart stopped beating or I could not breathe on my own, I would not want resuscitative measures (e.g. CPR, ventilator).</p>
	<p>COMFORT CARE ONLY: I want to receive only "comfort" care focused on relieving current suffering (e.g. pain or anxiety). I do not want care that would prolong my life.</p>
	<p>DPOA-HC SHOULD DECIDE: I wish my DPOA-HC to make this decision in consultation with my health care providers.</p>

CHOICE	NUTRITION AND FLUIDS (MILD DEMENTIA)
	<p>FULL NUTRITION AND FLUIDS: I want to receive any form of nutrition deemed appropriate by my caregivers and physicians. I would accept assisted feedings, tube feedings or intravenous nutrition.</p>
	<p>LIMITED NUTRITION AND FLUIDS: I would accept assisted feedings until I no longer willingly opening my mouth or otherwise indicate that I do not want to continue to receive nutrition. At that point, I would be willing to receive oral comfort care in the form of mouth swabs or ice chips. However, I do <u>not</u> want tube feeding or intravenous nutrition, but I would accept intravenous fluid replacement for dehydration or other reversible medical condition.</p>
	<p>NO NUTRITION OR FLUIDS: I want to receive <u>no</u> nutrition if I cannot feed myself. I do <u>not</u> want to be offered food or fluids in any form if I cannot feed myself. However, I would be willing to receive oral comfort care in the form of mouth swabs or ice chips. I realize it may not be possible to honor this preference in every circumstance, for example if I clearly request to eat or drink, or appear receptive to eating and drinking (show signs of enjoyment or positive anticipation), such that I would be agitated or upset by non-feeding.</p>
	<p>DPOA-HC SHOULD DECIDE: I wish my DPOA-HC to make this decision in consultation with my health care providers.</p>

CHOICE	LOCATION OF CARE (MILD DEMENTIA)
	<p>HOSPITAL OR HOSPICE: I am willing to be admitted to a hospital or hospice facility.</p>
	<p>HOSPICE BUT NOT HOSPITAL: I would be willing to be admitted to a hospice facility, but <u>not</u> a hospital.</p>
	<p>NO HOSPITAL OR HOSPICE ADMISSION: I do <u>not</u> want to be admitted to a hospital or hospice facility unless my comfort cannot be maintained in the environment in which I am residing at the time.</p>
	<p>DPOA-HC SHOULD DECIDE: I wish my DPOA-HC to make this decision in consultation with my health care providers.</p>

Additional Comments. You may also use page 9, if needed, for additional comments.
(_____ Initial here if you have written additional comments on page 9):

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CHOICES FOR CARE IF I HAVE MODERATE DEMENTIA AND LACK DECISIONAL CAPACITY:

CHOICE	MEDICAL CARE (MODERATE DEMENTIA)
	<p>FULL TREATMENT: I want to remain alive for as long as possible, and I want to undergo all medical treatments and other interventions in order to prolong my life, including the use of CPR or a ventilator, if necessary.</p>
	<p>LIMITED TREATMENT: I want to receive treatment to prolong life, or to see if I get better, but if my heart stopped beating or I could not breathe on my own, I would not want resuscitative measures (e.g. CPR, ventilator).</p>
	<p>COMFORT CARE ONLY: I want to receive only "comfort" care focused on relieving current suffering (e.g. pain or anxiety). I do not want care that would prolong my life.</p>
	<p>DPOA-HC SHOULD DECIDE: I wish my DPOA-HC to make this decision in consultation with my health care providers.</p>

CHOICE	NUTRITION AND FLUIDS (MODERATE DEMENTIA)
	<p>FULL NUTRITION AND FLUIDS: I want to receive any form of nutrition deemed appropriate by my caregivers and physicians. I would accept assisted feedings, tube feedings or intravenous nutrition.</p>
	<p>LIMITED NUTRITION AND FLUIDS: I would accept assisted feedings until I no longer willingly opening my mouth or otherwise indicate that I do not want to continue to receive nutrition. At that point, I would be willing to receive oral comfort care in the form of mouth swabs or ice chips. However, I do <u>not</u> want tube feeding or intravenous nutrition, but I would accept intravenous fluid replacement for dehydration or other reversible medical condition.</p>
	<p>NO NUTRITION OR FLUIDS: I want to receive <u>no</u> nutrition if I cannot feed myself. I do <u>not</u> want to be offered food or fluids in any form if I cannot feed myself. However, I would be willing to receive oral comfort care in the form of mouth swabs or ice chips. I realize it may not be possible to honor this preference in every circumstance, for example if I clearly request to eat or drink, or appear receptive to eating and drinking (show signs of enjoyment or positive anticipation), such that I would be agitated or upset by non-feeding.</p>
	<p>DPOA-HC SHOULD DECIDE: I wish my DPOA-HC to make this decision in consultation with my health care providers.</p>

CHOICE	LOCATION OF CARE (MODERATE DEMENTIA)
	<p>HOSPITAL OR HOSPICE: I am willing to be admitted to a hospital or hospice facility.</p>
	<p>HOSPICE BUT NOT HOSPITAL: I would be willing to be admitted to a hospice facility, but <u>not</u> a hospital.</p>
	<p>NO HOSPITAL OR HOSPICE ADMISSION: I do <u>not</u> want to be admitted to a hospital or hospice facility unless my comfort cannot be maintained in the environment in which I am residing at the time.</p>
	<p>DPOA-HC SHOULD DECIDE: I wish my DPOA-HC to make this decision in consultation with my health care providers.</p>

Additional Comments. You may also use page 9, if needed, for additional comments.
(_____ Initial here if you have written additional comments on page 9):

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CHOICES FOR CARE IF I HAVE SEVERE DEMENTIA AND LACK DECISIONAL CAPACITY:

CHOICE	MEDICAL CARE (SEVERE DEMENTIA)
	FULL TREATMENT: I want to remain alive for as long as possible, and I want to undergo all medical treatments and other interventions in order to prolong my life, including the use of CPR or a ventilator, if necessary.
	LIMITED TREATMENT: I want to receive treatment to prolong life, or to see if I get better, but if my heart stopped beating or I could not breathe on my own, I would not want resuscitative measures (e.g. CPR, ventilator).
	COMFORT CARE ONLY: I want to receive only "comfort" care focused on relieving current suffering (e.g. pain or anxiety). I do not want care that would prolong my life.
	DPOA-HC SHOULD DECIDE: I wish my DPOA-HC to make this decision in consultation with my health care providers.

CHOICE	NUTRITION AND FLUIDS (SEVERE DEMENTIA)
	FULL NUTRITION AND FLUIDS: I want to receive any form of nutrition deemed appropriate by my caregivers and physicians. I would accept assisted feedings, tube feedings or intravenous nutrition.
	LIMITED NUTRITION AND FLUIDS: I would accept assisted feedings until I no longer willingly opening my mouth or otherwise indicate that I do not want to continue to receive nutrition. At that point, I would be willing to receive oral comfort care in the form of mouth swabs or ice chips. However, I do <u>not</u> want tube feeding or intravenous nutrition, but I would accept intravenous fluid replacement for dehydration or other reversible medical condition.
	NO NUTRITION OR FLUIDS: I want to receive <u>no</u> nutrition if I cannot feed myself. I do <u>not</u> want to be offered food or fluids in any form if I cannot feed myself. However, I would be willing to receive oral comfort care in the form of mouth swabs or ice chips. I realize it may not be possible to honor this preference in every circumstance, for example if I clearly request to eat or drink, or appear receptive to eating and drinking (show signs of enjoyment or positive anticipation), such that I would be agitated or upset by non-feeding.
	DPOA-HC SHOULD DECIDE: I wish my DPOA-HC to make this decision in consultation with my health care providers.

CHOICE	LOCATION OF CARE (SEVERE DEMENTIA)
	HOSPITAL OR HOSPICE: I am willing to be admitted to a hospital or hospice facility.
	HOSPICE BUT NOT HOSPITAL: I would be willing to be admitted to a hospice facility, but <u>not</u> a hospital.
	NO HOSPITAL OR HOSPICE ADMISSION: I do <u>not</u> want to be admitted to a hospital or hospice facility unless my comfort cannot be maintained in the environment in which I am residing at the time.
	DPOA-HC SHOULD DECIDE: I wish my DPOA-HC to make this decision in consultation with my health care providers.

Additional Comments. You may also use page 9, if needed, for additional comments.
(_____ Initial here if you have written additional comments on page 9):

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Interpreting My Wishes for Care as Expressed in My Dartmouth Dementia Directive:

Specify your preference, below, by initialing the line next to your choice. If a line is initialed, it indicates that you agree with the statement. If a line is left blank, it indicates that you do not agree with the statement. You must indicate either Preference A or Preference B. Do not initial both preferences.

_____ **PREFERENCE A.** I direct my DPOA-HC to make the final decisions for care, after carefully considering these instructions, the current circumstances, and the opinion of my treating clinicians.

_____ **PREFERENCE B.** I direct my DPOA-HC and all treating clinicians to follow the instructions I have given above, no matter the current circumstances, and even if I express a different preference at the time a treatment decision needs to be made.

NOTE:

The name and contact information for the Durable Power of Attorney for Health Care (DPOA-HC) should be listed in the standard advance directive and will also apply to the Dartmouth Dementia Directive.

Signature of Person Completing The Dartmouth Dementia Directive:

Print Name: _____

Date Completed: _____

Witnesses

The Dartmouth Dementia Directive will not be valid unless it is signed in the presence of two (2) or more qualified witnesses who must both be present when you sign and who will acknowledge your signature on the directive, **OR** the document must be signed in the presence of a notary public, justice of the peace, commissioner of deeds or other authorized official. The following persons **may not** act as witnesses:

- The person you have designated as your Durable Power of Attorney for Healthcare
- Your spouse or heir at law or beneficiaries named in your will, trust or in a deed
- Your attending physician or APRN or person acting under the direction or control of the attending physician or APRN.

Only one of the two witnesses may be your health or residential care provider or one of your provider's employees.

The witnesses who sign this directive affirm the signature of the maker of this document and that it is being signed by that person as a free and voluntary act.

STATEMENT OF TREATMENT PREFERENCE
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NAME: _____

DATE OF BIRTH: _____

First Witness Signature: _____

Print Name: _____

Address: _____

Telephone: _____

Second Witness Signature: _____

Print Name: _____

Address: _____

Telephone: _____

Notary Public (in lieu of witnesses):

STATE: _____

COUNTY: _____

On _____ personally appeared _____
who acknowledged this instrument was signed by him/her as his/her free act and deed.

Before me, _____

Notary Public/Justice of the Peace
My commission expires:

The original of this Dartmouth Dementia Directive will be kept by me, with my important papers.
The following persons and institutions will have signed copies:

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

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NAME: _____

DATE OF BIRTH: _____

ADDITIONAL COMMENTS:

Signature: _____

Date: _____