



The Dartmouth Dementia Directive

THE DARTMOUTH DEMENTIA DIRECTIVE

An advance care document for dementia care planning

What is Dementia?

Dementia is a general term for a decline in mental abilities severe enough to interfere with daily life. It is one of the most common medical conditions of late life. It is estimated that by age 80, at least 20% of people will have dementia. By age 90, 40% to 50% of people may have dementia.

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, among others. Although the clinical features and course of illness differ in each of these, in most cases of dementia the condition progresses (worsens) over time, and causes impairments in a variety of domains, including memory, thinking, functioning, judgment, and decision-making.

Dementia and Decision-Making

Once dementia has progressed, it can be hard for people to know and/or to communicate the types of care they wish to receive. Although persons with dementia often require significant assistance from spouses, adult children, other family members, or friends, these helpers do not always know what kind of care a person with dementia would want.

Stages of Dementia and Decisional Capacity

Dementia is often described as mild, moderate or severe. Brief descriptions of each stage are found below; more detailed descriptions of the stages of dementia can be found on our website, at <https://sites.dartmouth.edu/dementiadirective/stages-of-dementia/>.

People with mild dementia are often able to express opinions about the care they want. However, as dementia progresses, most individuals will lose the capacity to understand the various options that are available and lose the ability to reliably express their preferences for care. The point at which the ability to make these decisions becomes lost varies greatly from person to person.

Decisional capacity should be re-assessed over time; we recommend revisiting this issue yearly, or whenever significant clinical changes occur. The factors involved in determining whether or not someone with dementia has the capacity to make decisions is addressed on our website, at <https://sites.dartmouth.edu/dementiadirective/determining-decisional-capacity/>.

NAME: _____ SIGNATURE: _____

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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. Commonly, advance directives are used in the case of an accident or illness when someone is suddenly unable to communicate his or her care preferences.

An advance directive, thoughtfully completed, together with periodic conversations with your health care provider and the individual appointed to act in the event of mental incapacity, can help ensure your wishes are heard and respected. It can also reduce the suffering of loved ones. It is important for family and other potential caregivers to be involved in planning for these circumstances.

If you have not already done so, please complete a standard advance directive. The standard advance directive enables you to state your care preferences in the event of your incapacity.

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

In your standard advance directive, you will name an individual to serve as your Durable Power of Attorney for Healthcare. If and when you are no longer able to make your own healthcare decisions, it becomes the responsibility of the Durable Power of Attorney for Healthcare named in your advance directive to ensure your wishes are followed. It is recommended you name a single Durable Power of Attorney for Healthcare. However, you should also name at least one additional individual to serve as an alternate, should your Durable Power of Attorney for Healthcare be unavailable when needed. Selecting your Durable Power of Attorney for Health Care and an alternate are extremely important decisions you should make only 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.

Gradual Loss of Decision-Making Ability

The Dartmouth Dementia Directive is a specialized advance directive. It is designed to address the **gradual** loss of decision-making ability which typically occurs in dementia. **The Dartmouth Dementia Directive is meant to supplement, not replace, the standard advance directive.**

There will be some wishes for care which 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, particularly for the severe stage 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 Illness
- (2) Nutrition and Fluids
- (3) Location of Care

For example, you may wish to have more aggressive medical care if you are in the stage of mild dementia, but in a later stage of dementia, you may wish to have care which is focused on

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comfort only, and would not wish to receive interventions which would prolong your life. Likewise, you may be willing to be hospitalized and to receive intravenous fluids if needed if you have mild dementia but prefer to not to be hospitalized or receive intravenous fluids if you are in a more advanced stage of illness.

A. Mild Dementia

Mild Dementia is usually characterized by short term memory problems and some difficulty performing certain daily activities. People with mild dementia generally need someone to assist them regularly with various tasks, but with this support they can function reasonably well in the community. Many people with mild dementia are able to make their own decisions regarding their health care but may rely on a family member or friend to assist with these decisions. However, whether or not someone with mild dementia has the ability to make healthcare decisions independently should be determined in each situation and reassessed at regular intervals.

1. Medical Illness (Mild Dementia)

*When my doctor or nurse practitioner certifies that I lack the capacity to make health care decisions and determines that I am in the stage of **mild dementia** I now declare the following:*

Indicate your preference for the type of care you wish to receive by initialing the appropriate 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.

Choice	Options for Medical Care (Mild Dementia)
	I want to remain alive as long as possible, no matter the circumstance, and I want to undergo all medical treatments and other interventions in order to prolong my life.
	I want to receive treatment to prolong life, but if my heart stopped beating or I could not breathe on my own, I would not want resuscitative measures (e.g. CPR, ventilator).
	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.
	I have no preference regarding medical treatment and wish my DPOA to make this decision in consultation with my primary physician.

Additional Comments:

NAME: _____ **SIGNATURE:** _____

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2. Nutrition & Fluids (Mild Dementia)

When my doctor or nurse practitioner certifies that I lack the capacity to make health care decisions and determines that I am in the stage of **mild dementia**, I now declare the following:

Indicate your preference for the type of care you wish to receive by initialing the appropriate 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.

Choice	Options for Nutrition (Mild Dementia)
	I want to receive nutrition deemed appropriate by my caregivers and physicians. I would accept assisted feedings, tube feedings or intravenous nutrition.
	I want to receive nutrition deemed appropriate by my caregivers and physicians. I would accept assisted feedings until I am no longer willingly opening my mouth or am otherwise indicating 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 not want tube feeding or intravenous nutrition.
	I want to receive no nutrition if I cannot feed myself. I do not want to be offered food or fluids in any form if I cannot feed myself. I would be willing to receive oral comfort care in the form of mouth swabs or ice chips.
	I have no preference regarding nutrition and fluids and wish my DPOA to make this decision in consultation with my primary physician.

Additional Comments:

NAME: _____ SIGNATURE: _____

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3. Location of Care (Mild Dementia)

When my doctor or nurse practitioner certifies that I lack the capacity to make health care decisions and determines that I am in the stage of **mild dementia**, I now declare the following:

Indicate your preference for the type of care you wish to receive by initialing the appropriate 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.

Choice	Options Regarding Location of Care (Mild Dementia)
	I am willing to be admitted to a hospital or hospice facility. My wishes regarding medical treatment and nutrition and fluids, as stated above in sections 1 and 2, are to be respected as much as possible.
	I would be willing to be admitted to a hospice facility, but not a hospital, unless my comfort cannot be maintained in a hospice facility.
	I do not 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. If I do not go to a hospital, I understand that this might mean I could not receive certain types of care (e.g. intensive nursing support).
	I have no preference regarding being admitted to a hospital or hospice facility and wish my DPOA to make this decision in consultation with my primary physician. However, if I am admitted to a hospital, my wishes regarding medical treatment, nutrition and fluids, as stated above in sections 1 and 2, are to be respected as much as possible.

Additional Comments:

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B. Moderate Dementia

Moderate Dementia signs and symptoms include more significant memory problems and greater difficulty with general functioning. People with moderate dementia usually need assistance with many activities of daily life, including managing their finances, cooking, shopping, and often getting dressed. Decision making in persons with moderate dementia is often impaired, particularly for complex matters such as healthcare choices, although this is variable and needs to be determined on an individual basis and reassessed at regular intervals.

1. Medical Illness (Moderate Dementia)

*When my doctor or nurse practitioner certifies that I lack the capacity to make health care decisions and determines that I am in the stage of **moderate dementia** I now declare the following:*

Indicate your preference for the type of care you wish to receive by initialing the appropriate 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.

Choice	Options for Medical Care (Moderate Dementia)
	I want to remain alive as long as possible, no matter the circumstance, and I want to undergo all medical treatments and other interventions in order to prolong my life.
	I want to receive treatment to prolong life, but if my heart stopped beating or I could not breathe on my own, I would not want resuscitative measures (e.g. CPR, ventilator).
	I want to receive only “comfort” care focused on relieving current suffering (e.g. pain or anxiety). I would not want care that would prolong my life.
	I have no preference regarding medical treatment and wish my DPOA to make this decision in consultation with my primary physician.

Additional Comments:

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2. Nutrition & Fluids (Moderate Dementia)

When my doctor or nurse practitioner certifies that I lack the capacity to make health care decisions and determines that I am in the stage of **moderate dementia**, I now declare the following:

Indicate your preference for the type of care you wish to receive by initialing the appropriate 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.

Choice	Options for Nutrition (Moderate Dementia)
	I want to receive nutrition deemed appropriate by my caregivers and physicians. I would accept assisted feedings, tube feedings or intravenous nutrition.
	I want to receive nutrition deemed appropriate by my caregivers and physicians. I would accept assisted feedings until I am no longer willingly opening my mouth or am otherwise indicating 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 not want tube feeding or intravenous nutrition.
	I want to receive no nutrition if I cannot feed myself. I do not want to be offered food or fluids in any form if I cannot feed myself. I would be willing to receive oral comfort care in the form of mouth swabs or ice chips.
	I have no preference regarding nutrition and fluids and wish my DPOA to make this decision in consultation with my primary physician.

Additional Comments:

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3. Location of Care (Moderate Dementia)

When my doctor or nurse practitioner certifies that I lack the capacity to make health care decisions and determines that I am in the stage of **moderate dementia**, I now declare the following:

Indicate your preference for the type of care you wish to receive by initialing the appropriate 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.

Choice	Options Regarding Location of Care (Moderate Dementia)
	I am willing to be admitted to a hospital or hospice. My wishes regarding medical treatment and nutrition and fluids, as stated above in sections 1 and 2, are to be respected as much as possible.
	I would be willing to be admitted to a hospice facility, but not a hospital, unless my comfort cannot be maintained in a hospice facility.
	I do not 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. If I do not go to a hospital, I understand that this might mean I could not receive certain types of care (e.g. intensive nursing support).
	I have no preference regarding being admitted to a hospital or hospice facility and wish my DPOA to make this decision in consultation with my primary physician. However, if I am admitted to a hospital, my wishes regarding medical treatment, nutrition and fluids, as stated above in sections 1 and 2, are to be respected as much as possible.

Additional Comments:

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C. Severe Dementia

Severe Dementia usually occurs after an individual has been ill for a number of years. Persons with severe dementia are not able to function in any manner without considerable assistance from others. Memory, use of language, awareness of the surroundings, and other basic cognitive abilities are significantly impaired. Individuals with severe dementia are generally not able to make medical or other important decisions independently.

1. Medical Illness (Severe Dementia)

*When my doctor or nurse practitioner certifies that I lack the capacity to make health care decisions and determines that I am in the stage of **severe dementia** I now declare the following:*

Indicate your preference for the type of care you wish to receive by initialing the appropriate 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.

Choice	Options for Medical Care (Severe Dementia)
	I want to remain alive as long as possible, no matter the circumstance, and I want to undergo all medical treatments and other interventions in order to prolong my life.
	I want to receive treatment to prolong life, but if my heart stopped beating or I could not breathe on my own, I would not want resuscitative measures (e.g. CPR, ventilator).
	I want to receive only “comfort” care focused on relieving current suffering (e.g. pain or anxiety). I would not want care that would prolong my life.
	I have no preference regarding medical treatment and wish my DPOA to make this decision in consultation with my primary physician.

Additional Comments:

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2. Nutrition & Fluids (Severe Dementia)

When my doctor or nurse practitioner certifies that I lack the capacity to make health care decisions and determines that I am in the stage of **severe dementia**, I now declare the following:

Indicate your preference for the type of care you wish to receive by initialing the appropriate 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.

Choice	Options for Nutrition (Severe Dementia)
	I want to receive nutrition deemed appropriate by my caregivers and physicians. I would accept assisted feedings, tube feedings or intravenous nutrition.
	I want to receive nutrition deemed appropriate by my caregivers and physicians. I would accept assisted feedings until I am no longer willingly opening my mouth or am otherwise indicating 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 not want tube feeding or intravenous nutrition.
	I want to receive no nutrition if I cannot feed myself. I do not want to be offered food or fluids in any form if I cannot feed myself. I would be willing to receive oral comfort care in the form of mouth swabs or ice chips.
	I have no preference regarding nutrition and fluids and wish my DPOA to make this decision in consultation with my primary physician.

Additional Comments:

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3. Location of Care (Severe Dementia)

When my doctor or nurse practitioner certifies that I lack the capacity to make health care decisions and determines that I am in the stage of **severe dementia**, I now declare the following:

Indicate your preference for the type of care you wish to receive by initialing the appropriate 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.

Choice	Options Regarding Location of Care (Severe Dementia)
	I am willing to be admitted to a hospital or hospice facility. My wishes regarding medical treatment and nutrition and fluids, as stated above in sections 1 and 2, are to be respected as much as possible.
	I would be willing to be admitted to a hospice facility, but not a hospital, unless my comfort cannot be maintained in a hospice facility.
	I do not 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. If I do not go to a hospital, I understand that this might mean I could not receive certain types of care (e.g. intensive nursing support).
	I have no preference regarding being admitted to a hospital or hospice facility and wish my DPOA to make this decision in consultation with my primary physician. However, if I am admitted to a hospital, my wishes regarding medical treatment, nutrition and fluids, as stated above in sections 1 and 2, are to be respected as much as possible.

Additional Comments:

NAME: _____ SIGNATURE: _____

DATE OF BIRTH: _____ TODAY'S DATE: _____

I want my Durable Power of Attorney for Healthcare to follow the above directive to the best of his/her ability. I realize it may not be possible to honor all of these preferences in every circumstance. This directive is given to provide guidance and is not given to limit the authority of my Durable Power of Attorney for Healthcare. I want my Durable Power of Attorney for Healthcare to have the power to make any decision he or she chooses, just as if I were making the decision myself.

PRIMARY Durable Power of Attorney for Healthcare: (signature not required)

Print Name: _____

Address: _____

Telephone: _____ Email Address: _____

ALTERNATE Durable Power of Attorney for Healthcare: (signature not required)

Print Name: _____

Address: _____

Telephone: _____ Email Address: _____

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 on the next page of 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.

(see next page)

NAME: _____ **SIGNATURE:** _____

DATE OF BIRTH: _____ **TODAY'S DATE:** _____

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 Advance Directive for Dementia will be kept at home and the following persons and institutions will have signed copies:

_____	_____
_____	_____
_____	_____
_____	_____

NAME: _____ **SIGNATURE:** _____

DATE OF BIRTH: _____ **TODAY'S DATE:** _____

What to Do with Your Dartmouth Dementia Directive After Completing It

1. Make sure you have signed and dated each page.
2. Have your completed Dartmouth Dementia Directive signed by either two witnesses or a notary public.
3. Make copies of your completed Dartmouth Dementia Directive and share it with your friends and family.
4. If you haven't completed a standard advance directive and selected a Durable Power of Attorney for Health Care (DPOA-HC), you should do that as soon as possible.
5. Make sure your DPOA-HC has a copy of your Dartmouth Dementia Directive.
6. Share the Dartmouth Dementia Directive with your primary health care provider.
7. Ask to have the Dartmouth Dementia Directive included in your medical record.
8. Review a copy of your completed Dartmouth Dementia Directive with your personal attorney (lawyer) and provide a copy of the directive for his or her files.
9. Place the original copy of your completed Dartmouth Dementia Directive in a safe place, with your other important papers.
10. Set a reminder to yourself to revisit your completed Dartmouth Dementia Directive every 1-2 years.

Questions:

If you have any questions regarding your Dartmouth Dementia Directive, please contact us at:
DDDirective@gmail.com

The Dartmouth Dementia Directive Team

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