STATEMENT OF TREATMENT PREFERENCE

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

NAME: _____

DATE OF BIRTH: _____

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 clinician 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 healthcare 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.

NAME: _____

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 healthcare provider. The role of the DPOA is to ensure that your wishes, as expressed in the Dartmouth Dementia Directive, are followed to the extent that is feasible. Selecting your Durable Power of Attorney for Health Care is an extremely important decision. You should make this decision after considerable thought and discussion with your loved ones. The individual you select needs to be aware you have chosen them and must agree to serve in this important role. He or she must be more than 18 years of age. The name and contact information of the individual you select for your Durable Power of Attorney for Health Care should be given on the standard advance directive, and should 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 retain the capacity to 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 capacity in persons with moderate dementia is often impaired. This is particularly true for complex matters such as healthcare choices.

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. There 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 generally lack the capacity 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 Interventions; (2) Location of Care; and (3) Nutrition and Hydration.** 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. Following each area (Medical Interventions, Location of Care, and Nutrition and Hydration) there is a space for you to write any additional comments or instructions for your DPOA.

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

Your healthcare provider 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 the choices for care that you have 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

Note: The Dartmouth Dementia Directive also gives you an opportunity to express your preferences regarding participation in research (See Part III, below).

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 clinician 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. Your DPOA-HC should follow the wishes for care you have indicated, to the extent it is feasible to do so.

NAME: _____

DATE OF BIRTH: _____

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. If you wish, you may also add additional comments.

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

MEDICAL INTERVENTIONS	**MILD DEMENTIA**	**MODERATE DEMENTIA**	**SEVERE DEMENTIA**
	Initial One Below	*Initial One Below*	*Initial One Below*
FULL TREATMENT: I want to remain alive for as long as possible, and I want to undergo all medical treatments and other interventions to prolong my life, including antibiotics, 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- FOCUSED TREATMENT 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. I want antibiotics only if these are necessary for my comfort.			
DPOA-HC SHOULD DECIDE: I do not wish to express any choices for medical interventions now. I wish my DPOA-HC to make these decisions in consultation with my healthcare providers.			

ADDITIONAL COMMENTS REGARDING TREATMENT PREFERENCES FOR MEDICAL INTERVENTIONS, INCLUDING DIRECTIONS TO MY DPOA-HC, MY FAMILY, AND/OR HEALTH CARE PROVIDERS
[ATTACH ADDITIONAL PAGE(S) IF NECESSARY]:

NAME: _____

DATE OF BIRTH: _____

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. If you wish, you may also add additional comments.

CHOICES FOR CARE IF I HAVE DEMENTIA AND LACK DECISIONAL CAPACITY, CONT.:

LOCATION OF CARE	**MILD DEMENTIA**	**MODERATE DEMENTIA**	**SEVERE DEMENTIA**
	Initial One Below	*Initial One Below*	*Initial One Below*
HOSPITAL OR INPATIENT HOSPICE: I am willing to be admitted to a hospital or an inpatient hospice facility, or to receive hospice care at home.			
HOSPICE BUT NOT REGULAR HOSPITAL CARE: I would be willing to be admitted to a hospital for inpatient hospice care, but otherwise I do **not** want to be admitted **to** a hospital. I am willing to receive hospice care at home.			
NO HOSPITAL OR INPATIENT HOSPICE ADMISSION: I do not want to be admitted to a hospital or inpatient hospice facility unless my comfort cannot be maintained in the environment in which I am residing at the time. I would be willing to receive hospice care at home.			
DPOA-HC SHOULD DECIDE: I do not wish to express any location of care choices now. I wish my DPOA-HC to make these decisions in consultation with my healthcare providers.			

ADDITIONAL COMMENTS REGARDING TREATMENT PREFERENCES FOR LOCATION OF CARE, INCLUDING DIRECTIONS TO MY DPOA-HC, MY FAMILY, AND/OR HEALTH CARE PROVIDERS [ATTACH ADDITIONAL PAGE(S) IF NECESSARY]:

NAME: _____

DATE OF BIRTH: _____

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. If you wish, you may also add additional comments.

CHOICES FOR CARE IF I HAVE DEMENTIA AND LACK DECISIONAL CAPACITY, CONT.:

NUTRITION AND HYDRATION	**MILD DEMENTIA**	**MODERATE DEMENTIA**	**SEVERE DEMENTIA**
	Initial One Below	*Initial One Below*	*Initial One Below*
FULL NUTRITIONAL SUPPORT: 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 NUTRITIONAL SUPPORT: I would accept assisted feedings until I no longer willingly open 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 not want tube feeding or intravenous nutrition, but I would accept intravenous fluid replacement for dehydration or other reversible medical condition.			
NO NUTRITIONAL SUPPORT: 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. However, I would be willing to receive oral comfort care in the form of mouth swabs or ice chips.			
DPOA-HC SHOULD DECIDE: I do not wish to express any nutrition or hydration choices now. I wish my DPOA-HC to make these decisions in consultation with my health care providers.			

ADDITIONAL COMMENTS REGARDING TREATMENT PREFERENCES FOR NUTRITION AND HYDRATION, INCLUDING DIRECTIONS TO MY DPOA-HC, MY FAMILY, AND/OR HEALTH CARE PROVIDERS [ATTACH ADDITIONAL PAGE(S) IF NECESSARY]:

PART III – PARTICIPATION IN DEMENTIA RESEARCH

This document also gives you an opportunity to indicate your preferences regarding participation in dementia research.

SECTION 1: ABOUT DEMENTIA RESEARCH

There are two broad categories of dementia research that involve human subjects:

(1) Some research studies in dementia, such as clinical trials of medications, offer the possibility that the participant may directly benefit.

(2) Other studies do not offer the possibility of a direct benefit to the participant. These studies are classified as "non-therapeutic research". They enable scientists to examine and better understand the disease under study. While this research does not specifically help the participant, it may ultimately help future dementia suffers. Some individuals with dementia wish to participate in non-therapeutic research to contribute to scientific progress and help those who may have dementia in the future.

You may or may not wish to participate in one or both types of research.

SECTION 2: PREFERRED PARAMETERS OF PARTICIPATION IN RESEARCH

In Section 2A, you will find examples of research procedures that may involve varying degrees of risk of harm ("Parameter 1") and physical or psychological discomfort ("Parameter 2"). The examples included below do not constitute an exhaustive list of procedures that might be employed in current or future research projects. However, they are described to inform you as you consider what degree of risk and discomfort you might be willing to tolerate in a research study if you develop dementia.

Novel research techniques, developed as science progresses, will likely be evaluated along similar dimensions of risk and discomfort, based on similar existing procedures. If, because of dementia, you are no longer able to make healthcare decisions, your healthcare proxy and your healthcare provider will consult with a representative from the research team to understand the risk and discomfort that a novel procedure might pose for you, in the event of dementia.

In Sections 2B and 2C, you will indicate whether you wish to participate in research. You will place your initials at a point on each of the scales given. The location of your initials will represent the maximum levels of risk of harm (Parameter 1) and risk of discomfort (Parameter) that you might be willing to endure as a part of research, should you develop dementia. These scales are designed as tools to guide your healthcare proxy. If you develop dementia and wish to participate in a research study, your healthcare proxy will be able to look at the location of your initials on the scale and consider whether the present study appears to fall within the boundaries of the preferences you have indicated here.

However, the location of your initials does not dictate what your healthcare proxy *must* do. The location of existing or novel procedures along the discomfort and risk scales below will vary, based on factors such as the experience of the person performing the procedure as well as the physical, emotional, and mental state of the individual undergoing the procedure. These factors will be considered by your healthcare proxy and healthcare provider when the time comes. In the event of dementia, your healthcare proxy and healthcare provider will together arrive at a decision regarding research participation that would align most closely with your values and safeguard your health.

SECTION 2A: EXAMPLES RESEARCH PROCEDURES

Interviews:
Speaking with the research team to gather information about experiences and attitudes. Most people would consider this to be very low risk of harm (Parameter 1) and very low physical or psychological discomfort (Parameter 2).

Blood Tests:
Usually, these are not considered uncomfortable. However, some individuals with dementia might be sensitive to being touched or pricked by needles. Generally low risk, although complications can occasionally occur. Thus, most people would consider blood tests to involve low risk of harm (Parameter 1) and a low level of discomfort (Parameter 2).

Experimental Medications:
Some research projects study the efficacy of therapeutic drugs, which might have the potential to treat a condition or improve its symptoms. Participants in a clinical trial are usually randomly assigned to either the "treatment" group, in which case they would receive the drug, or the control group, in which they would receive a placebo. The risk of harm would vary depending on the drug itself (Parameter 1).
An experimental medication might be administered through an oral, intravenous, or intramuscular route. Depending on the route of administration, this might involve a low or moderate level of discomfort (Parameter 2),

CT Scan:
CT scans give detailed images of your bones, soft tissues, and blood vessels. Most people would not consider a CT scan uncomfortable. However, an individual is exposed to a brief amount of radiation during a CT scan, which introduces a low level of risk. Thus, a CT scan involves a low risk of harm (Parameter 1). and usually, a low risk of discomfort (Parameter 2).

MRI Scan:
MRI scans use magnetic fields and radio waves to capture detailed images of your insides. Some might consider an MRI somewhat uncomfortable or anxiety-provoking, as you will be asked to stay still within an enclosed cylinder. Some people are also bothered by the loud sounds the MRI machine makes. An individual with dementia might be particularly sensitive to these factors. MRIs are quite low risk because unlike CT scans, they do not require exposure to radiation. Thus, an MRI generally involves a low risk of harm (Parameter 1), but some might experience a moderate level of discomfort (Parameter 2).

PET Scan:
A PET scan is used to detect metabolic activity or other processes in the organ being examined. It involves the infusion of a "tracer" through an intravenous catheter. A tracer is a compound that has a small amount of radioactivity. This small amount of radiation introduces a low level of risk. The process of infusion can cause mild to moderate discomfort, and you might feel a cold sensation in your veins as the tracer spreads. Some people also experience anxiety or discomfort from being enclosed in the scanner. As mentioned in the MRI section, an individual with dementia might be particularly bothered by this. Thus, a PET scan generally involves a low risk of harm (Parameter 1), but some might experience a moderate level of discomfort (Parameter 2).

Lumbar Puncture:
A lumbar puncture, or spinal tap, involves placing a needle into the spinal canal in the back, to remove some spinal fluid for analysis. For some individuals, a lumbar puncture can be uncomfortable. If you are upset by being restrained or held, this might cause anxiety. The level of discomfort or anxiety an individual experiences might depend on the anatomy of their spine and the difficulty the clinician encounters when inserting the needle. When performed by an experienced clinician, this procedure is usually well tolerated. There can also be post-procedure discomforts such as 'spinal headache.' There are some risks to a lumbar puncture, including bleeding at the puncture site or into the epidural space, though this is rare. Thus, most physicians consider a lumbar puncture to involve a relatively low risk of harm (Parameter 1), although some might experience moderate to significant discomfort from the procedure (Parameter 2).

SECTION 2B: CONSENT TO PARTICIPATE IN RESEARCH WHICH OFFERS THE POSSIBILITY OF DIRECT BENEFIT TO ME:

Initial on the line below and then place your initials at a point on each of the scales below. The location of your initials will represent the maximum levels of risk and discomfort that you might be willing to endure as a part of research, should you develop dementia.

_____ **I give permission to my DPOA to enroll me in research which offers the possibility of direct benefit to me and, if my DPOA does so they should consider the risk and harm parameters I have indicated below:**

Parameter 1: Level of risk of *harm* I am willing to accept if I participate in research which offers the possibility of direct benefit to me:

_____

Low **Medium** **High**

Parameter 2: Level of physical or psychological *discomfort* I am willing to accept if I participate in research which offers the possibility of direct benefit to me:

_____

Low **Medium** **High**

Please note that if a research procedure or intervention is too unpleasant, as evidenced by your verbalizations or bodily reactions, it will be terminated.

_____ **I do NOT wish to participate in research which offers the possibility of direct benefit to me.**

ADDITIONAL COMMENTS REGARDING PARTICIPATION IN RESEARCH WHICH OFFERS THE POSSIBILITY OF DIRECT BENEFIT TO ME, INCLUDING DIRECTIONS TO MY DPOA-HC AND HEALTH CARE PROVIDERS [ATTACH ADDITIONAL PAGE(S) IF NECESSARY]:

NAME: _____

DATE OF BIRTH: _____

SECTION 2C: CONSENT TO PARTICIPATE IN "NON-THERAPEUTIC" RESEARCH

Initial on the line below and then place your initials at a point on each of the parameter scales below. The location of your initials will represent the maximum levels of risk and discomfort that you might be willing to endure as a part of research, should you develop dementia.

_____ I give permission to my DPOA to enroll me in "non-therapeutic" research, and, if my DPOA does so they should consider the risk and harm parameters I have indicated below:

Parameter 1: Level of risk of *harm* I am willing to accept if I participate in "non-therapeutic" research:

_____

Low Medium High

Parameter 2: Level of physical or psychological *discomfort* I am willing to accept if I participate in "non-therapeutic" research

_____

Low Medium High

If any research procedure or intervention is too unpleasant, as evidenced by my verbalizations or bodily reactions, it should be terminated.

_____ I do NOT wish to participate in "non-therapeutic" research.

ADDITIONAL COMMENTS REGARDING PARTICIPATION IN "NON-THERAPEUTIC" RESEARCH, INCLUDING DIRECTIONS TO MY DPOA-HC AND HEALTH CARE PROVIDERS [ATTACH ADDITIONAL PAGE(S) IF NECESSARY]:

NAME: _____

DATE OF BIRTH: _____

PART IV – SIGNATURES

Signature of Person Completing The Dartmouth Dementia Directive:

_____

Print Name: _____

Date Completed: _____

Name and Contact Information for your Durable Power of Attorney for Healthcare:

Name:_____

Address: _____

Email address: _____

Telephone: _____

*(Note: The Durable Power of Attorney for Healthcare (DPOA–HC) for your Dartmouth Dementia Directive must be the same person as you have named in your Advance Directive. Your DPOA-HC does **NOT** need to sign this document)*

Witnesses

The Dartmouth Dementia Directive is a supplemental document. We recommend it be signed in accordance with your local state's law for Advance Directives and other health care proxies.

In New Hampshire, an Advance Directive must be signed in the presence of two (2) or more qualified witnesses who must both be present when you sign and who acknowledge your signature on the directive or in the presence of a notary public, justice of the peace or other qualified official. In Vermont, an Advance Directive must be signed in the presence of two (2) or more qualified witnesses who must both be present when you sign and who acknowledge your signature on the directive.

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 healthcare provider or person acting under the direction or control of your healthcare provider

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.

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 copies (paper or electronic).

_____ _____

_____ _____

_____ _____

_____ _____