CurePSP is committed to providing its constituents—patients, families, caregivers, and healthcare providers—with up-to-date educational information about topics relevant to living with prime-of-life neurodegenerative diseases.

It is of utmost importance that patients understand the disease and its potential treatments, decide their wishes for future care—including end-of-life care—and discuss these wishes with their family. The earlier in disease progression these topics are addressed, the better for everyone—patient, family, and healthcare providers. The benefits of Advance Planning are many-fold; for example: a comfort or freeing-up feeling in knowing one’s plans for possible disease complications; diminishing of fears through the course of the disease; helping the family and the team to stay “on the same page” in their ability to honor and carry out the patient’s wishes.

This pamphlet will help you to learn about the possible late-stage treatment options for neurodegenerative disease, as well as to understand the various kinds of planning documents.

CurePSP is the leading nonprofit organization working to improve awareness, education, care, and cure for devastating prime of life neurodegenerative diseases. These include progressive supranuclear palsy (PSP), corticobasal degeneration (CBD), multiple system atrophy (MSA), and others. They often strike when people have careers, family responsibilities, and active lives. Their symptoms are incapacitating and there are no known causes, treatments, or cures.

Research has shown that there are important links between prime of life diseases and more common neurodegenerative conditions, such as Alzheimer’s disease and Parkinson’s disease. Your support will help advance this research, provide resources for families and caregivers of patients, and better educate the healthcare community. Together we are unlocking the secrets of brain disease.

CurePSP is a not-for-profit 501(c)(3) organization. Gifts and pledges of support are encouraged and donations are tax deductible to the extent allowed by law.
THE BASICS
Making healthcare decisions involves trying to understand a lot of information that may be confusing, daunting, and scary. There are multiple issues to consider and a variety of documents to obtain, draw up, sign, and periodically review. The definitions below provide a basic introduction to the documents and will help you to decide which ones are pertinent for you. The Resources in this pamphlet will guide you to more detailed information and “next steps.”

Values history
A form designed to help individuals understand and make health care decisions in line with one’s values.

Resuscitation orders
In the event that one’s heart ceases to beat or is in a life-threatening abnormal rhythm, an individual has the right to choose what, if any, type of resuscitative intervention he or she would accept.

Do Not Resuscitate (DNR) (Also called: Do Not Attempt Resuscitation (DNAR) and Allow Natural Death (AND))
Instruct medical personnel not to try to return your heart to a normal rhythm by any means: cardiopulmonary resuscitation (CPR), electric shocks (defibrillation), and/or medications. In addition, these orders mean that you will not be able to speak or to make one’s own decision. Names alternate or successor agents to serve - one at a time, in order.
Can include instructions re: life-support measures, artificial nutrition (tube feeding) and hydration (intravenous fluids), mechanical ventilation (tracheotomy), comfort care, if/when to end life-sustaining measures, CPR, anatomical organ gifts, disposition of remains.
Should be periodically reviewed, re-dated, and initialed.
Can be ended any time by informing physician and agent, and destroying document, or by drafting and signing a new DPOA-HC.

Practitioner orders for life-sustaining treatment (POLST) or Medical orders for life-sustaining treatment (MOLST)
Provide guidance about one’s care near the end of life. If signed, practitioner’s orders. The type of practitioners who can sign the POLST varies by state, and may include physician, nurse practitioner, and physician assistant.
Enable healthcare personnel to act immediately, in line with your wishes, in an emergency.

Living Will
Allows one to put into writing his or her wishes about medical treatment should one have a terminal condition and be unable to communicate.
Can specify directions about death-delaying procedures one does or does not want (e.g. artificial life support, transfusions, dialysis).

Durable Power of Attorney for Healthcare (DPOA-HC)
Designates and authorizes an agent to carry out a person’s health care and life-support wishes at any time one loses the ability to speak or to make one’s own decision.

Guardian
A legally responsible individual who is court-appointed – on a limited-time or full-time basis – when an individual is not able to make decisions for him or herself and no Advance directives exist.

The takeaway message:
With this basic information in hand, we hope you will discuss and draw up your wishes in conversation with your family, your physician, and an experienced social worker or nurse. Doing so will provide you with control over decisions about your care even if you are unable to communicate in the future, and will provide your family or agent with valuable information about your care wishes.

Five wishes
Designates who will make health care decisions when or if the patient is unable.
Defines the treatments the person wants and does not want.
Describes the patient wants to be treated.
Informs loved ones of information important to the patient.

MYTH AND FACT

Myth: An attorney is required in order to complete one’s Advance Directives.
Fact: Legal forms are required, but the services of a lawyer are not. The conversation is best started with one’s physician and closest family members or trusted person. An attorney can be helpful in drafting personalized documents.

Myth: Some states in the US do not recognize Advance Directives.
Fact: Advance Directives are recognized in all 50 states. However, states differ regarding requirements such as whether a witness or notary is required. Some states maintain registries that allow quick access by agents and healthcare providers.

Myth: Advance Directives should be kept in a safe deposit box with other important papers.
Fact: Keep a copy readily available at home. Also give a copy to your physician and your proxy (agent). Make extra copies in the event you need to be admitted to the hospital.

Myth: With an Advance Directive in place, the person gives up control.
Fact: Drawing up an Advance Directive gives you the opportunity to decide, state, and put in writing the end-of-life care you want, thereby helping your agent to represent your choices when the time comes.