

Integration of Supportive and Palliative Care into Parkinson's Disease Treatment

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Outline

- Definition of Palliative Care
- Why are we talking about Palliative now?
- What we know – new research
- Case
- What is Advance Care Planning?
- What is Hospice?
- Questions



What is Palliative Care?

- Specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.
- Palliative care is provided by a specially trained team of palliative care physicians, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.

So what
does that
look like?

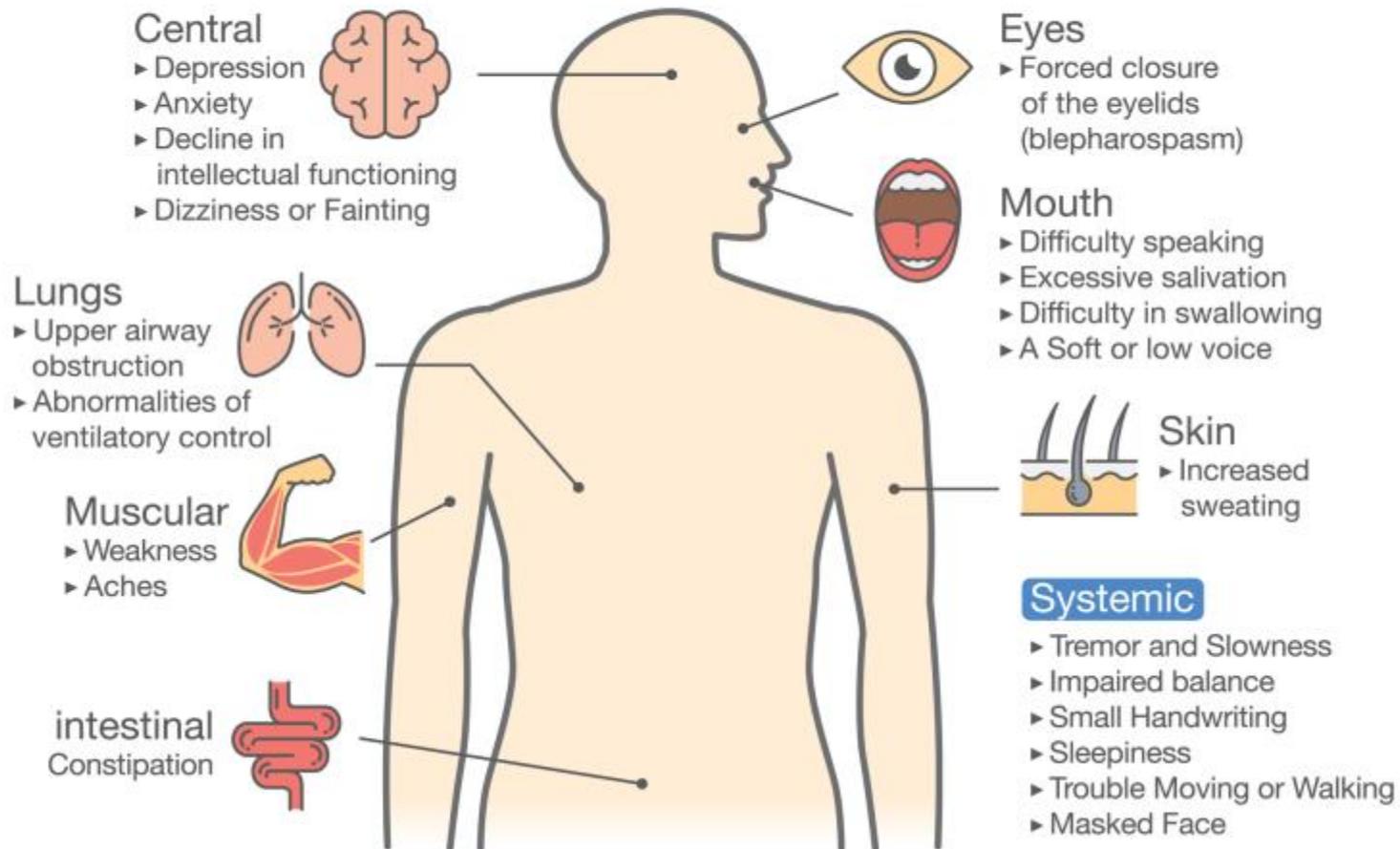
Care Decisions: including open discussion about treatment choices and Advanced Care Planning

Overwhelming Symptoms: For example, pain, shortness of breath, fatigue, nausea, loss of appetite, and difficulty sleeping

Psychosocial Distress: that may include anxiety, depression, fears, and spiritual tension

Examining Support: uncovering what systems of support give you strength, and what values drive your preferences in care

Symptoms of Parkinson's Disease



Parkinson's Disease and SPC

Palliative care involves a team of professionals who work together to improve the quality of life of seriously ill patients and their families. Palliative care helps manage the following:

- Physical symptoms (pain, constipation, fatigue)
- Psychological challenges (grief, worry)
- Preparing for the future (advance care planning)
- Spiritual support (finding hope and meaning)
- Education about diagnosis (progression)

In a person with Parkinson disease, the palliative care team may include:



Neurologist



Nurse



Spiritual guide



Palliative physician

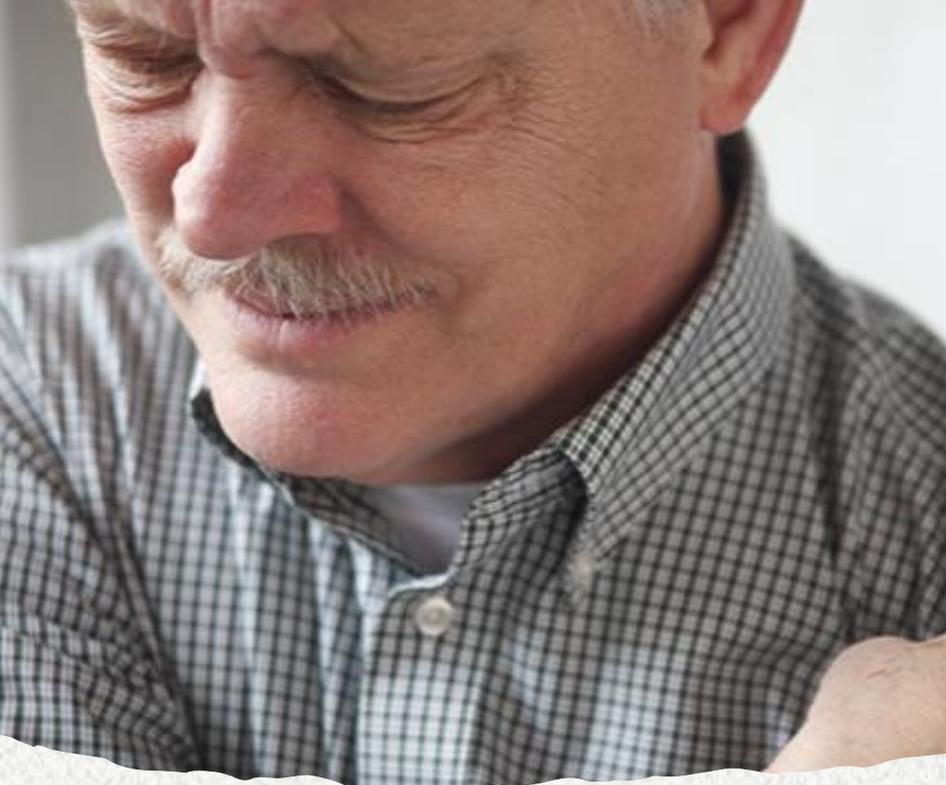


Social worker



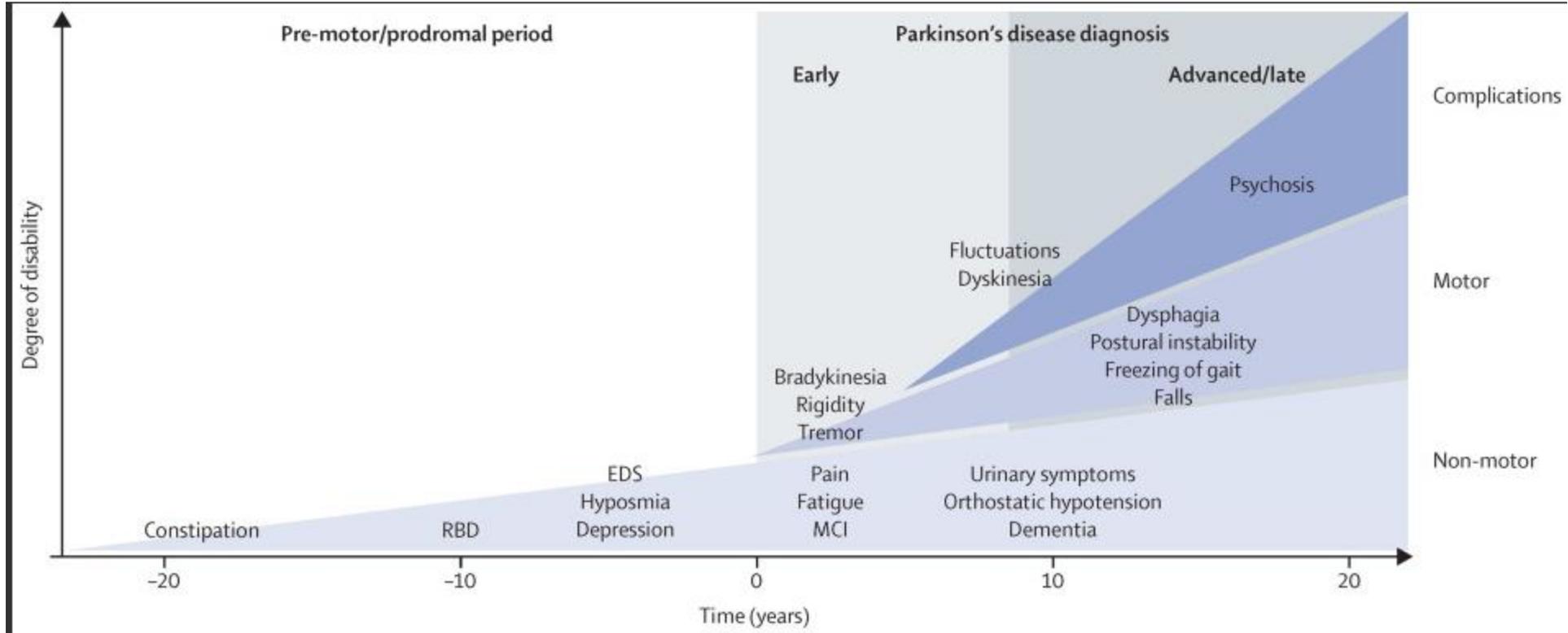
Living with Parkinson's Disease





But we know there
is this side too

Natural History of PD



Why now? What is the evidence?

REVIEW

CLINICIAN'S CORNER

Effectiveness of Specialized Palliative Care A Systematic Review

Camilla Zimmermann, MD, MSc
Rachel Riechelmann, MD
Monika Krzyzanowska, MD, MPH
Gary Rodin, MD
Ian Tannock, MD, PhD

Context Specialized palliative care teams are increasingly providing care for the terminally ill. However, the impact of such teams on quality of life, satisfaction with care, and economic cost has not been examined systematically using detailed criteria for study quality.

Objective To systematically review the evidence for effectiveness of specialized palliative care.

Data Sources We performed a keyword search of the following databases from their inception to January 2008: MEDLINE, Ovid Healthstar, CINAHL, EMBASE, and the Cochrane Central Register of Controlled Trials.

Study Selection We included all randomized controlled trials in which specialized palliative care was the intervention and for which outcomes included quality of life, satisfaction with care, or economic cost.

Data Extraction Data on population, intervention, outcome, methods, and methodological quality were extracted by 2 investigators using standardized criteria.

Results Of 396 reports of randomized controlled trials, 22 met our inclusion criteria. There was most consistent evidence for effectiveness of specialized palliative care in improvement of family satisfaction with care (7 of 10 studies favored the intervention). Only 4 of 13 studies assessing quality of life and 1 of 14 assessing symptoms showed a significant benefit of the intervention; however, most studies lacked statistical power to report conclusive results, and quality-of-life measures were not specific for terminally ill patients. There was evidence of significant cost savings of specialized palliative care in only 1 of the 7 studies that assessed this outcome. Methodological limitations were identified in all trials, including contamination of the control group, failure to account for clustering in cluster randomization studies, and substantial problems with recruitment, attrition, and adherence.

Conclusions The evidence for benefit from specialized palliative care is sparse and limited by methodological shortcomings. Carefully planned trials, using a standardized palliative care intervention and measures constructed specifically for this population, are needed.

JAMA. 2008;299(14):1698-1709

www.jama.com

THERE IS INCREASING AWARENESS of the suffering of patients with terminal illnesses, including pain, other physical symptoms, and psychosocial distress, which may arise many months before the patient's death.^{1,2} Specialized palliative care services have proliferated worldwide, initially focusing on terminal cancer care,³ but increasingly expanding to include patients with cancer and other terminal diseases who are at earlier stages of their disease trajectory.⁴ The objective of such services is to improve the symptom control and quality of life of patients with terminal illnesses and to coordinate care of the patient and support for the family.⁵ With the increasing development of such services, it is important to determine their effectiveness compared with other models of care.

There have been previous reviews

ORIGINAL CONTRIBUTION

Effects of a Palliative Care Intervention on Clinical Outcomes in Patients With Advanced Cancer The Project ENABLE II Randomized Controlled Trial

Marie Bakken, DNSc, APFN

Context There are few randomized controlled trials on the effectiveness of palliative care.

ORIGINAL ARTICLE

Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer

Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A., Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H., Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N., Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H.,

JOURNAL OF CLINICAL ONCOLOGY

ORIGINAL REPORT

Early Versus Delayed Initiation of Concurrent Palliative Oncology Care: Patient Outcomes in the ENABLE III Randomized Controlled Trial

Marie A. Bakken, Tor D. Tonness, Zhigang Li, Kathleen D. Lyons, Jay G. Hail, Zhongze Li, J. Nicholas Dionne-Oden, Jennifer Frost, Kristinette H. Dragnon, Mark T. Hogg, Andrea Azoum, and Tim A. Ahler

See accompanying editorial doi: 10.1200/JCO.2014.80.5386 and article doi: 10.1200/JCO.2014.58.7824

ABSTRACT

Marie A. Bakken, J. Nicholas Dionne-Oden, and Andrea Azoum, University of Minnesota at Minneapolis; Benjamin A. Al, Marie A. Bakken, Jennifer Frost, and Kristinette H. Dragnon, Dorroutch-Metroplex Medical Center; Zhigang Li, Steve Cohen Cancer Center; Leifon Tu, D. Tonness, Kathleen D. Lyons, and Mark T. Hogg, Dorroutch School of Medicine at Dorroutch; Zhigang Li and Jay G. Hail, Dorroutch College, Hancock, Minn; and Tim A. Ahler, Memorial Sloan-Kettering Cancer Center, New York, NY.

Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial

Camilla Zimmermann, Nadia Swami, Monika Krzyzanowska, Breffni Hannon, Natasha Leigh, Amit Oz, Gary Rodin, Ian Tannock, Allan Donner, Christopher Lo

Summary

Background Patients with advanced cancer have reduced quality of life, which tends to worsen as the disease progresses.

Original Investigation

Emergency Department-Initiated Palliative Care in Advanced Cancer A Randomized Clinical Trial

Corita R. Gruden, MD, MSHS, Lynne D. Richardson, MD, Pauline N. Johnson, BS, Ming Hu, PhD, Binhuang Wang, PhD, Joanna M. Ortiz, BA, Emmett A. Kistler, MD, Angela Chen, MD, R. Sean Morrison, MD

An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial

Irene J. Higginson, Claudia Buszewski, Charles C. Reilly, Wei Gao, Marjolien Gysels, Mendwah Dzingira, Paul McCrone, Sara Booth, Ahn Moaxham

Breathlessness is a common and distressing symptom, which increases in many diseases as they progress to manage. We assessed the effectiveness of early palliative care integrated with respiratory services for



Lancet Respir Med 2014; 2: 379-87



Evidence for palliative care in PD has been limited

- Few studies
- Limited information in clinical practice
- Palliative care is the “new specialty on the block”
- But it makes sense, lots of parallels in care and care needs.

Original Investigation



February 10, 2020

Comparison of Integrated Outpatient Palliative Care With Standard Care in Patients With Parkinson Disease and Related Disorders

A Randomized Clinical Trial

Benzi M. Kluger, MD^{1,2}; Janis Miyasaki, MD³; Maya Katz, MD⁴; [et al](#)

[» Author Affiliations](#) | [Article Information](#)

JAMA Neurol. 2020;77(5):551-560. doi:10.1001/jamaneurol.2019.4992

Study Results

- Parkinson's disease and related disorders have consequences for quality of life
- Despite growing interest, there are few studies of PD and PC
- JAMA study integrated primary PC interventions by the PD team, with guidance and involvement with a PC specialist
- Patients who had the PC intervention had better quality of life.
 - Also completed advance directives, addressed caregiver anxiety and burden, and motor and non-motor symptom burden.

Generalist plus Specialist Palliative Care — Creating a More Sustainable Model

Timothy E. Quill, M.D., and Amy P. Abernethy, M.D.

Palliative care, a medical field that has been practiced informally for centuries, was recently granted formal specialty status by the American Board of Medical Specialties. The demand for palliative care specialists is growing rapidly, since timely palliative care consultations have been shown to improve the quality of care, reduce overall costs, and sometimes even increase longevity.^{1,2} The field grew out of a hospice tradition in which palliative treatment was delivered only at the end of life, but its role has expanded so that palliative care specialists now also provide palliative treatment in the earlier stages of disease alongside disease-directed medical care, improving quality of care and medical decision making regardless of the stage of illness. In an era when

health care organizations may soon receive capitated payments for all services that patients receive, many are investing in palliative care to improve overall value.

Although this trend has fostered rapid growth of the palliative care specialty, the current model adds another layer of specialized care for seriously ill patients on top of an already complex, expensive health care environment. As in any medical discipline, some core elements of palliative care, such as aligning treatment with a patient's goals and basic symptom management, should be routine aspects of care delivered by any practitioner. Other skills are more complex and take years of training to learn and apply, such as negotiating a difficult family meeting, addressing veiled existential distress, and managing re-

fractory symptoms. Now that the value of palliative care has been recognized, specialists are sometimes called on for all palliative needs, regardless of complexity.

Although it may theoretically seem optimal for palliative medicine specialists to take on all palliative aspects of care, this model has negative consequences. First, the increasing demand for palliative care will soon outstrip the supply of providers. Second, many elements of palliative care can be provided by existing specialist or generalist clinicians regardless of discipline; adding another specialty team to address all suffering may unintentionally undermine existing therapeutic relationships. Third, if palliative care specialists take on all palliative care tasks, primary care clinicians and other specialists may begin to be-

Representative Skill Sets for Primary and Specialty Palliative Care.

Primary Palliative Care

- Basic management of pain and symptoms
- Basic management of depression and anxiety
- Basic discussions about

Prognosis

Goals of treatment

Suffering

Code status

Specialty Palliative Care

- Management of refractory pain or other symptoms
- Management of more complex depression, anxiety, grief, and existential distress
- Assistance with conflict resolution regarding goals or methods of treatment
 - Within families
 - Between staff and families
 - Among treatment teams
- Assistance in addressing cases of near futility

PD Care Team

- Amazing care model!
- Specialized multidisciplinary teams
- Long term continuity of care
- Goals:
 - Maintain health
 - Disease specific education
 - Symptom management

What does this look like?



Patient Case

- Patient is an 83 y/o gentleman with past medical history of a traumatic brain injury and subdural hematoma s/p a fall in 12 years ago, Parkinson's Disease diagnosed 10 years ago
- He has had a mental and functional decline over the past few months. Patient was hospitalized in for worsening confusion and hallucinations, after which, he transitioned to a rehabilitation facility due to his increased needs.
- The family has been questioning what happened, and why he worsened so much with the hospitalization/rehab stay. He has been on carbidopa/levodopa, this was discontinued in the hospital and restarted in during SNF stay. During the past few months he had been in rehab and has not yet followed up with neurology.
- Patient has received physical therapy since home (has been home a few weeks) and was discharged due to not being able to obtain further goals.
- Family has met with a hospice agency for information. They have questions regarding next steps and were referred by their PCP to our team to discuss all options
- Patient has an advance directive. His wife is his POA and his living will states he is a DNR.

Patient Case

- Discussed the patient's baseline mental and functional status, and the decline experience over the past few months.
- Her goal is to improve his quality of life, if that is possible. If there are no options available, he and his wife would like to change the focus of care to comfort. "We don't want him to suffer and linger in a state he doesn't want to be in".
- Collaborated with the patient's neurologist and PCP to identify options for his care and medications. Neurology recommended some medication changes that may make PT more successful
- Patient sometimes wakes up at night agitated. Recommended standing Tylenol at bedtime to assist with discomfort. Added a bowel regimen for his constipation.
- Discussed hospice services, the patient and family's goals, and indications for when hospice may be the right choice for him.
- Patient improved some with PT and new medications, and after more discussion we decided to consider hospice again if his quality of life declines despite being on the right medications, or his condition worsens.

What is an Advance Directive

- An advance directive is a legal document that goes into effect **only** if one is incapacitated and unable to speak for themselves
- For patients: This could be the result of disease or severe injury—no matter how old you are.
- Examples:
 - A living will
 - A durable POA for Health Care

Advance Care Planning

- Learning about the types of decisions that might need to be made for medical care, considering those decisions ahead of time, and then letting others know about your preferences

Why fill out an advance directive?

It helps others know what type of medical care you want. It also allows you to express your values and desires related to end of life care.

You might think of an advance directive as a living document—one that you can adjust as your situation changes because of new information or a change in your health.

Barriers to Patients Engaging in ACP?

- Reluctance to plan
- Fear, denial, about death
- Plans change over time
- Lack of awareness of ACP
- Lack of understanding about illness
- Time
- Cognitive impairment/lack of decision maker present

Documents Available

- DE State Document
- Five Wishes
- DMOST
- DPOA



FIVE WISHES[®]

MY WISH FOR:

- The Person I Want to Make Care Decisions for Me When I Can't
- The Kind of Medical Treatment I Want or Don't Want
- How Comfortable I Want to Be
- How I Want People to Treat Me
- What I Want My Loved Ones to Know

Close to death:

If my doctor and another health care professional both decide that I am likely to die within a short period of time, and life-support treatment would only delay the moment of my death (Choose *one* of the following):

- I want to have life-support treatment.
- I do not want life-support treatment. If it has been started, I want it stopped.
- I want to have life-support treatment if my doctor believes it could help. But I want my doctor to stop giving me life-support treatment if it is not helping my health condition or symptoms.

In A Coma And Not Expected To Wake Up Or Recover:

If my doctor and another health care professional both decide that I am in a coma from which I am not expected to wake up or recover, and I have brain damage, and life-support treatment would only delay the moment of my death (Choose *one* of the following):

- I want to have life-support treatment.
- I do not want life-support treatment. If it has been started, I want it stopped.
- I want to have life-support treatment if my doctor believes it could help. But I want my doctor to stop giving me life-support treatment if it is not helping my health condition or symptoms.

Permanent And Severe Brain Damage And Not Expected To Recover:

If my doctor and another health care professional both decide that I have permanent and severe brain damage, (for example, I can open my eyes, but I can not speak or understand) and I am not expected to get better, and life-support treatment would only delay the moment of my death (Choose *one* of the following):

- I want to have life-support treatment.
- I do not want life-support treatment. If it has been started, I want it stopped.
- I want to have life-support treatment if my doctor believes it could help. But I want my doctor to stop giving me life-support treatment if it is not helping my health condition or symptoms.

In Another Condition Under Which I Do Not Wish To Be Kept Alive:

If there is another condition under which I do not wish to have life-support treatment, I describe it below. In this condition, I believe that the costs and burdens of life-support treatment are too much and not worth the benefits to me. Therefore, in this condition, I do not want life-support treatment. (For example, you may write "end-stage condition." That means that your health has gotten worse. You are not able to take care of yourself in any way, mentally or physically. Life-support treatment will not help you recover. Please leave the space blank if you have no other condition to describe.)

Delaware's Advance Health Directive Form

Delaware's Advance Health Directive Form
<http://www.dhss.delaware.gov/dsaapd/advance1.html>

A. END OF LIFE INSTRUCTIONS

1. Choice To Prolong Life

_____ I want my life to be prolonged as long as possible within the limits of generally accepted health care standards.

OR

2. Choice Not To Prolong Life

I do not want my life to be prolonged if (please check all that apply)

_____ (i) I have a terminal condition (an incurable condition from which there is no reasonable medical expectation of recovery and which will cause my death, regardless of the use of life-sustaining treatment). In this case, I give the specific directions indicated:

	I want used	I do not want used
Artificial nutrition through a conduit	_____	_____
Hydration through a conduit	_____	_____
Cardiopulmonary resuscitation	_____	_____
Mechanical respiration	_____	_____
Other (explain) _____	_____	_____

_____ (ii) I become permanently unconscious (a medical condition that has existed at least four (4) weeks and has been diagnosed in accordance with currently accepted medical standards and with reasonable medical certainty as total and irreversible loss of consciousness and capacity for interaction with the environment. The term includes, without limitation, a persistent vegetative state or irreversible coma) and regarding the following, I give the specific directions indicated:

	I want used	I do not want used
Artificial nutrition through a conduit	_____	_____
Hydration through a conduit	_____	_____
Cardiopulmonary resuscitation	_____	_____
Mechanical respiration	_____	_____
Other (explain) _____	_____	_____

DELAWARE MEDICAL ORDERS FOR SCOPE OF TREATMENT (DMOST)

- FIRST, follow the orders below. THEN contact physician or other health-care practitioner for further orders, if indicated.
- The DMOST form is voluntary and is to be used by [a] patient with serious illness or frailty whose health care practitioner would not be surprised if the patient died within next year.
- Any section not completed requires providing the patient with the full treatment described in that section.
- Always provide comfort [measures], regardless of the level of treatment chosen.
- The Patient or the Authorized Representative has been given a plain-language explanation of the DMOST form.
- The DMOST form must accompany the patient at all times. It is valid in every health care setting in Delaware.

+	Print Patient's Name (last, first, middle)	Date of Birth	last four digits of SSN
A	Goals of Care (see reverse for instructions. This section does not constitute a medical order.)		
B 	Cardiopulmonary Resuscitation (CPR) <i>Patient has no pulse and/or is not breathing</i> <input type="checkbox"/> Attempt resuscitation/CPR. <input type="checkbox"/> Do not attempt resuscitation/DNAR.		
C	Medical Interventions: <i>Patient is breathing and/or has a pulse.</i> <input type="checkbox"/> Full Treatment: Use all appropriate medical and surgical interventions, including intubation and mechanical ventilation in an intensive care setting, if indicated to support life. Transfer to a hospital, if necessary. <input type="checkbox"/> Limited Treatment: Use appropriate medical treatment, such as antibiotics and IV fluids, as indicated. May use oxygen and noninvasive positive airway pressure. Generally avoid intensive care. <input type="checkbox"/> Transfer to hospital for medical interventions. <input type="checkbox"/> Transfer to hospital only if comfort needs cannot be met in current setting. <input type="checkbox"/> Treatment of Symptoms Only/Comfort Measures: Use any medications, including pain medication, by any route, positioning, wound care, and other measures to keep clean, warm, dry, and comfortable. Use oxygen, suctioning, and manual treatment of airway obstruction as needed for comfort. Use antibiotics only to promote comfort. Transfer only if comfort needs cannot be met in current setting [location]. <input type="checkbox"/> Other Orders: _____		
D	Artificially Administered Fluids and Nutrition: <i>Always offer food/fluids by mouth if feasible and desired.</i> <input type="checkbox"/> Long-term artificial nutrition <input type="checkbox"/> Defined trial period of artificial nutrition: Length of trial: _____ Goal: _____ <input type="checkbox"/> No artificial nutrition <input type="checkbox"/> hydration only <input type="checkbox"/> none (check one box)		
E	Orders Discussed With: <input type="checkbox"/> Patient _____ ph.# _____ <input type="checkbox"/> Guardian <input type="checkbox"/> Surrogate (per DE Surrogacy Statute) _____ Printed Name & phone number _____ <input type="checkbox"/> Other <input type="checkbox"/> Agent under healthcare POA/or AHCD _____ Signature _____ <input type="checkbox"/> Parent of a minor _____ Print Name of Authorized Representative Relation to Patient Address Phone # If I lose capacity, my Authorized Representative may not change or void this DMOST _____ <div style="text-align: right;">Patient Signature</div>		
F	SIGNATURES: Patient/Authorized Representative/Parent (mandatory) I have discussed this information with my Physician / APRN / PA Signature _____ Date _____ <small>If authorized representative signs, the medical record must document that a physician has determined the patient's incapacity & the authorized representative's authority, in accordance with DE law.</small>	Physician / APRN / PA Signature _____ Date _____ Time _____ Print Name _____ Print Address _____ License Number _____ Phone # _____	

What can I expect in End-Stage Parkinson's Disease

Regardless of how long it takes to get there, when patients reach stage 4 symptoms can become debilitating

Later symptoms include visible bradykinesia and rigidity

Need assistance to walk, stand, and move

Stage 5 is the final state- severe posture issues in back, neck, hips, require wheelchair, often bedridden

Also increase in non-motor symptoms including incontinence, insomnia and dementia

What is Hospice?

A program designed to improve quality of life through focusing on comfort and quality of life

Indicated at the transition from curative care to comfort based care

The goal is to provide quality of life and a peaceful death, support the patient and family with nursing, physician, home health aide, spiritual, and psychosocial support.

Can provide bereavement services after death

Covered by insurance, pays all equipment, meds relating comfort based care of the "terminal condition"

On average can be instituted when expected prognosis is 6 months- but many people live longer

Earlier hospice enrollment often provides better outcomes and quality of life.

When do I consider Hospice in neurodegenerative disease?

Difficulty breathing including dyspnea at rest or Oxygen need at rest

Rapid progression to wheelchair or bedbound

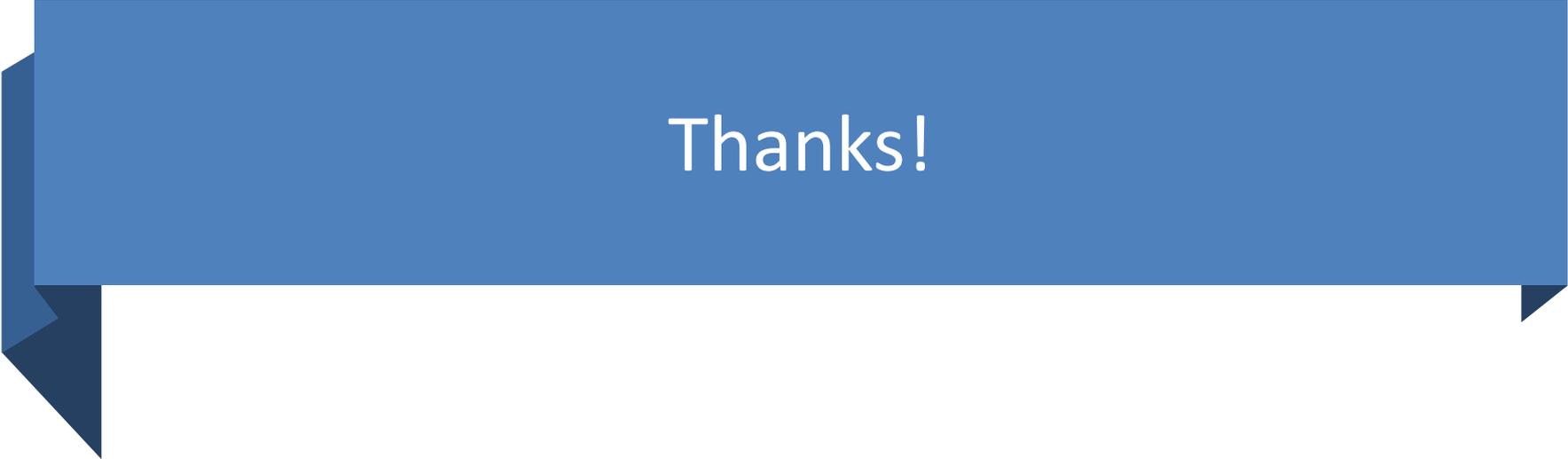
Unintelligible speech

Inability to perform ADL without assistance

Inability to eat or drink sufficiently

Complications arise including pneumonia, sepsis, pyelonephritis, pressure ulcers

Additional comorbidities



Thanks!

- Thanks to the ChristianaCare Parkinson's Disease Team for inviting us today!
- Thank you to all of the wonderful individuals with PD and their family and friends who have allowed us to participate in their care and share with us what matters most

Referrals

- Patients can call 302-320-1912
- For Providers:
 - Cerner – eComm Palliative OR message to Palliative Care Referral and Authorizations Pool
 - Curbside me any time!
 - New Vocera: Outpatient Palliative Care
- Linsey O'Donnell, DO
 - Office: 302-320-1912
 - Fax: 302-325-5874