June 10, 2023

Neuropalliative Care

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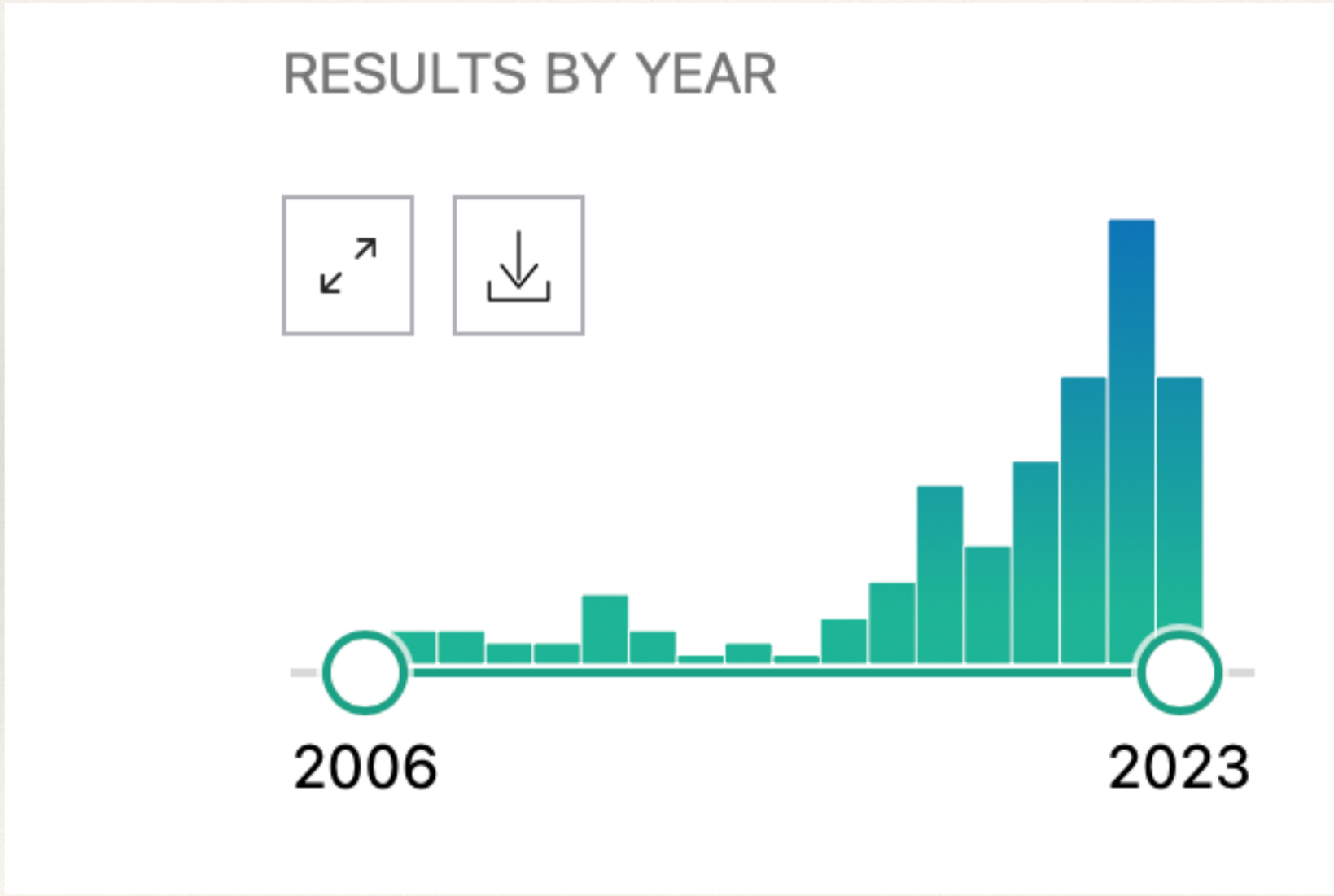
Case #1

- A patient with ALS has filled out paperwork to be DNR/DNI
- Family calls frantically because he had an unexpected illness and now is stating that he would like to be intubated but the doctors are warning him that it is unlikely that he will be successfully extubated
- They ask for your advice as the treating physician

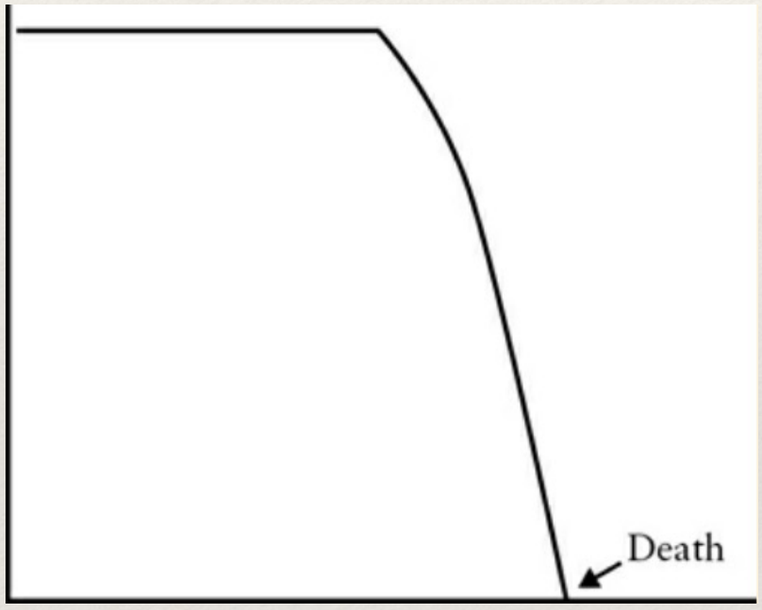
What is neuropalliative care and why is it relevant?

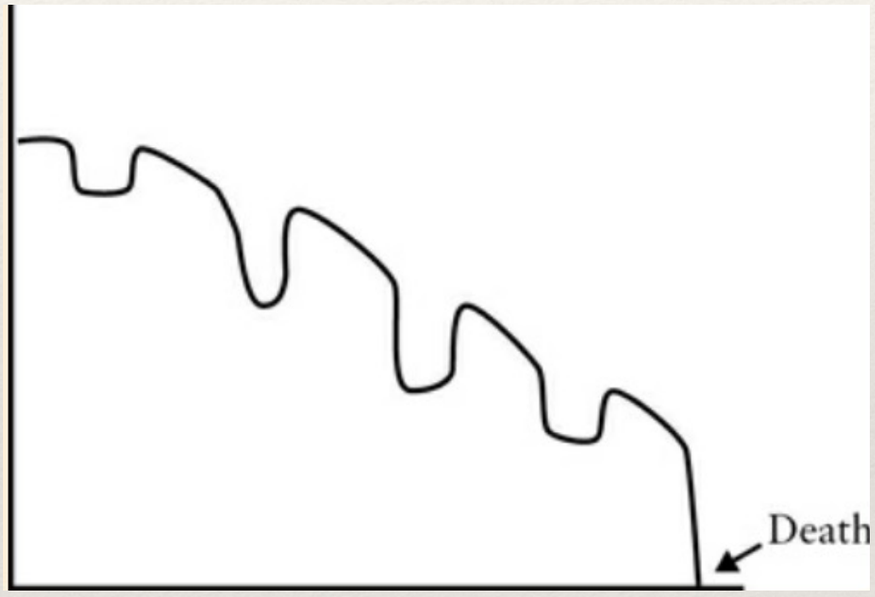
Pubmed: “Neuropalliative”

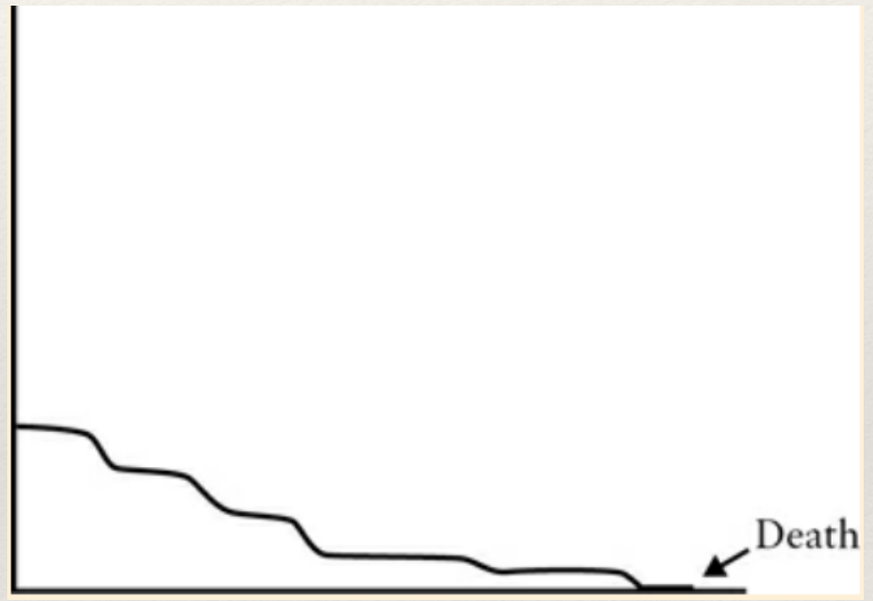


From acute to chronic decline

More than 1 in 10 deaths globally are caused by a neurologic disease







"Those of us in medicine don't help, for we often regard the patient on the downhill as uninteresting unless he or she has a discrete problem we can fix."

Gawande, Atul. Being Mortal (p. 27). Henry Holt and Co. 2014.

STANFORD SCHOOL OF MEDICINE | Palliative Care

"Modern medicine has not only prolonged living but has also **prolonged dying**. Recent advances in biomedicine have converted grave illnesses like cancer into chronic illnesses.

About 2 million Americans will die this year. **Less than 10%** of this population will experience a sudden or relatively rapid death due to cardiac diseases, trauma etc.

Most will be diagnosed and live and endure life with a chronic illness for a prolonged period of time before transitioning into death.

Yet, the delivery of health care services has only just recently begun adapting to this reality (Lynn).

Who will ultimately deliver palliative care?

- "While palliative and neuropalliative specialists may be well-positioned to provide this care, there is a shortage of specialists to address these needs. As a result, much of the upfront palliative care will naturally be provided by the **treating neurologist**. It is imperative that all neurologists receive quality training in primary palliative care skills."

- "In a 1996 position statement, the American Academy of Neurology Ethics and Humanities Subcommittee declared that **the provision of primary palliative care is the responsibility of all neurologists, and this position remains unchanged**."

- Neha M. Kramer, Jessica Besbris, Christine Hudoba,. Chapter 15 - Education in neuropalliative care. Editor(s): Janis M. Miyasaki, Benzi M. Kluger. *Handbook of Clinical Neurology*. Elsevier, Volume 191, 2023, pages 259-272.

- Taylor LP, Besbris JM, Graf WD, Rubin MA, Cruz-Flores S, Epstein LG; Ethics, Law, and Humanities Committee, a joint committee of the American Academy of Neurology

What is palliative care?

SPECIAL ARTICLE

Clinical Guidance in Neuropalliative Care

An AAN Position Statement

- Etymology comes from the Latin word “palliare” meaning “to cloak” which has been interpreted to mean to ease symptoms without curing the underlying disease.
- “An approach that supports patients by focusing on improving their quality of life through symptom control, both physical and psychological, rather than on the diagnosis and treatment of their underlying disease”

- Taylor LP, Besbris JM, Graf WD, Rubin MA, Cruz-Flores S, Epstein LG; Ethics, Law, and Humanities Committee, a joint committee of the Ame

Dame Cicily Saunders

"It appears that many patients feel deserted by their doctors at the end. Ideally the doctor should remain the centre of a team who work together to **relieve where they cannot heal**, to keep the patient's own struggle within his compass and to bring hope and consolation to the end."

Back to Case #1: What are the options?

- Overrule the patient, state that he clearly had a DNR/DNI in place
- Intubate the patient
- Implement a time-limited trial of intubation

Time-Limited Trials

- Have an agreed upon goal outcome and time period to reevaluate
- Allows you to constantly reassess a dynamic process
- This ideally allows you to avoid over or undertreating your patients in situations with unclear prognoses

Rutz Voumard R, Dugger KM, Kiker WA, Barber J, Borasio GD, Curtis JR, Jox RJ, Creutzfeldt CJ. Goal-Concordant Care After Severe Acute B

Case #1 Conclusion

- The patient decided to reverse his DNR order (the patient was very clear about his wishes, I discussed with the family options if needed in the future such as time-limited trials)
- He remained full code but ultimately did not require intubation
- 2 weeks later, he asked to be moved to hospice and specifically comfort care only and died peacefully

What is another reason someone may reverse their DNR/DNI?

PERGAMON

Social Science & Medicine 48 (1999) 977–988

SOCIAL SCIENCE & MEDICINE

The disability paradox: high quality of life against all odds

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University of Illinois at Chicago, School of Public Health, 2035 West Taylor Street, Chicago, IL 60612, USA

Abstract

This paper builds on the work of Sol Levine to examine a disability paradox: Why do many people with serious and persistent disabilities report that they experience a good or excellent quality of life when to most external observers these individuals seem to live an undesirable daily existence? The paper uses a qualitative approach to develop an explanation of this paradox using semi-structured interviews with 153 persons with disabilities. 54.3% of the respondents with moderate to serious disabilities reported having an excellent or good quality of life confirming the existence of the disability paradox. Analysis of the interviews reveals that for both those who report that they have a good and those who say they have a poor quality of life, quality of life is dependent upon finding a balance between body, mind and spirit in the self and on establishing and maintaining an harmonious set of relationships within the person's social context and external environment. A theoretical framework is developed to express these relationships. The findings are discussed for those with and without disabilities and directions are given for future

Two years earlier, in the office with Case #1

- The patient has been referred for progressive, painless weakness and has an EMG showing diffuse denervation
- Physical examination shows UMN and LMN signs and the history and examination are consistent with a diagnosis of ALS
- How do you deliver the news?

Serious Illness Conversation Guide

CONVERSATION FLOW	PATIENT-TESTED LANGUAGE
1. ***Set up the conversation*** · Introduce purpose · Prepare for future decisions · Ask permission	"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — **is this okay?**"
2. ***Assess understanding and preferences***	"What is your **understanding** now of where you are with your illness?" "How much **information** about what is likely to be ahead with your illness would you like from me?"
3. ***Share prognosis*** · Share prognosis · Frame as a "wish...worry", "hope...worry" statement · Allow silence, explore emotion	"I want to share with you **my understanding** of where things are with your illness..." *Uncertain:* "It can be difficult to predict what will happen with your illness. I **hope** you will continue to live well for a long time but I'm **worried** that you could get sick quickly, and I think it is important to prepare for that possibility." OR *Time:* "I **wish** we were not in this situation, but I am **worried** that time may be as short as ___ *(express as a range, e.g. days to weeks, weeks to months, months to a year)*." OR *Function:* "I **hope** that this is not the case, but I'm **worried** that this may be as strong as you will feel, and things are likely to get more difficult."
4. ***Explore key topics*** · Goals · Fears and worries · Sources of strength · Critical abilities · Tradeoffs · Family	"What are your most important **goals** if your health situation worsens?" "What are your biggest **fears and worries** about the future with your health?" "What gives you **strength** as you think about the future with your illness?" "What **abilities** are so critical to your life that you can't imagine living without them?" "If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?" "How much does your **family** know about your priorities and wishes?"
5. ***Close the conversation*** · Summarize · Make a recommendation · Check in with patient · Affirm commitment	"I've heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, I **recommend** that we ___. This will help us make sure that your treatment plans reflect what's important to you." "How does this plan seem to you?" "I will do everything I can to help you through this."
6. ***Document your conversation***	
7. ***Communicate with key clinicians***	

ARIADNE LABS

Real examples

- “I know that you came to me because you noticed that your body has gotten progressively weaker and that everything you have tried to get stronger has not worked. Is there anything specific you are worried this might be?”
  - A common answer: “yes I googled the symptoms and I am worried I have ALS.”
- Follow up question: “what is it that you read about it?”
  - Typically the patient tells me the diagnostic criteria for ALS and why they think they have it.
    - Follow up response “After examining you today and hearing your story, I do think that ALS is the diagnosis.”
      - Based on the reaction, I then go to the following:

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ARIADNE LABS

Case #2

- Patient presents with painless, progressive weakness over time in addition to cognitive complaints
- Exam shows diffuse LMN findings in the face, UE, and LE, no clear UMN findings at this time

Real examples

- “I know that you came to me because you noticed that your body has gotten progressively weaker and that everything you have tried to get stronger has not worked. Is there anything specific you are worried this might be?”
  - Answer: “No, I have no idea what it is. I just want to know if there is a cure.”
    - Follow up question: “Have any other doctors mentioned what they might have been worried about or why they sent you to me?”
      - Answer: “No.”
        - Follow up: “I have an idea about what might be going on and causing these symptoms. Would you like me to explain?”
          - Answer: “No.”
            - Follow up: “I understand that your main question is whether or not there is a cure. The disease I am concerned about unfortunately does not have a cure. Let’s order the required additional testing and discuss further at a follow up appointment.”

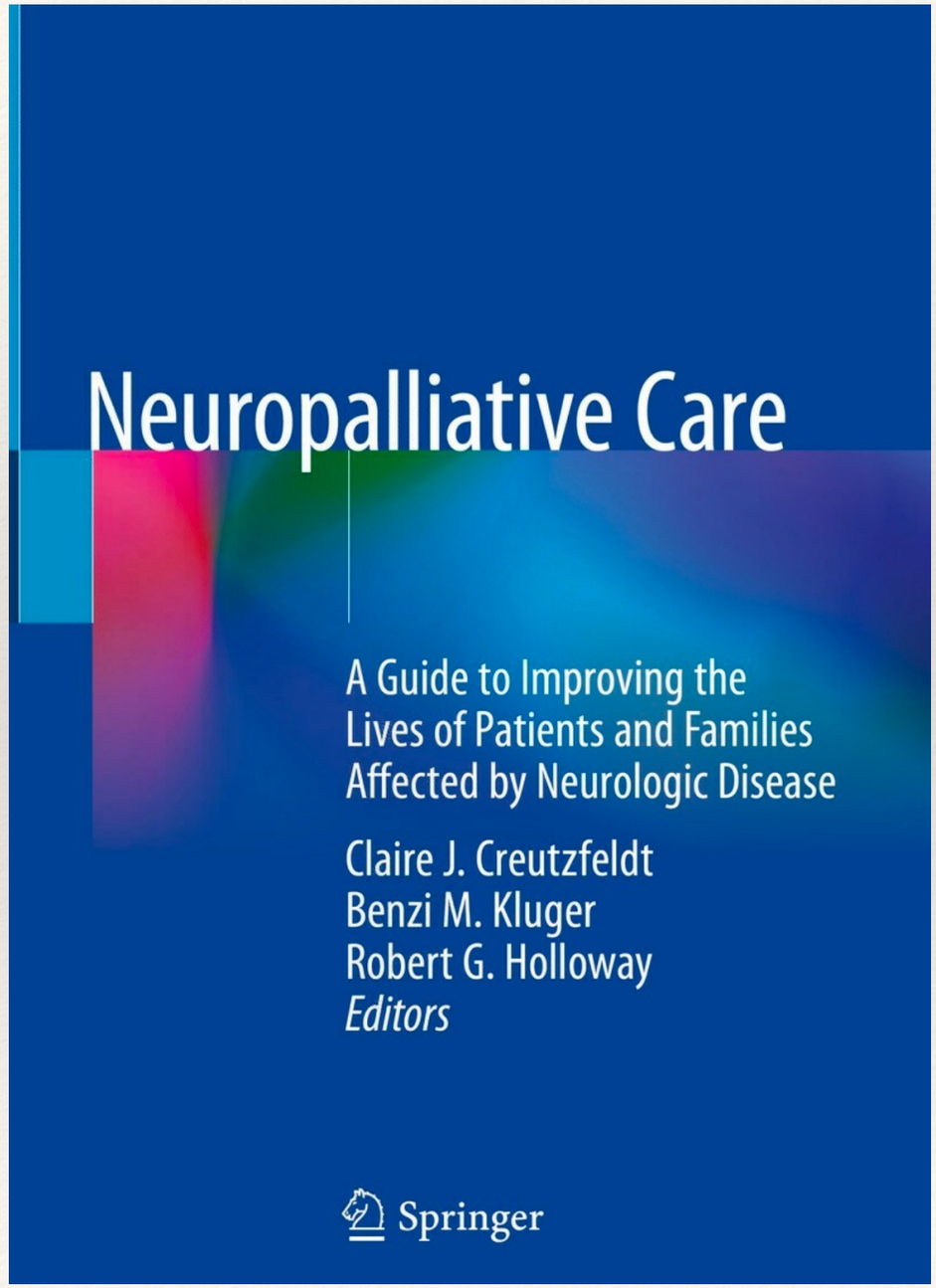
Real examples continued

- The wife was by his side and said that she had seen how quickly he had deteriorated and was worried as his medical proxy that she did not know what he wanted if he continued to progress and no longer had capacity
- Even though the details of the disease were not discussed yet, this is still an entry point to discuss pressing topics: can use **best case/worst case** scenarios

Best Case/Worst Case Scenarios

- "One way to present prognostic uncertainty is to frame the anticipated trajectory as **best case, worst case and most likely case scenarios.** This is congruent with the palliative care model of offering patients and families the ability to simultaneously hope for the best and prepare for the worst and should always include an assurance from the clinician of a meaningful engagement and non-abandonment during the course of the patient's illness."

- Claire J. Creutzfeldt; Benzi M. Kluger; Robert G. Holloway. Neuropalliative Care (p. 344). Springer International Publishing. Kindle Edition.

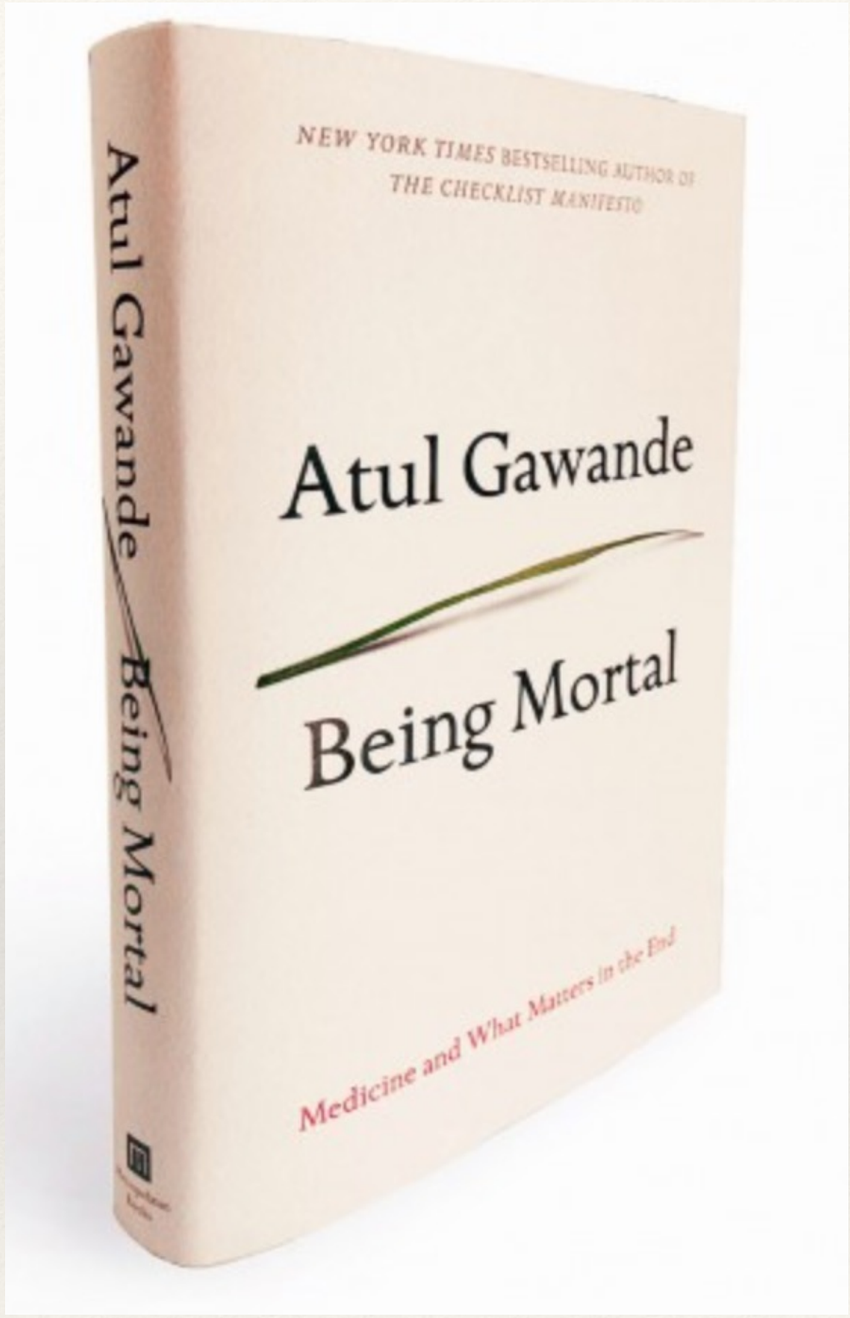


Case #2 Conclusion

- Even though we have not discussed the disease, the patient and his wife started to discuss goals of care

- “If end of life discussions were a drug, the FDA would have approved it."

“You have to understand that a family meeting is a procedure, and it requires no less skill than performing an operation.”



Gawande, Atul. Being Mortal. Henry Holt and Co. 2014

Table Neuropalliative Resources, Courses, and Communities

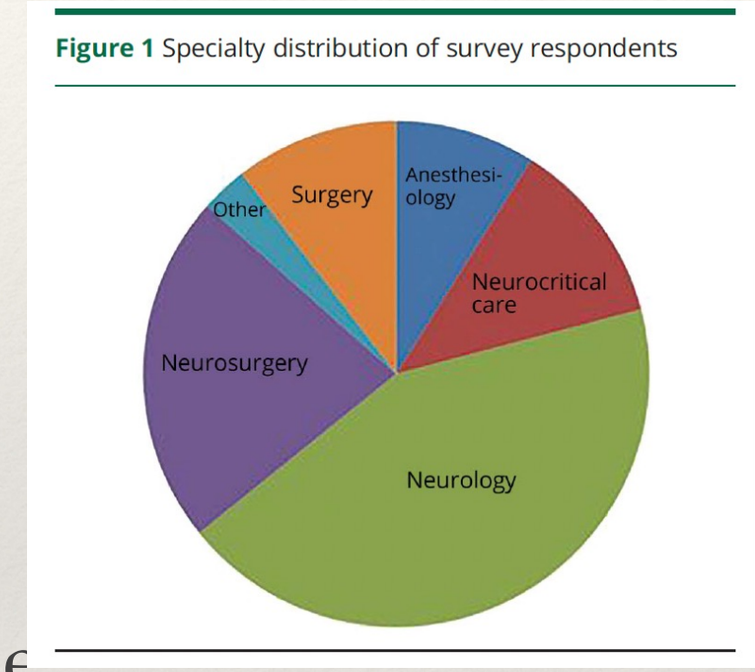
Name	Description	Link
American Academy of Hospice and Palliative Medicine (AAHPM)	Information on Hospice and Palliative Medicine (HPM) fellowship training and links to certificate and master's programs	aahpm.org/career/clinical-training
AAHPM Annual Assembly	National palliative care meeting with neuropalliative sessions and social gatherings	aahpm.org/meetings/assembly
AAHPM Neuropalliative Special Interest Group	Subcommunity of AAHPM members focused on neuropalliative care	aahpm.org/membership/communities#SIGs
American Academy of Neurology (AAN) Annual Meeting	National neurology meeting with neuropalliative poster sessions, programs on "Pain and Palliative Care," and social gatherings	aan.com/events/annual-meeting
AAN Palliative Care Section	Subcommunity of AAN members focused on palliative care	aan.com/membership/join-an-aan-section-or-community
Center to Advance Palliative Care (CAPC)	Resources for clinicians caring for people with serious illness	capc.org
Education in Palliative and End-of-Life Care—Neurology (EPEC-N)	Primary palliative care skills curriculum for healthcare professionals providing neurologic care	inpcs.org/epec-n
Fundamental Role of Arts and Humanities in Medical Education (FRAHME)	Initiative by the Association of American Medical Colleges to integrate arts and humanities into medical education	aamc.org/what-we-do/mission-areas/medical-education/frahme
Harvard Medical School Center for Palliative Care	Courses for physicians, nurses, and social workers to gain palliative care competencies	pallcare.hms.harvard.edu/courses
International Neuropalliative Care Society (INPCS)	Interprofessional and international community focused on neuropalliative care. Annual conference and resources available	inpcs.org
INPCS Certification Courses	Courses for physicians to develop a neuropalliative skill set	inpcs.org/i4a/pages/index.cfm?pageid=3363
Vital Talk	Evidence-based communication tools and courses	vitaltalk.org

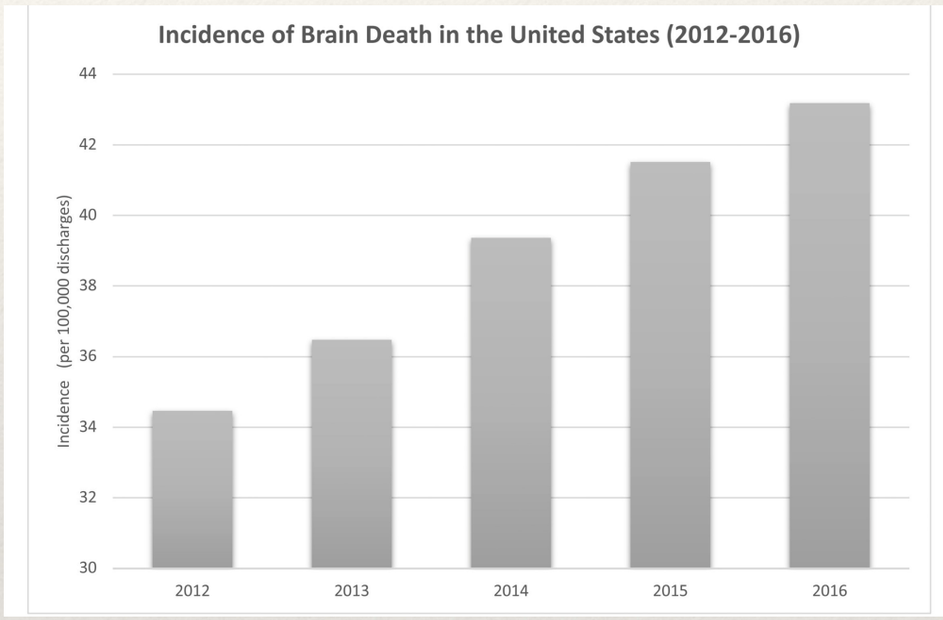
Ng M, McFarlin J, Holloway RG, Miyasaki J, Kramer NM. Emerging Subspecialties in Neurology: Cortical Careers in Neuropalliative Care. Ne

Shifting topics to the very practical side of neuropalliative care: brain death updates

Relevance: incidence of brain death is increasing

- Will be consulted for brain death exams more frequently
- Stakes are high: no room for false positives
- Who is performing the exams now?





Braksick SA, Robinson CP, Gronseth GS, Hocker S, Wijdicks EFM, Rabinstein AA. Variability in reported physician practices for brain death determination. Neurology. 2019 Feb 26;92(9):e888-e894.

A brief history of brain death/death by neurologic criteria (BD/DNC)

- The advent of ventilators in conjunction with organ transplantation necessitated the definition for brain death (1950s and 1960s)
- 1980s: United States adopts a formal definition
- 1990s-2020: no clearly accepted definition across the world and even discrepancies among individual states in the US

World Brain death project: published 2020

Clinical Review & Education

JAMA | Special Communication

Determination of Brain Death/Death by Neurologic Criteria
The World Brain Death Project

IMPORTANCE There are inconsistencies in concept, criteria, practice, and documentation of brain death/death by neurologic criteria (BD/DNC) both internationally and within countries.

OBJECTIVE To formulate a consensus statement of recommendations on determination of BD/DNC based on review of the literature and expert opinion of a large multidisciplinary, international panel.

PROCESS Relevant international professional societies were recruited to develop recommendations regarding determination of BD/DNC. Literature searches of the Cochrane, Embase, and MEDLINE databases included January 1, 1992, through April 2020 identified pertinent articles for review. Because of the lack of high-quality data from randomized clinical trials or large observational studies, recommendations were formulated based on consensus of contributors and medical societies that represented relevant disciplines, including critical care, neurology, and neurosurgery.

EVIDENCE SYNTHESIS Based on review of the literature and consensus from a large multidisciplinary, international panel, minimum clinical criteria needed to determine BD/DNC in various circumstances were developed.

Brain Death Definition in the United States

COUNCIL OF THE DISTRICT OF COLUMBIA

NOTICE

D.C. LAW 4-68

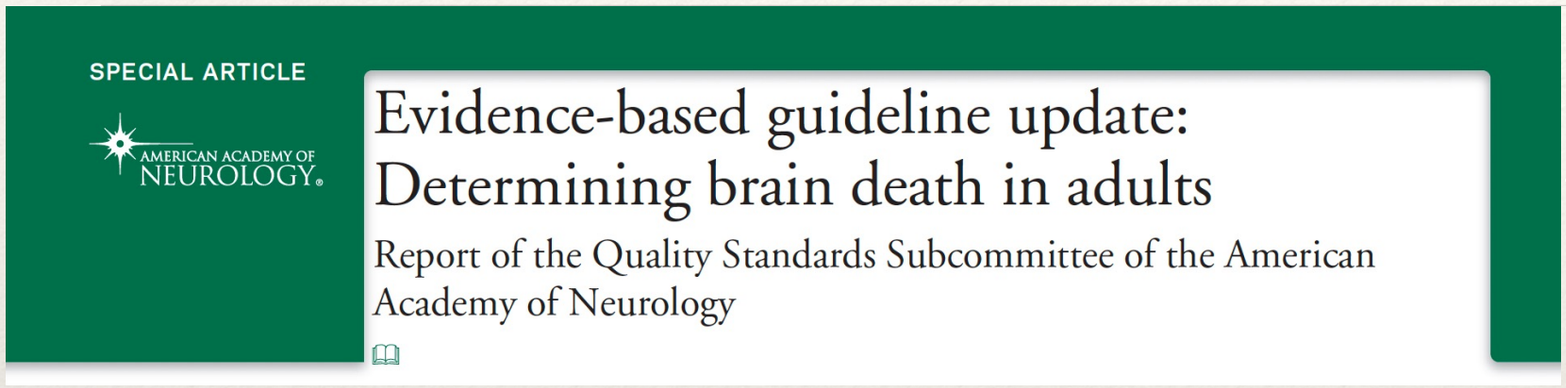
"Uniform Determination of Death Act of 1981".

Sec. 2. Standard for Determining Death.

An individual who has sustained either: (1) irreversible cessation of circulatory and respiratory functions; or (2) irreversible cessation of all functions of the entire brain, including the brain stem; is dead. A determination of death must be made in accordance with accepted medical standards.

code.dccouncil.gov

How is "irreversible cessation of all functions of the entire brain" determined?


SPECIAL ARTICLE

AMERICAN ACADEMY OF NEUROLOGY

Evidence-based guideline update: Determining brain death in adults

Report of the Quality Standards Subcommittee of the American Academy of Neurology

AAN, World Brain Death Project (WBDP), State law, hospital policy, Neurocritical Care Society


Clinical Review & Education

JAMA | Special Communication

Determination of Brain Death/Death by Neurologic Criteria
The World Brain Death Project


LOG IN

NEUROCRITICAL CARE SOCIETY

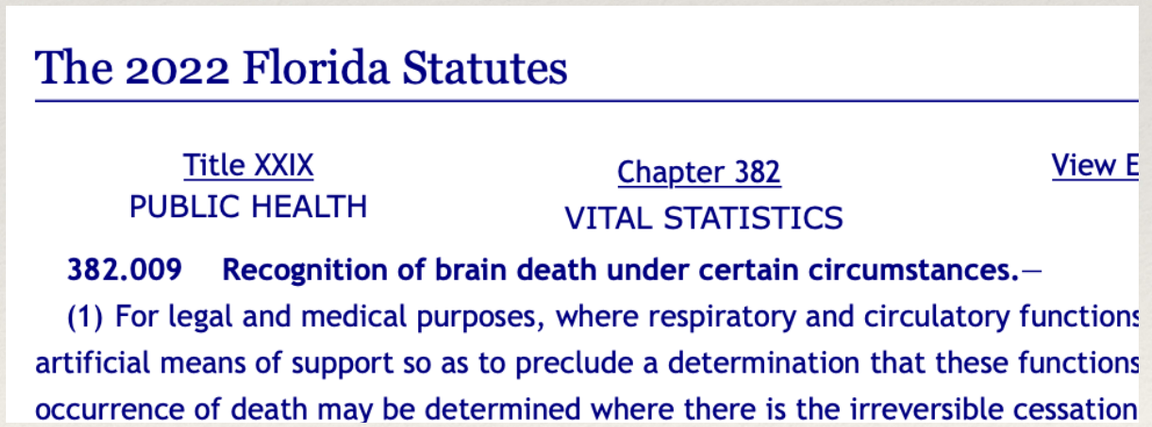
STORE DONATE

ABOUT NCS EVENTS RESOURCES RESEARCH PUBLICATIONS EDUCATION

BRAIN DEATH DETERMINATION

STANDARDIZING THE PROCESS OF BRAIN DEATH DIAGNOSIS THROUGH ONLINE CREDENTIALING

Presented by the Neurocritical Care Society


The 2022 Florida Statutes

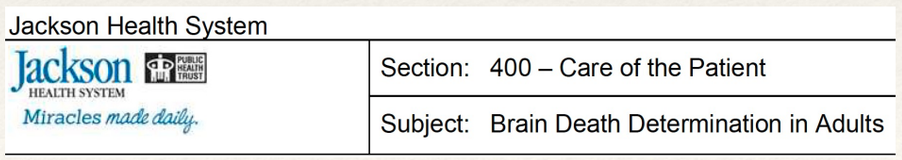
Title XXIX
PUBLIC HEALTH

Chapter 382
VITAL STATISTICS

View E

382.009 Recognition of brain death under certain circumstances.—

(1) For legal and medical purposes, where respiratory and circulatory functions artificial means of support so as to preclude a determination that these functions occurrence of death may be determined where there is the irreversible cessation


Jackson Health System

Jackson HEALTH SYSTEM
Miracles made daily.

Section:	400 – Care of the Patient
Subject:	Brain Death Determination in Adults

Common sources of confusion

- Number of examiners required
- Whether or not consent for brain death testing is required
- The appropriate use of ancillary testing
- Choice of ancillary testing

How do we move forward in this ever-evolving landscape?

- The following slides demonstrate an approach that compares the AAN, WBDP, state law, and hospital policy to compare and contrast
  - Key: knowledge of the most conservative criteria

The 2022 Florida Statutes

Title XXIX
PUBLIC HEALTH

Chapter 382
VITAL STATISTICS

View Entire Chapter

382.009 Recognition of brain death under certain circumstances.—

(1) For legal and medical purposes, where respiratory and circulatory functions are maintained by artificial means of support so as to preclude a determination that these functions have ceased, the occurrence of death may be determined where there is the irreversible cessation of the functioning of the entire brain, including the brain stem, determined in accordance with this section.

(2) Determination of death pursuant to this section shall be made in accordance with currently accepted reasonable medical standards by two physicians licensed under chapter 458 or chapter 459. One physician shall be the treating physician, and the other physician shall be a board-eligible or board-certified neurologist, neurosurgeon, internist, pediatrician, surgeon, or anesthesiologist.

(3) The next of kin of the patient shall be notified as soon as practicable of the procedures to determine death under this section. The medical records shall reflect such notice; if such notice has not been given, the medical records shall reflect the attempts to identify and notify the next of kin.

(4) No recovery shall be allowed nor shall criminal proceedings be instituted in any court in this state against a physician or licensed medical facility that makes a determination of death in accordance with this section or which acts in reliance thereon, if such determination is made in accordance with the accepted standard of care for such physician or facility set forth in s. 766.102. Except for a diagnosis of brain death, the standard set forth in this section is not the exclusive standard for determining death or for the withdrawal of life support systems.

History.—s. 1, ch. 80-216; s. 8, ch. 87-387; s. 84, ch. 2014-17.

Note.—Former s. 382.085.

How many examiners are required to diagnose BD/DNC?

	Number of examiners required for brain death determination
AAN	1
WBDP	1
State of Florida	2
Hospital	2

Important tip: verify state rules and obtain a copy of your hospital's policy

Is consent required prior to BD testing? Is notification of family required?

	Consent required	Notification of family required prior to exam/documentation ofnotification and attempt to do so
AAN	No	Yes
WBDP	No	Yes
State of Florida	No mention of this topic	Yes
Hospital	No	Yes

Important documentation tip: verify with primary team that they have spoken to family or attempted to do so and document this

After cardiac arrest, is there a minimum observation period prior to BD testing?

AAN	Insufficient evidence to make a formal recommendation
WBDP	Minimum of 24 hours
State of Florida	No mention of this topic
Hospital	No mention of this topic

Tip: most updated recommendation is to wait 24 hours to proceed with BD testing

Is ancillary testing required in all cases?

	Ancillary testing required in all cases
AAN	No
WBDP	No
State of Florida	No mention of this topic
Hospital	No
Most conservative	No

When is ancillary testing required? (According to WBDP)

- Components of the examination cannot be completed because of the underlying medical condition
- Uncertainty regarding interpretation of spinal mediated motor reflexes
- High cervical spine injury
- Uncertainty about drug elimination
- Severe metabolic, acid-base, or endocrine derangements that cannot be corrected and are judged to potentially be contributing to loss of brain function
- The whole-brain death formulation is being followed and there is isolated brainstem pathology
- Law/regional guidance mandates ancillary testing

Are there ancillary tests that are preferred over others?

	Formal Four-vessel catheter angiography	Transcranial Doppler (TCD)	Radionuclide cerebral blood flow scan (SPECT preferred)	EEG
AAN	Yes	Yes	Yes	Yes
WBDP	Yes	Yes	Yes	No
State of Florida	No mention of this topic	No mention of this topic	No mention of this topic	No mention of this topic
Hospital	Yes	Yes	Yes	Yes

Tip: WBDP recommends against using EEG if possible

WBDP defined use: EEG only if mandated by regional law or policy or if craniovascular impedance has been affected by open skull fracture, decompressive craniectomy, or an open fontanelle/ sutures, in which case it should be performed in conjunction with somatosensory and brainstem auditory evoked potentials

Do you need more than one set of TCDs?

	Number of TCD studies
AAN	No specific mention of this topic
WBDP	2 sets of TCDs at least 30 min apart
State of Florida	No mention of this topic
Hospital	No mention of this topic

Tip: WBDP has a suggestion in place to obtain 2 sets at least 30 min apart

An outdated law for an increasingly frequent condition

- Expect for this to be an ongoing debate with many more revisions

CONTEMPORARY ISSUES IN PRACTICE, EDUCATION, & RESEARCH OPEN ACCESS

Revise the Uniform Determination of Death Act to Align the Law With Practice Through Neurorespiratory Criteria

In summary

- NPC is a burgeoning field of neurology with exponentially expanding research and implementation
- In difficult situations, can use the following:
  - 1) Time-limited trials
  - 2) Best-case / worst-case scenarios
- Consent is not required for brain death, but notification is

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