

Expanding Your Care Team as Needs Change: Middle to Later Stage

Joshua Hauser, MD

Buehler Center on Aging, Health and Society

Darby Morhardt, PhD, LCSW

Cognitive Neurology and Alzheimer's Disease Center

Northwestern University Feinberg School of Medicine



Objectives

- Recognizing when more care and support is needed
- Finding appropriate care and support options
- Approaches to implementing and evaluating care and support



Frontotemporal Degeneration Disorders – FTD

- FTD is the most common form of dementia in persons under age 65
- FTD family stress and burden is higher
- FTD families have more difficulty finding community support services

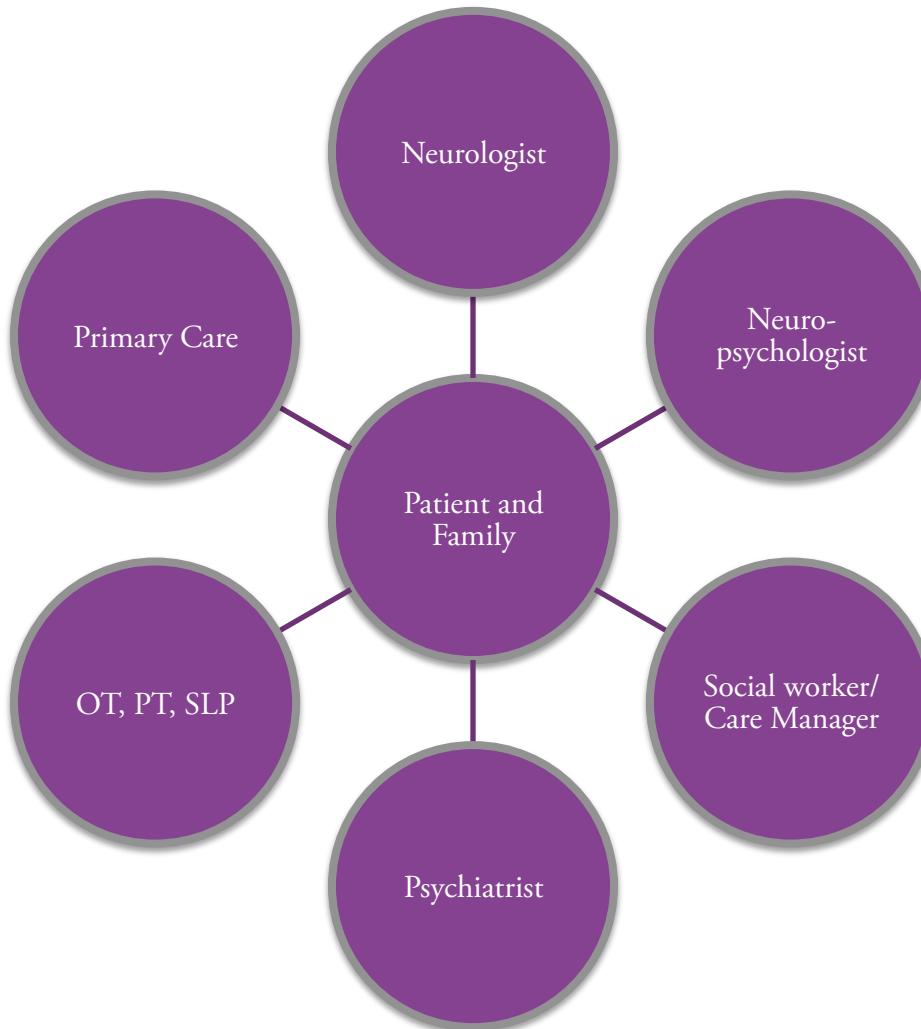


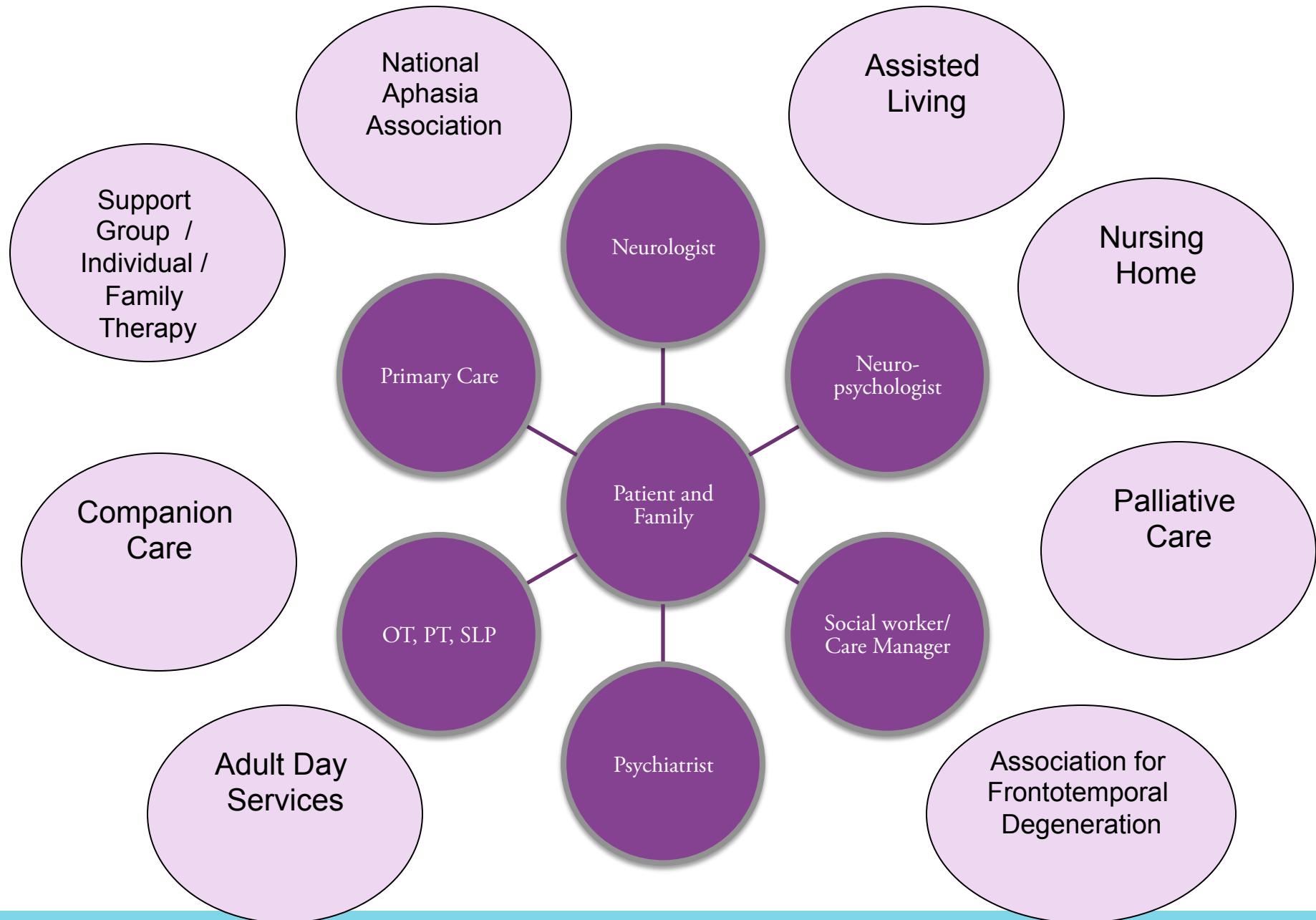
Early to Middle Stage Tasks

- Organize your Care Team
- Disease education
- Financial / Legal Issues
 - Establish Power of Attorney for Healthcare and Property
 - Apply for Social Security Disability
 - Develop a financial plan for care
- Disclose diagnosis to family and friends
- Safety Issues (driving, being alone, handling money)
- Occupational and Speech therapy evaluations
- Seek research opportunities
- Learn helpful communication strategies
- Assess availability of friends and family
- Find meaningful activity
- Learn about community resources
- Assess what needs to change – *“Find your new normal”*
- Maintain physical and emotional health



Interdisciplinary Care Team



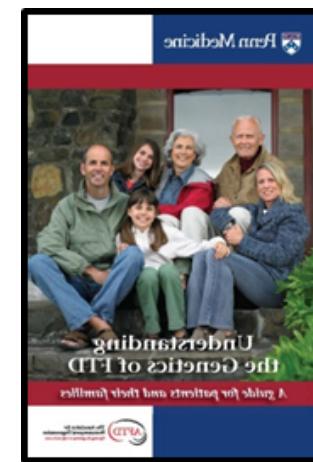
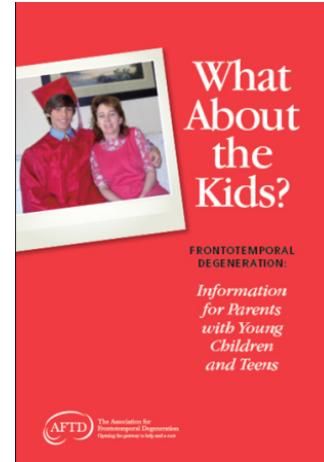
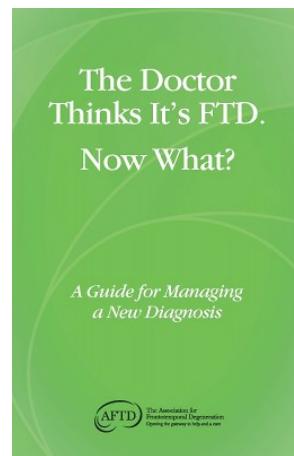
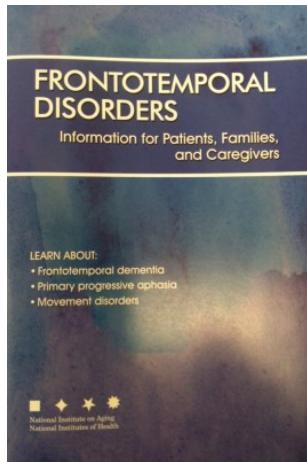


Middle to Later Stage Tasks

- Continue to gain disease knowledge
- Continue to assess safety issues
- Continue to learn about available community resources and find meaningful activity
- Continue occupational and speech therapy
- Expand support network as needs change
- Maintain physical and emotional health
- Integrate palliative and hospice care
- Recognize importance of
'staying connected while letting go'



Education



Source: <http://www.theaftd.org>

Safety Issues

- Driving
 - Occupational Therapy Driving Evaluations
 - Determine alternative transportation options
- Home Safety Evaluations
 - Occupational and Physical Therapy Referrals
- Power Tools / Firearms
- Safe Return / Medic Alert



Care & Support

- Long Term Care Services
 - In-Home and Adult Day Services
 - <http://www.homecareaoa.org>
 - <http://www.nadsa.org>
 - Respite
 - Assisted Living
 - Nursing Home
- Palliative Care / Hospice



Care & Support

- Long Term Care Services
 - Funding sources may include:
 - Private Pay
 - Private Long Term Care Insurance
 - Public Funding, such as:
 - Medicaid
 - Older Americans Act (National Family Caregiver Support Program serves caregivers who are caring for individuals of any age with Alzheimer's disease or a related disorder), or
 - Other state/local sources

What is available may vary. Go to <http://www.eldercare.gov/> for your Area Agency on Aging / Aging & Disability Resource Center.



What is an Adult Day Service?

- A coordinated program of professional and compassionate services for adults in a community-based group setting.
- Designed to provide social and some health services to adults who need supervised care in a safe place outside the home during the day.
- Afford caregivers respite from the demanding responsibilities of caregiving.
- Generally operate during normal business hours five days a week.
- Some offer services in the evenings and on weekends.

<http://www.nadsa.org/>



Adult Day Services - Programs

- Social Activities
- Transportation
- Meals and snacks
- Personal care
- Therapeutic activities



Short-Term & Long-Term Residential Care

- Long-Term
 - Assists individuals with support services to meet health and personal needs on a long-term basis
- Short-Term
 - Allows for individuals a short-term stay in a long-term care facility
 - Allows caregiver respite
 - Can be a “test” for longer-term stay



Assisted Living

- Provides supervision or assistance with personal care
- Coordinates services of outside health care providers
- Monitors resident activities to ensure health, safety and well-being.
- Administers or supervises medication and/or personal care services
- Alternative on continuum of care for persons who cannot live independently, but do not need 24 hour nursing home care
- Regulations vary state by state

National Center for Assisted Living

www.ahcancal.org/ncal



Nursing Home Care

- A place of residence for people who require constant supervision and care for activities of daily living.
- May receive physical, occupational and other rehabilitative therapies
- Nursing Home Compare - www.Medicare.gov

CENTERS FOR MEDICARE & MEDICAID SERVICES

Medicare's Nursing Home Compare



Need to find a nursing home?
Nursing Home Compare can help.

www.medicare.gov/NHCompare

Partners in FTD Care

Education for community healthcare professionals

- Introductory training materials
- Quarterly newsletter - case study, interventions and practical tips (“What to do About...”)
- Interactive on-line forum

Partners in FTD Care A quarterly newsletter for healthcare professionals
SUMMER 2012

Cognitive Behavior in Frontotemporal Degeneration

Frontotemporal degeneration can affect anyone with frontotemporal degeneration (FTD). These individuals can exhibit unpredictable, inappropriate, or inappropriate behavior. They may ignore social cues, blurt out things at times, argue, insult others, swear, chew gum, or do things that are inappropriate. In addition, walking, chewing, dressing, and eating can become problematic at times or places, such as "home" and "work". What can healthcare professionals do to assist someone who is exhibiting these behaviors? This issue of Partners in FTD Care discusses some strategies that healthcare professionals can use to help people with FTD at all of these locations.

David Smith

David is a 77-year-old former insurance producer and insurance agent. He was diagnosed with FTD in the summer of 2009 and has steadily declined since. When his son, David's mother, and brother noticed major changes in his personality and behavior, they sought to learn more about FTD. After visiting their doctor, David was diagnosed with frontotemporal degeneration, and taught what it means to have FTD. His diagnosis of dementia has been a challenge, but he is taking it well. David stopped working, gained 30 pounds since his diagnosis, and has struggled with adult onset diabetes.

David's son, now an insurance broker himself, has been managing his father's care. He researches new treatments, finds a new doctor every six months, books doctor's visits to see him, and arranges for him to stay home. David's son, wife, and daughter, "we are," the three sisters, and the response was amazing. David's family ultimately decided to place him in an assisted living facility (ALF) that is close to the Alzheimer's Association office and the middle of town and took much time to located something in the location they wanted.

(During David's first week in the ALF, one "neighbor" immediately started to tease him, embarrassing him in public, and making fun of him. David refused to let this happen and took the large television set in the community room, his personal belongings, and the large lamp from his room and put them in the center of the room. He then sat down in a chair and got down on his hands and knees. This was the exact moment that his wife, son, and daughter came to visit him. He also returned to the doctor for those same after dinner teeth cleaning. By the end of the first week, David had stopped by himself.)

The ALF called a community meeting for the other residents and explained their new neighbor. The other residents were shocked and asked what David was doing. David responded that the doctor just wouldn't spend so little time with him. When David presented the idea, he was given a thumbs up by the police. In addition, several new social activities to assist others that make daily routines easier. David's son, wife, and daughter have been instrumental in the community effort to help set up the ongoing activities in the community room.

SERVE PEOPLE WITH FTD WITH CONFIDENCE

People with FTD need access to quality facility care. Patients in FTD need to know that there are available to treat and support them. **Partners in FTD Care** is here to help. **Partners in FTD Care** is a non-profit organization that is dedicated to providing education and resources to healthcare professionals who work with people with FTD. To learn more, visit our website at www.theaftd.org or email us at info@theaftd.org.

Source: <http://www.theaftd.org>

Accessing Community Based and Long Term Care Services

- How are you emotionally and physically?
 - What are the goals for the person's QoL? Your QoL? Your family?
 - What are the person's needs? Your needs?
- Organize your support network – don't wait for a crisis
 - Family/Friends
 - Support group – in-person and/or on-line
 - What community supports would be helpful?
- Talk to providers in your community
 - Previous experience with FTLD or difficult behaviors
 - Get examples and if possible ask to speak with previous clients' families
 - How open are they to additional training?
 - Do they know and understand the principles of person-centered care?
 - What are the costs?



Where to learn more

- Association for Frontotemporal Degeneration (AFTD)
 - <http://www.theaftd.org/>
- CurePSP: Foundation for PSP CBD and related Brain Diseases
 - <http://www.psp.org/>
- National Aphasia Association (NAA)
 - <http://www.aphasia.org/>
- Alzheimer's Association
 - <http://www.alz.org>
- ADEAR - Alzheimer Disease Education and Research Center - National Institute on Aging
 - <http://www.nia.nih.gov/alzheimers>

Staying Connected & Letting Go

- Anticipatory grief – normal grief reaction
- One grieves what is, what will not be, what was
- Withholding feelings diminishes relationships
- Spend time together – Spend time apart
- Do not forget the needs of others – especially children – balance their needs with yours
- Practice relentless self-care
- Practice forgiveness



Outline

1. What to expect from your physician
2. Is there a distinction between hospice and palliative care?
3. A specific example of something that families can do now to plan for the future: advance care planning

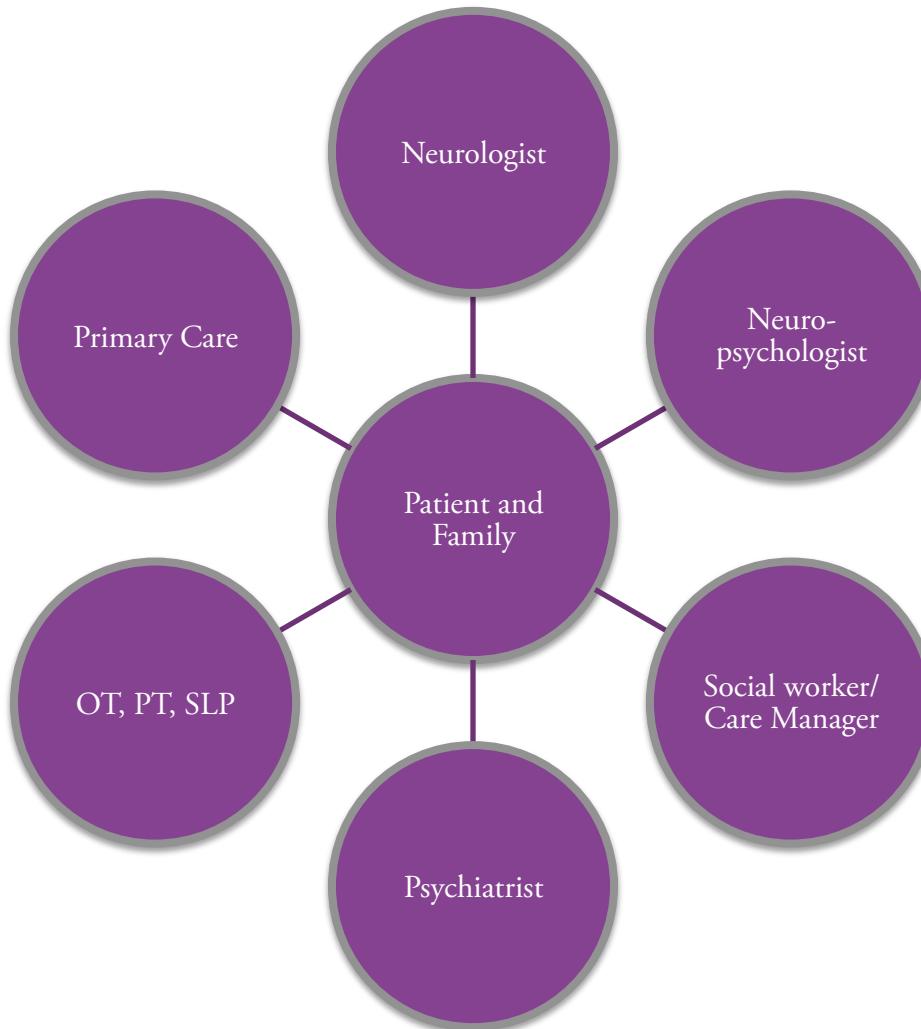


What to expect from your physician?

- Or is it physicians?
 - A brief survey....



Interdisciplinary Care Team



Role of your physician



Role of your physician

- Honesty
- Clear information about disease and disease and progression
 - Issue of prognosis
- Advice and counsel
- Coordination

Which one of these can you be most helpful with?



Outline

1. What to expect from your physician
2. Is there a distinction between hospice and palliative care?
3. A specific example of something that families can do now to plan for the future: advance care planning



Palliative Care vs. Hospice

Hospice focuses on caring, not curing and, in most cases, care is provided in the patient's home. Hospice care also is provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities.

Palliative care extends the principles of hospice care to a broader population that could benefit from receiving this type of care earlier in their illness or disease process. No specific therapy is excluded from consideration. An individual's needs must be continually assessed and treatment options should be explored and evaluated in the context of the individual's values and symptoms.

A family member's definition

“I’ve heard of hospice; it’s where you go when everything else hasn’t worked....like you throw in the towel.”

- Husband of a patient

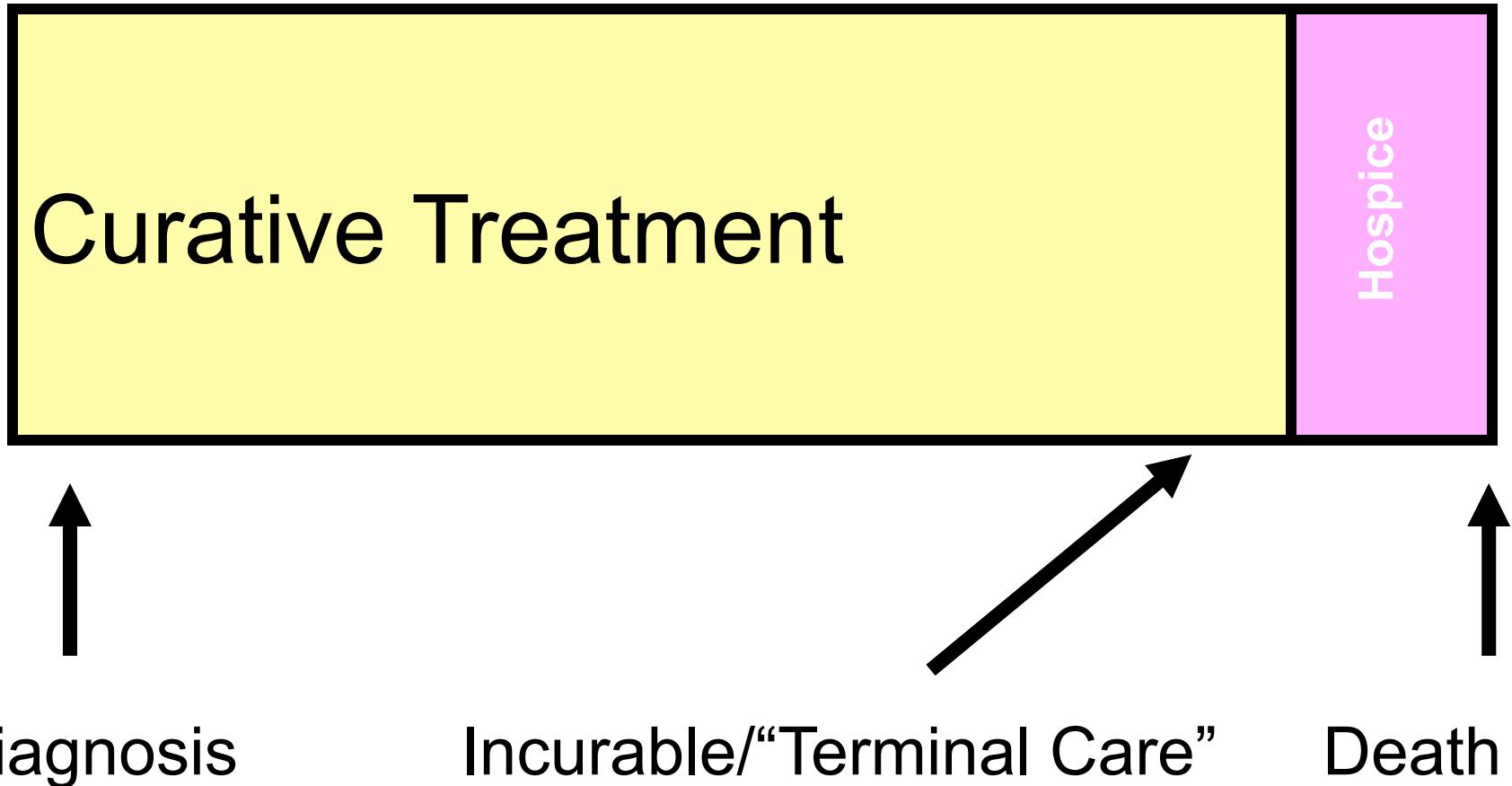
Palliative Care: World Health Organization

“An approach that improves quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment of pain and other problems, physical, psychosocial and spiritual.”

- WHO

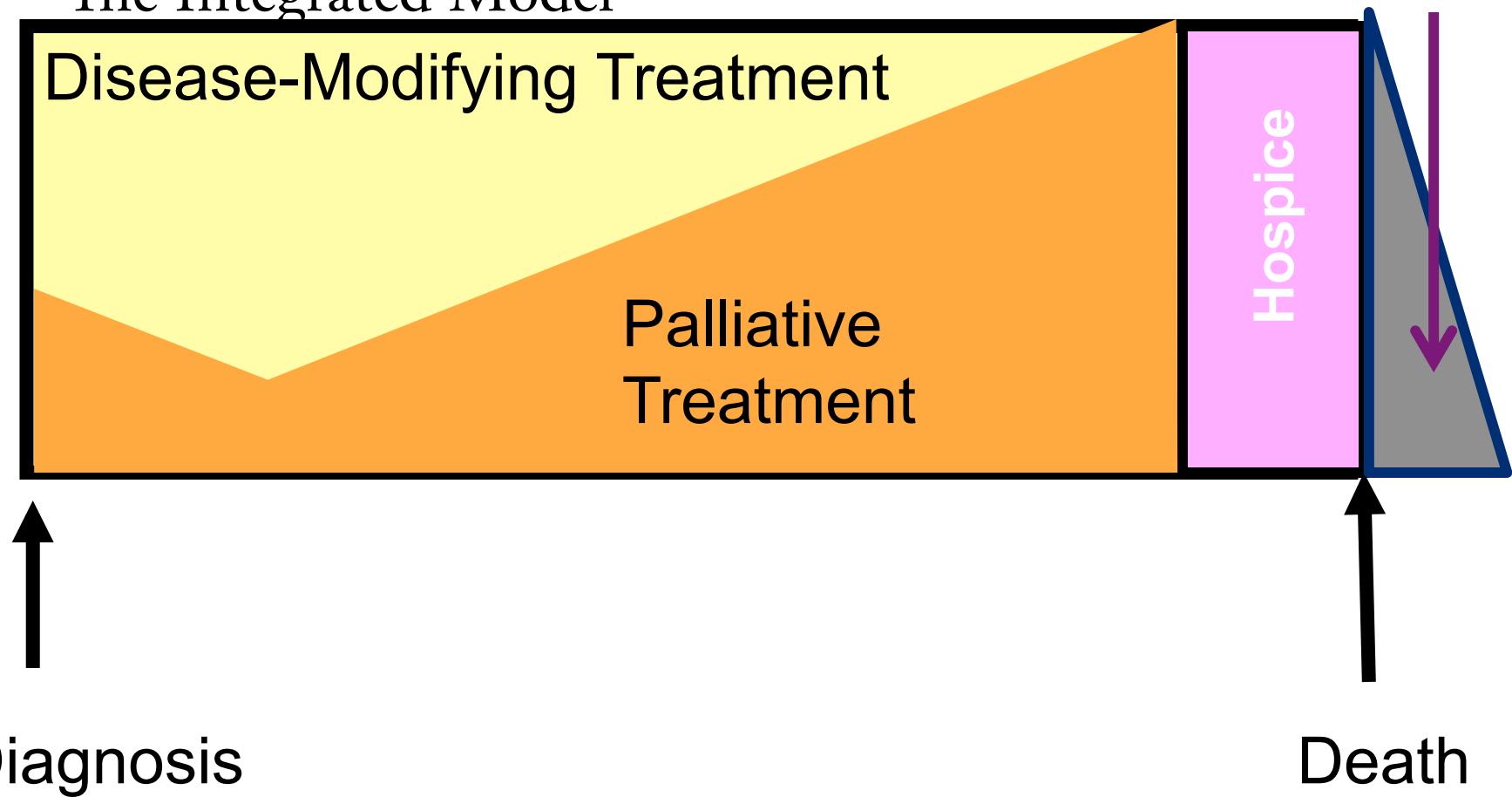
Hospice and Palliative Care

- The Traditional Model



Hospice and Palliative Care

- The Integrated Model



Myths

- It's all about giving up...
- You have to die in 6 months....or you get kicked out
- I can never go back to the hospital
- No one ever smiles

GET PALLIATIVE **CARE**

[What Is It](#) [How to Get It](#) [Is It Right for You](#) [Blog & Resources](#)



Right now an estimated
6,000,000 people in the
US need palliative care.

RESOURCES

Links



Videos, Podcasts &
Livechats



For the Media



For Clinicians



For Policymakers



Access the Provider
Directory

Choose State ▾

Sign Up for Our
Newsletter

Your Email

Donate Now

Make a fast and secure
donation through
groundspring.org

When you are facing a serious illness, you need relief from symptoms. You need to better understand your condition and choices for care. You need to improve

Advance Care Planning

- A process to plan for care in the future
- Advance Directives
 - Living Will
 - Medical or Durable Power of Attorney
- Advance care planning documents and tools
 - Five Wishes
 - POLST

Resources: www.nhpco.org: section on state advance directives

POLST.org

Steps in Advance Care Planning

- Talk to your health care provider and family about your values and wishes.
- Decide on a health care proxy to make your decisions.
 - Discuss it with him or her
- Obtain documents so that your wishes are in writing.
- Review documents and decisions periodically.

What are the kinds of decisions that might come up?

- Artificial nutrition
 - What do we know about it?
- Cardiopulmonary resuscitation (CPR)
 - What do we know about it?

How on earth can a family member make such decisions?

doctor's role:

family's role:

What to expect from your doctor in this process

- Honesty
- Clear information about disease and disease and progression
 - Issue of prognosis
- Advice and counsel
- Coordination



Summary

1. What to expect from your physician
2. Is there a distinction between hospice and palliative care?
3. A specific example of something that families can do now to plan for the future: advance care planning



Thank you

Joshua Hauser, MD

j-hauser@northwestern.edu

Buehler Center on Health, Aging and Society
Northwestern University Feinberg School of
Medicine

750 N. Lake Shore Drive, Suite 601
Chicago, IL 60611
312-503-3087

www.aging.northwestern.edu

Darby Morhardt, PhD, LCSW

d-morhardt@northwestern.edu

Cognitive Neurology and Alzheimer's Disease
Center

Northwestern University Feinberg School of
Medicine

320 E. Superior St, Searle 11
Chicago, IL 60611
312.926.1851

www.brain.northwestern.edu

Northwestern Neurobehavior and Memory
Clinic

676 N. St. Clair, Suite 945
Chicago, IL 60611
312.695.9267