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

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Objectives

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

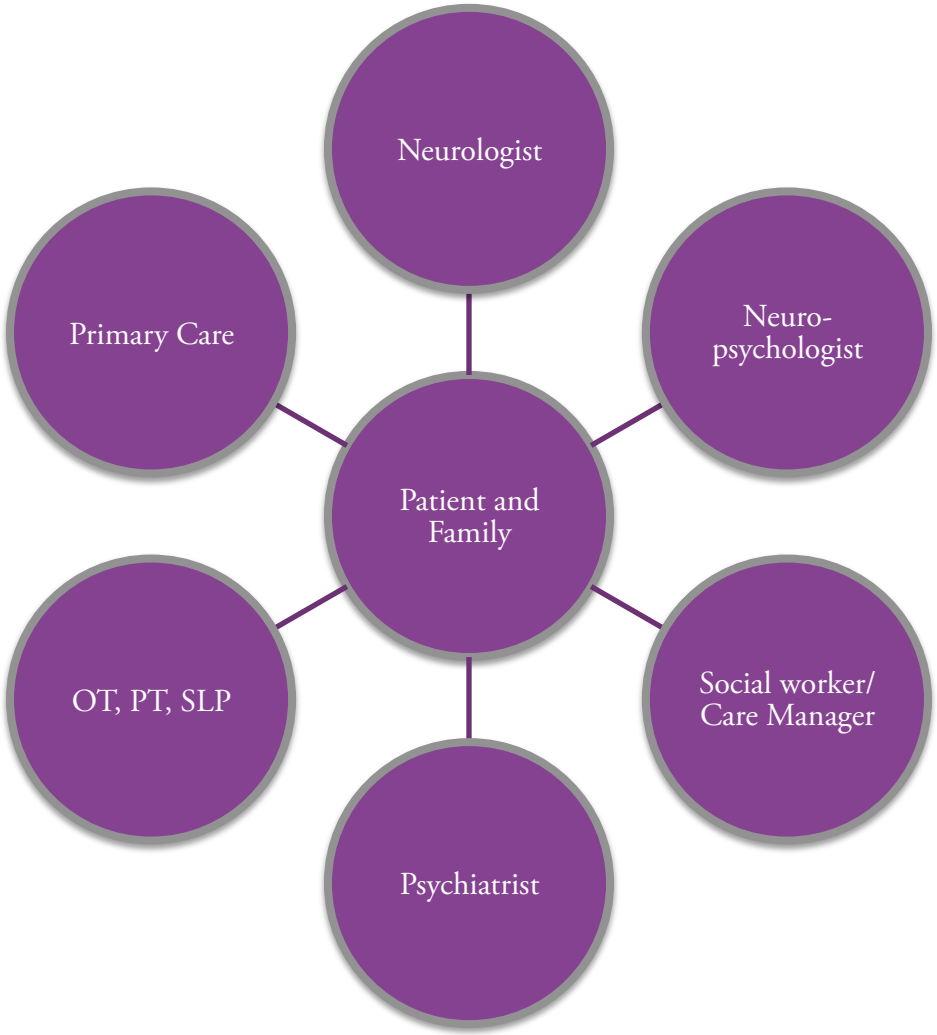
Frontotemporal Degeneration Disorders – FTD

- 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



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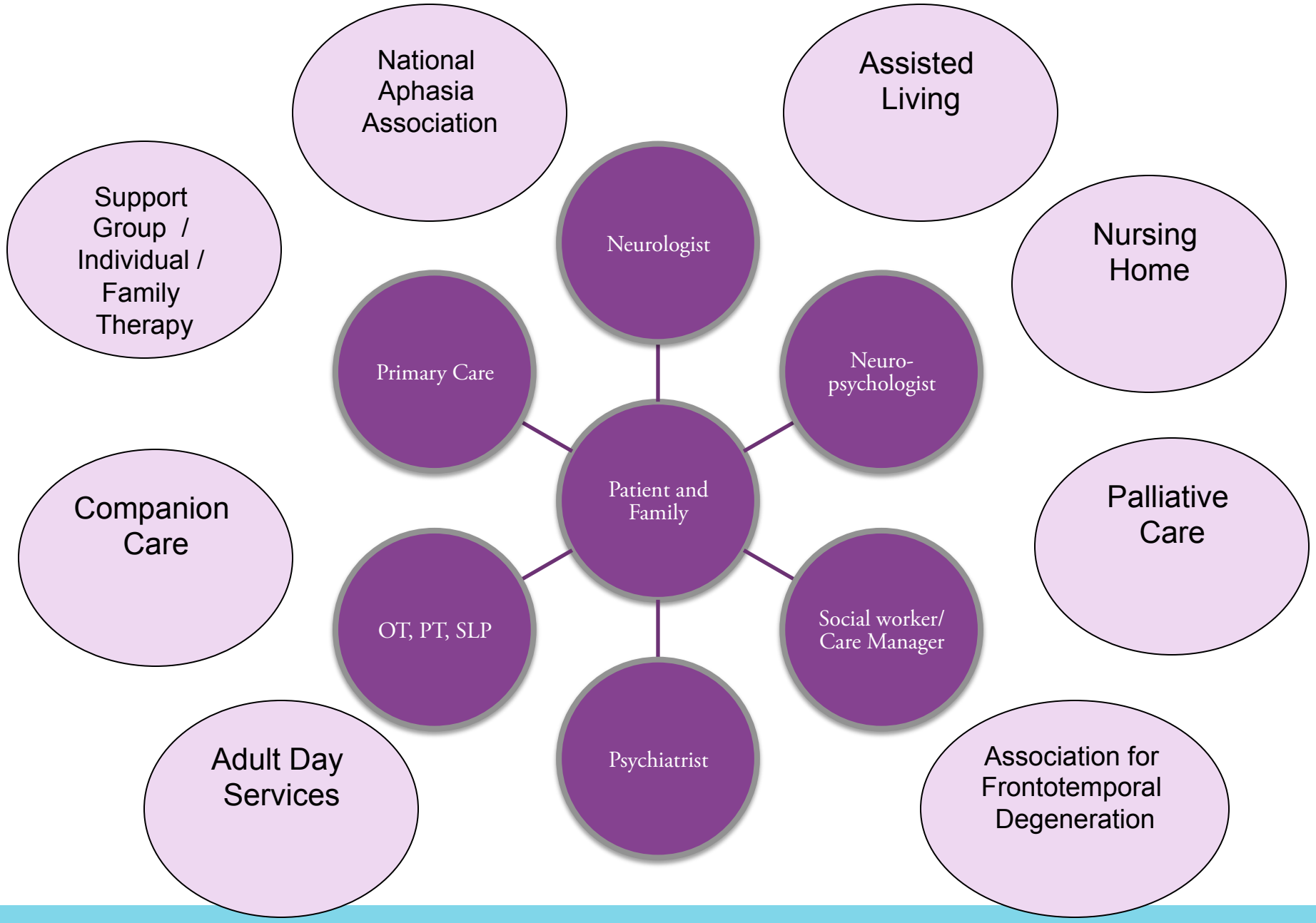
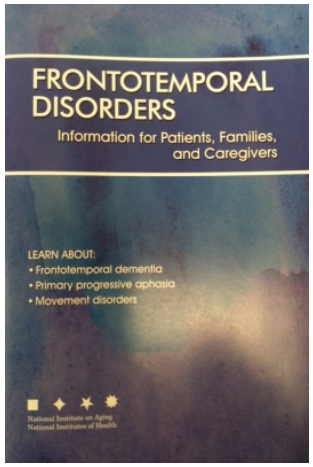
Expanded Care Team

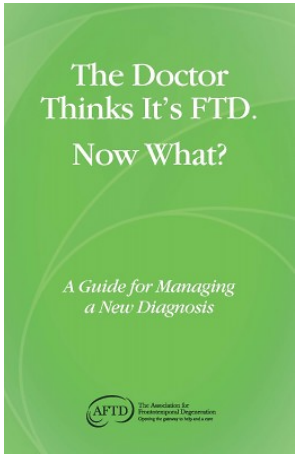


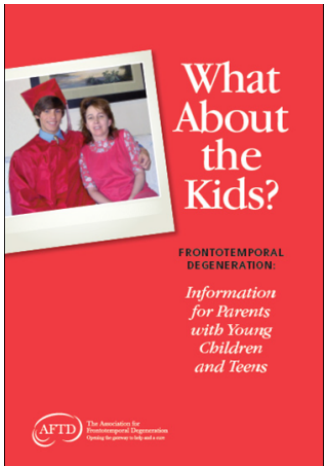
Middle to Later Stage Tasks

- 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 l
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/

nadsa
National Adult Day Services Association
The National Voice for the Adult Day Services Community

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

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

Comparative Behavior in Frontotemporal Degeneration

Join the AFTDHCP Community: Online Forum is Launched

Serve People with FTD with Confidence

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

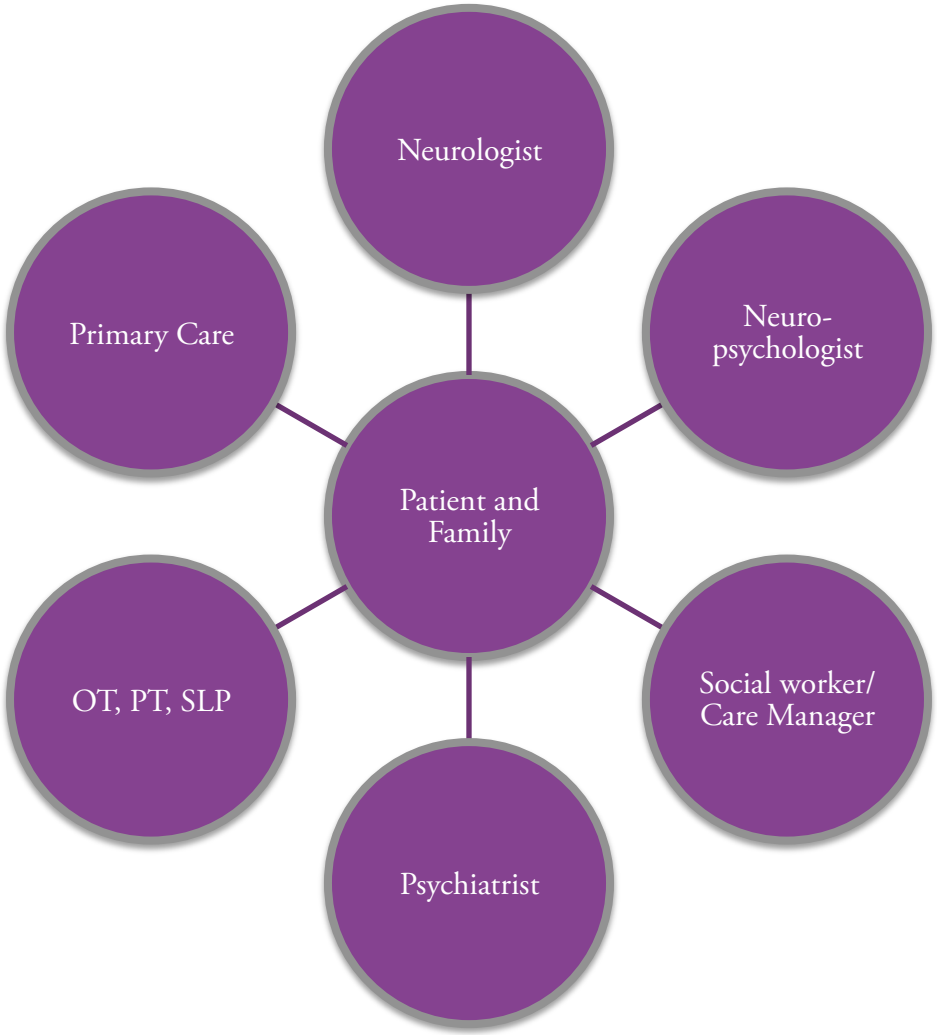
Outline

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?

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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.

- NHPCO

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

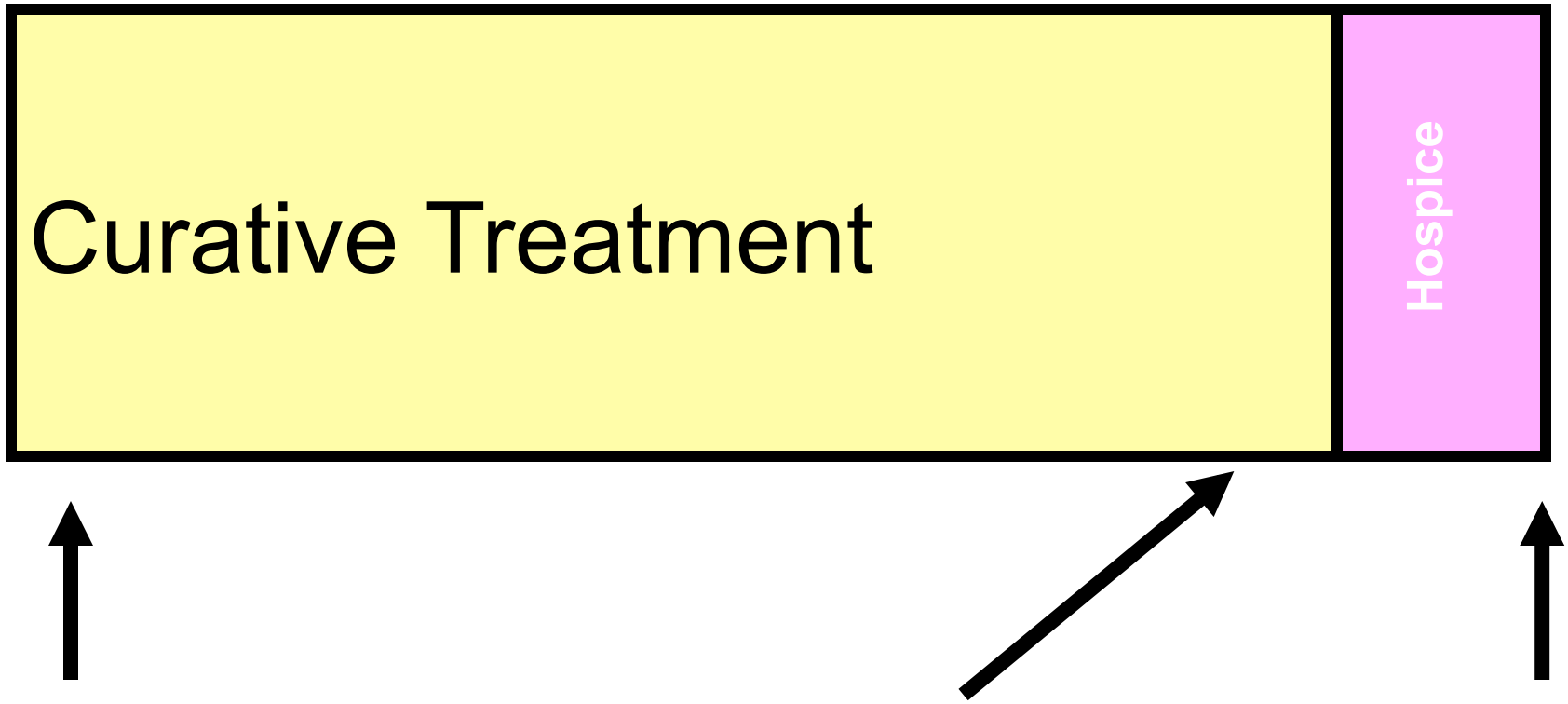
Palliative Care: World Health Organization

"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

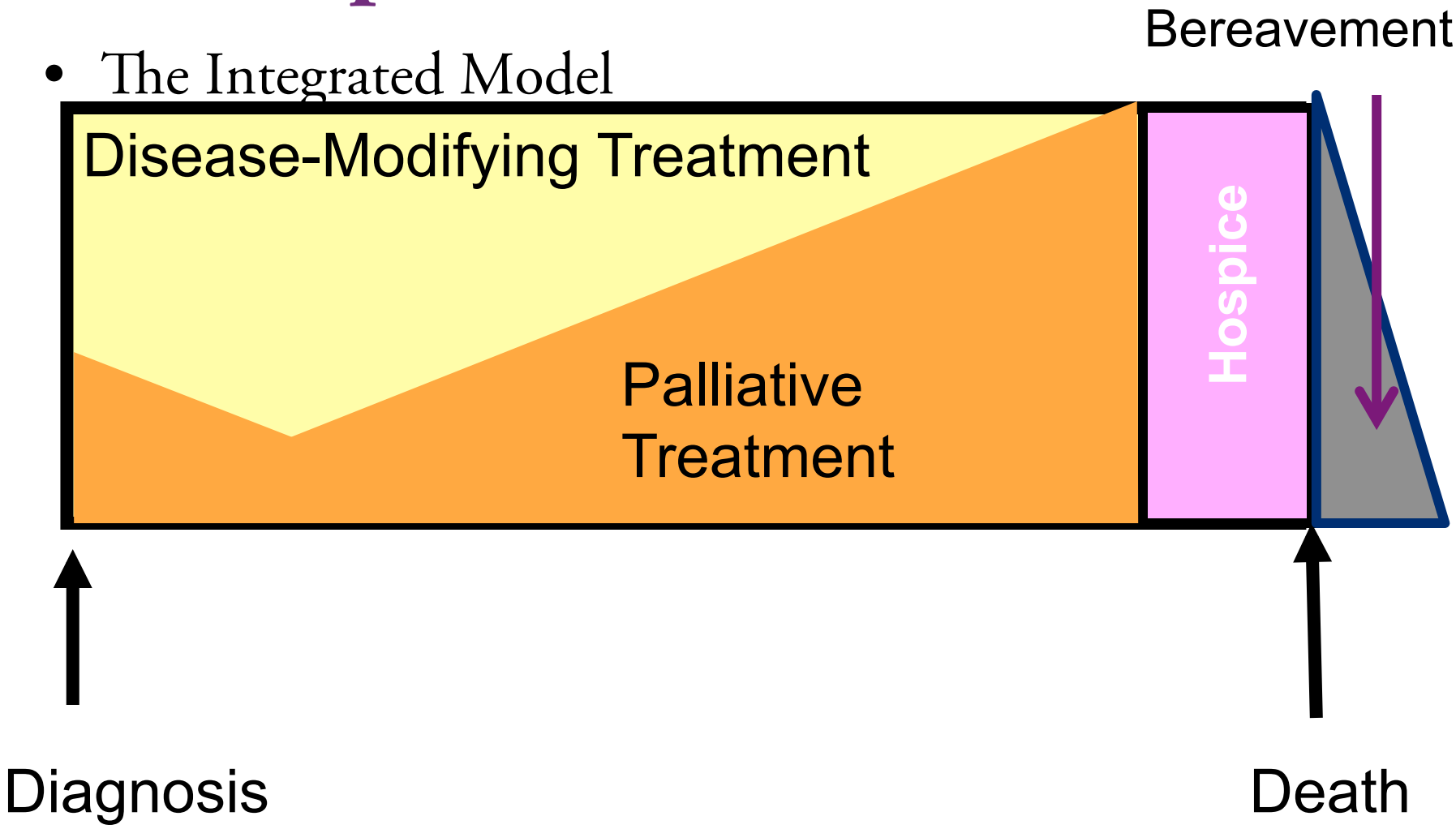
Hospice and Palliative Care

- 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

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Firefox | Palliative Care

www.getpalliativecare.org

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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

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