

# Palliative Care: When Should the Palliative Care Team Be Included in the Neuromuscular Team?

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**Parent** JOIN THE FIGHT.  
END DUCHENNE.  
**Project**  
**Muscular**  
**Dystrophy**

# Objectives for this Session

- Define pediatric palliative care
- Explore the relationship between pediatric palliative care (PPC) and Duchenne Muscular Dystrophy
- Explore families' perspectives on decision-making regarding available care options for their children

# What is Pediatric Palliative Care?



Why is it relevant or important  
in neuromuscular disease?

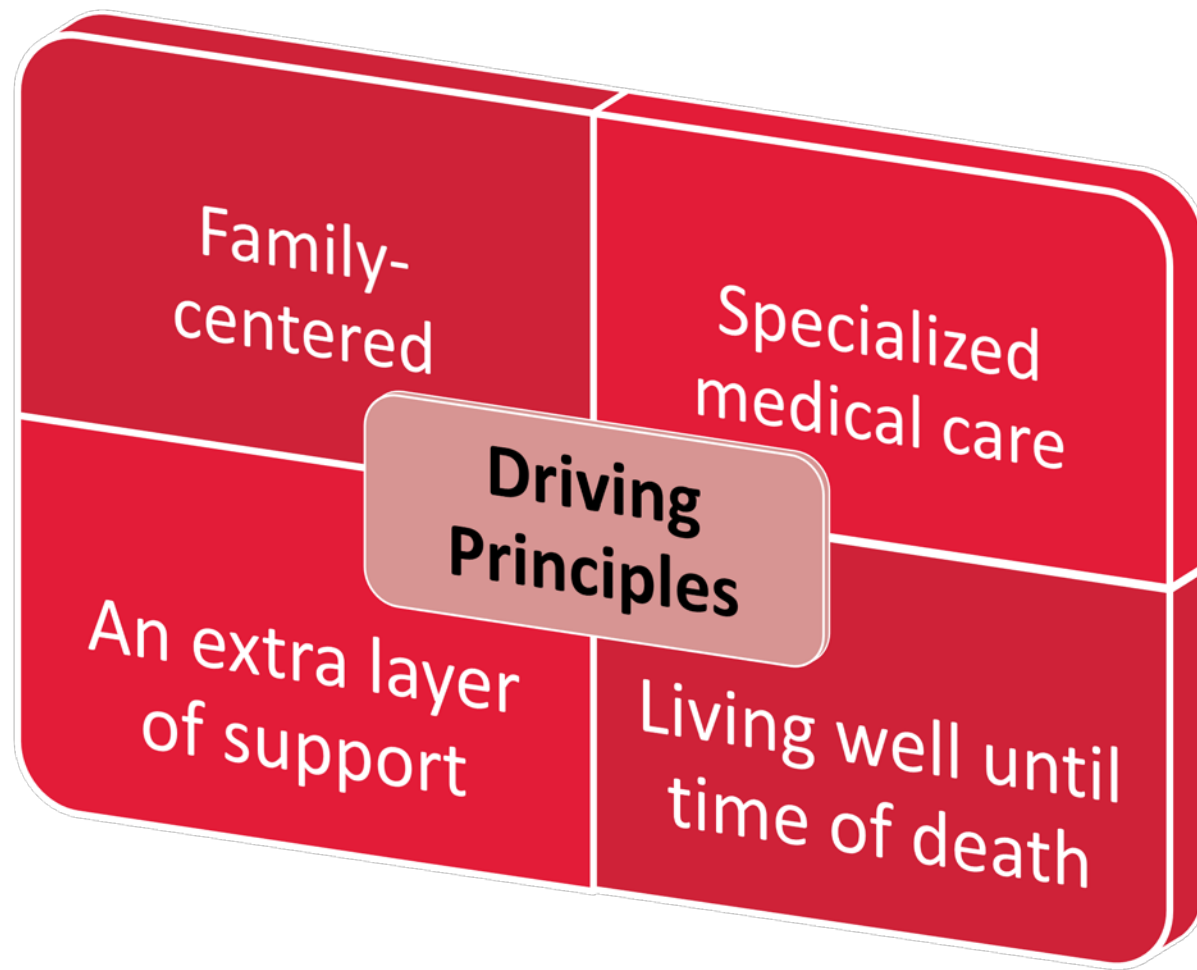
# The Definition of Palliative Care

- Aims to improve quality of life of patients facing life-threatening illnesses, and their families, through the prevention and relief of suffering by early identification and treatment of pain and other problems, whether physical, psychological, social, or spiritual.

WHO, 2002

# Palliative Care Goals

- Improve quality of life
- Provide collaborative & interdisciplinary care
- Support children's & families' goals/wishes
- Relief of pain and symptoms
- Attend to emotional, spiritual, and social needs
- Support for family and community members



Palliative care is about aligning patients' and families' goals, hopes, and values with disease directed treatments.

# Tenants of Decision-Making

Understanding goals of care

- Who is your child?
- What is most important regarding your child's care?

Exploring options

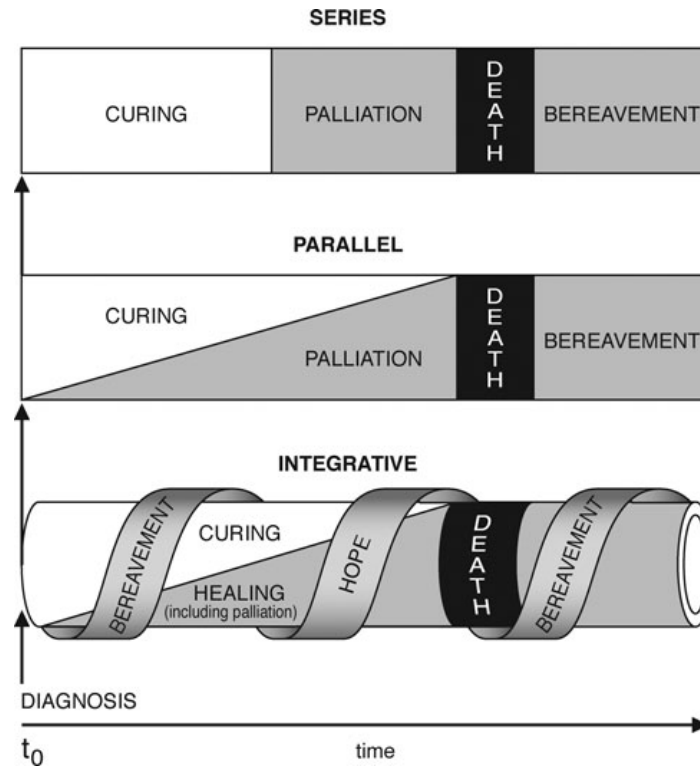
- What are your hopes and fears regarding your child's illness?
- What trade-offs are you willing to make for more time?

Using goals to help with decisions

- Where do you find support and strength?
- Is religion and/or spirituality important?
- Does your family make decisions privately or with others?



# Integrative Model of Care



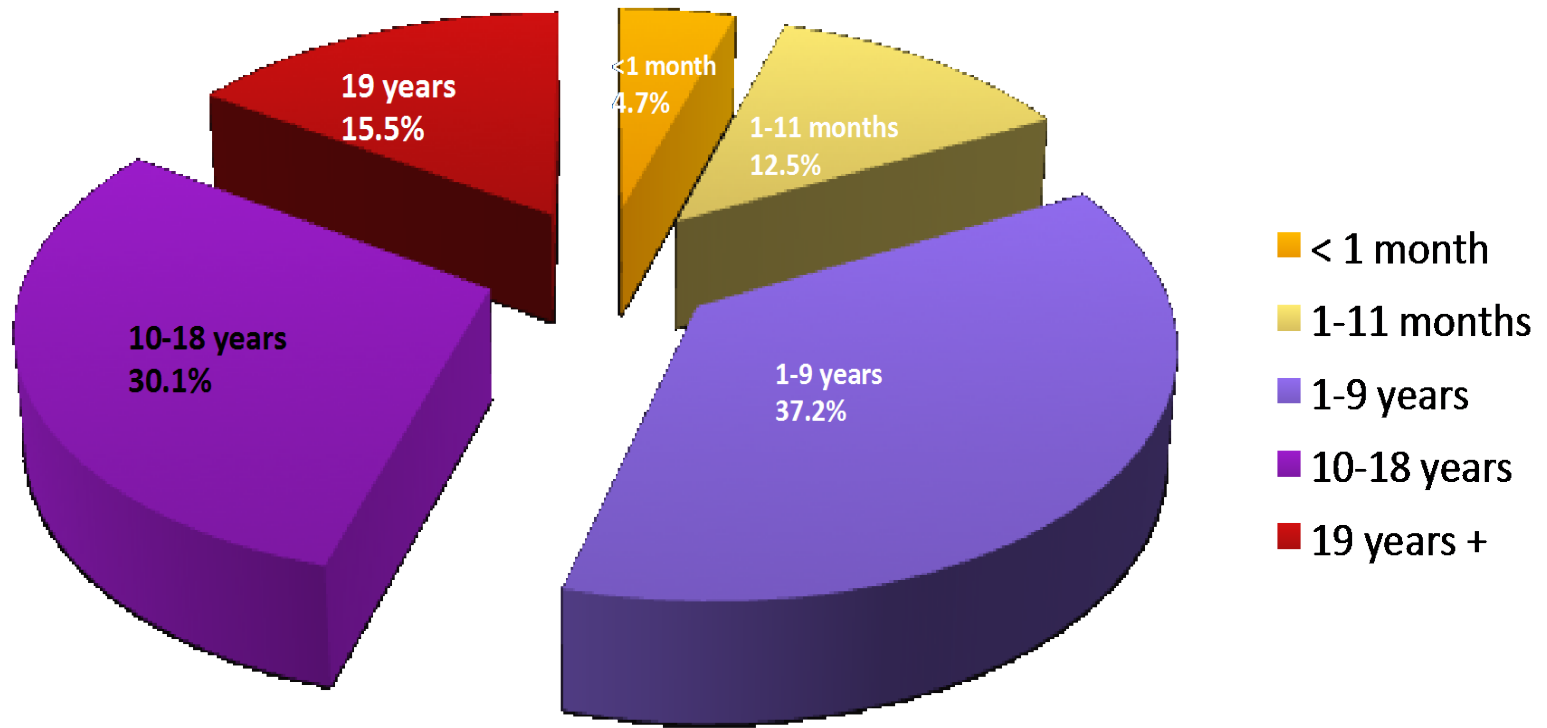
(Kobler et al., 2011)

# A Snapshot of the PPC Patients in Hospitals

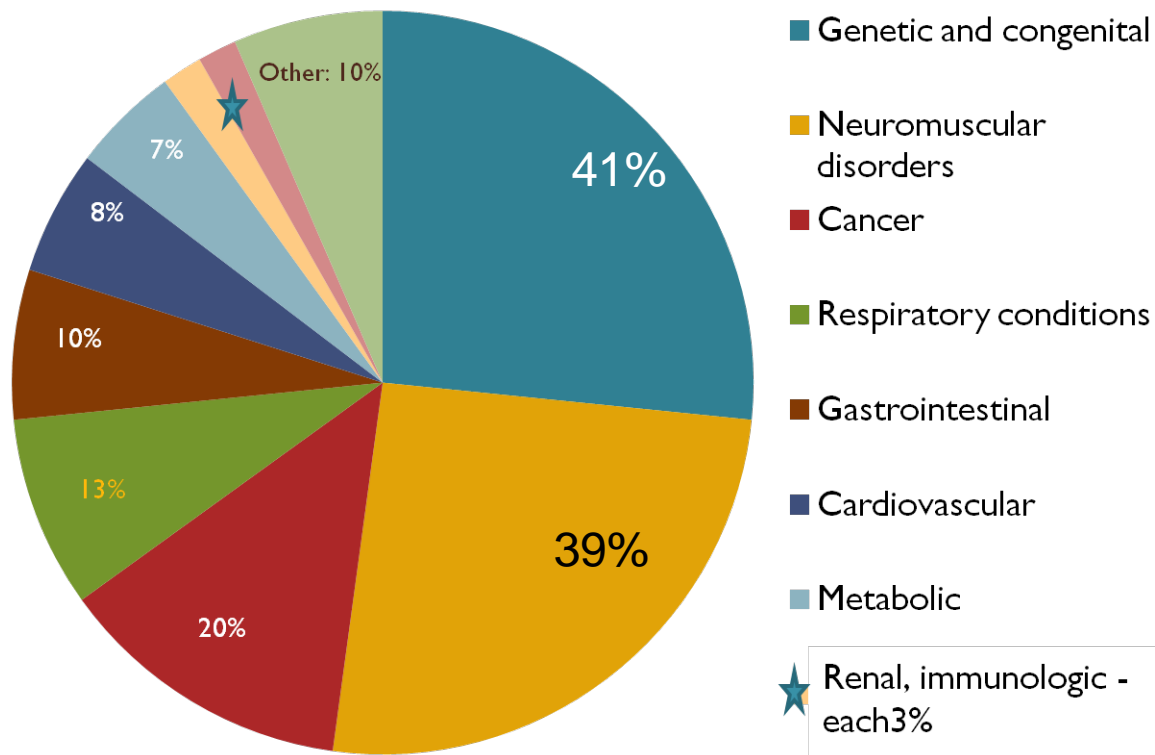
- Prospective observational cohort study
- 6 sites in the United States and Canada, with established hospital-based PPC teams
- Patients served by teams from January-March 2008 were eligible for enrollment
- Subjects were observed for 3 months

# Results: Demographics

Age of Study Group n=512



# Leading Conditions in Pediatric Palliative Care



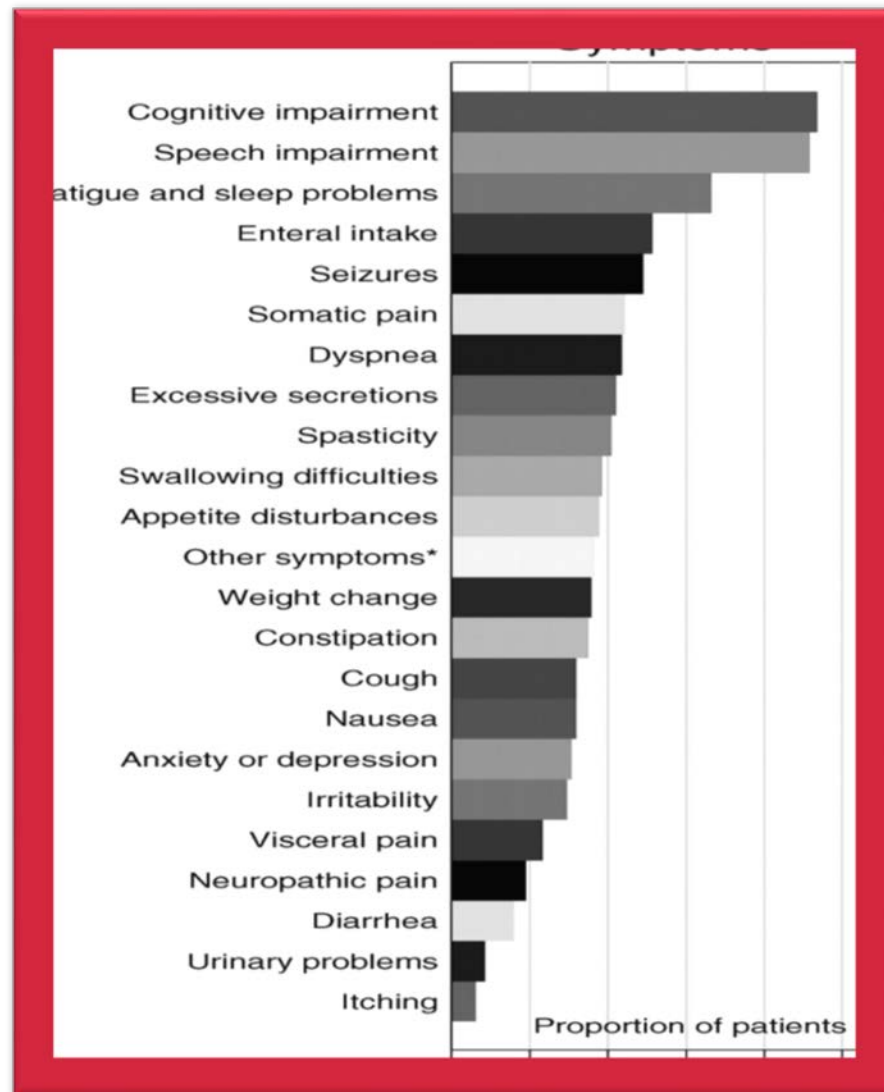
(Feudtner et al., 2011)

# Medical Technology of Pediatric Palliative Care Patients

Medical technology	#	%
None	105	20.4
Any feeding tubes	307	59.6
Gastrostomy tube	250	48.5
Nasogastric tube	51	9.9
Jejunostomy tube	50	9.7
Central venous catheter	115	22.3
Tracheostomy	52	10.1
Noninvasive ventilation	49	9.5
Ventilator-dependent	44	8.5
Wheelchair	21	4.1
VP/VJ shunt	15	2.9

(Feudtner et al., 20

# Signs and symptoms of patients who received pediatric palliative care consultation services:



(Feudtner et al., 2011)

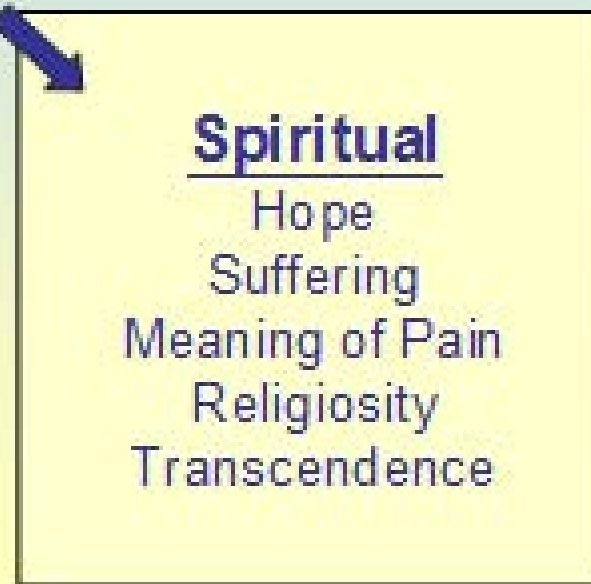
# The Goals of PPC in DMD



Support for the whole family throughout  
their life journey with NMD



Quality of Life





# Integrating Palliative Care

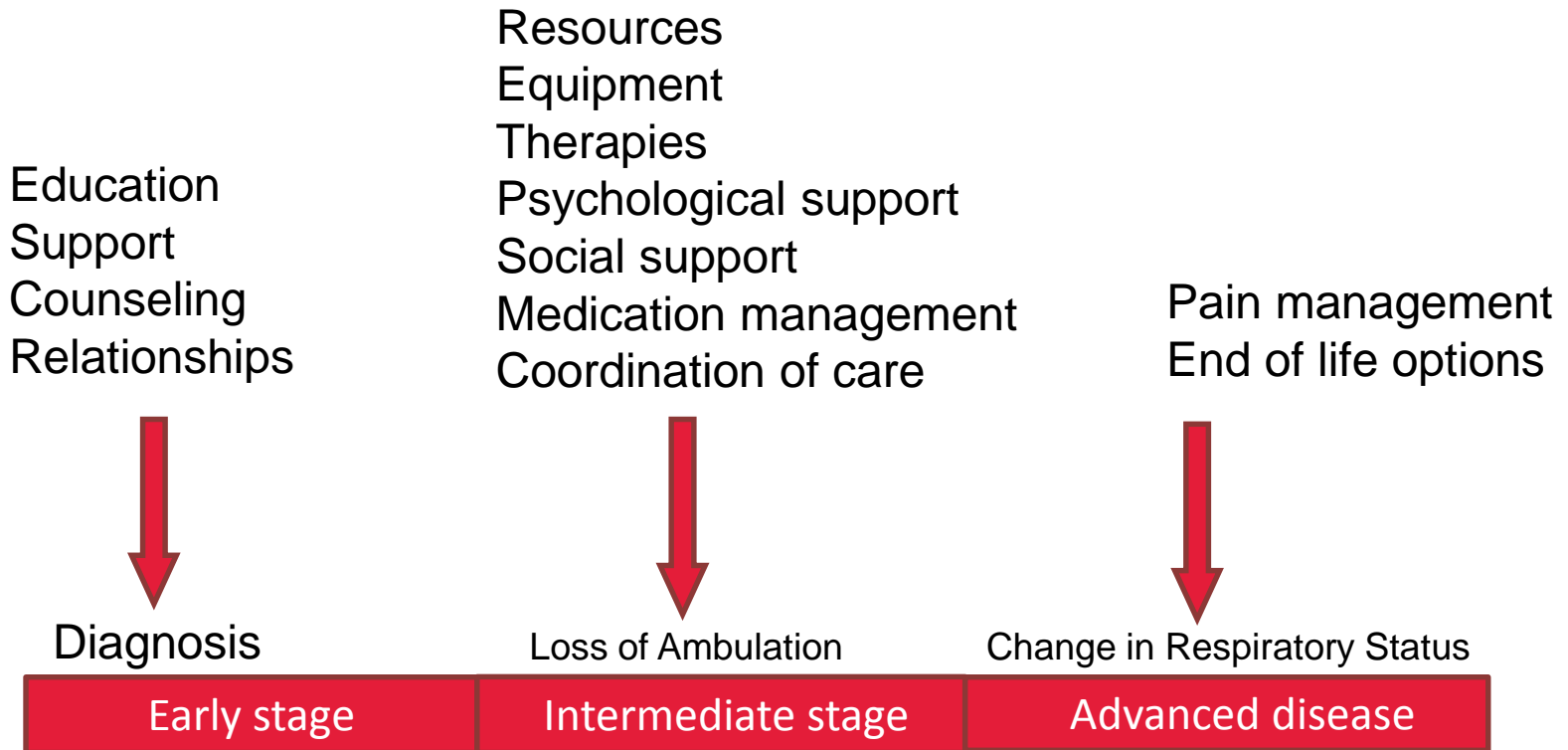
## Integrating Palliative Care in Life-Limiting Pediatric Neuromuscular Conditions: The Case of SMA-Type I and Duchenne Muscular Dystrophy

- Identified four transition points and opportunities for PPC at each stage
  - Peri-diagnostic
  - Treatment decision-making
  - Life-threatening events
  - End-of-life

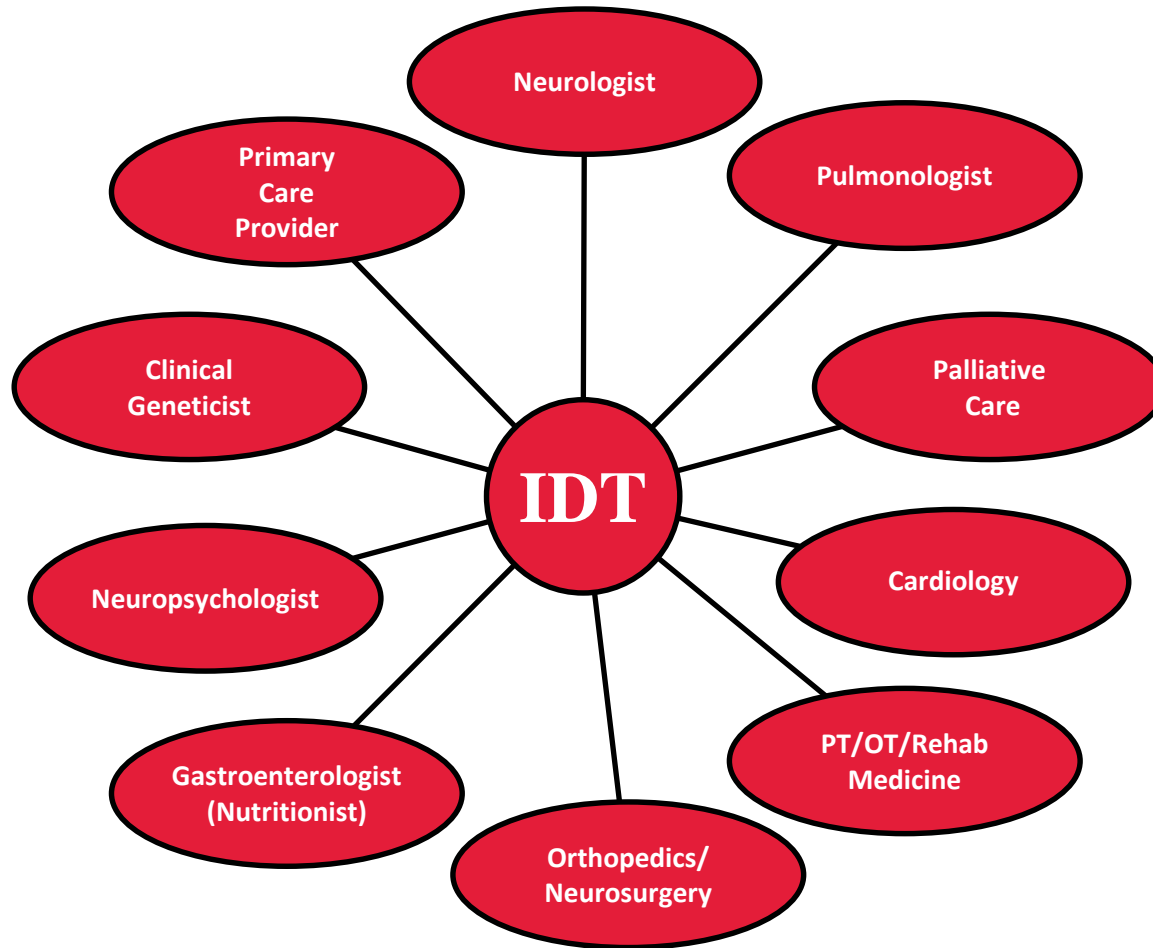
Rushton, Erby, Cohn, & Geller, 2012

# A Model for Neuromuscular Disease

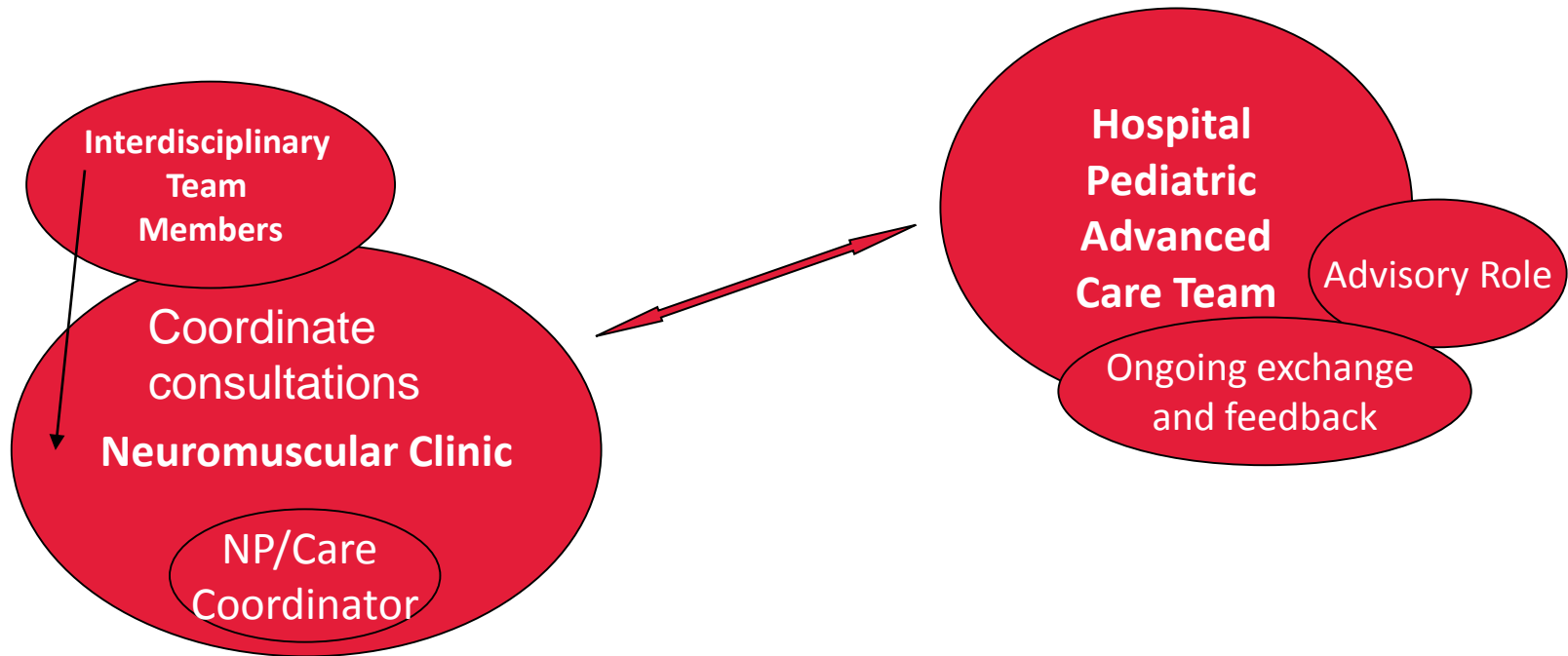
## Family-Centered Palliative Care for Neuromuscular Disease



# Interdisciplinary Team and Effort



# Palliative Care Partnership



# What Are the Options?

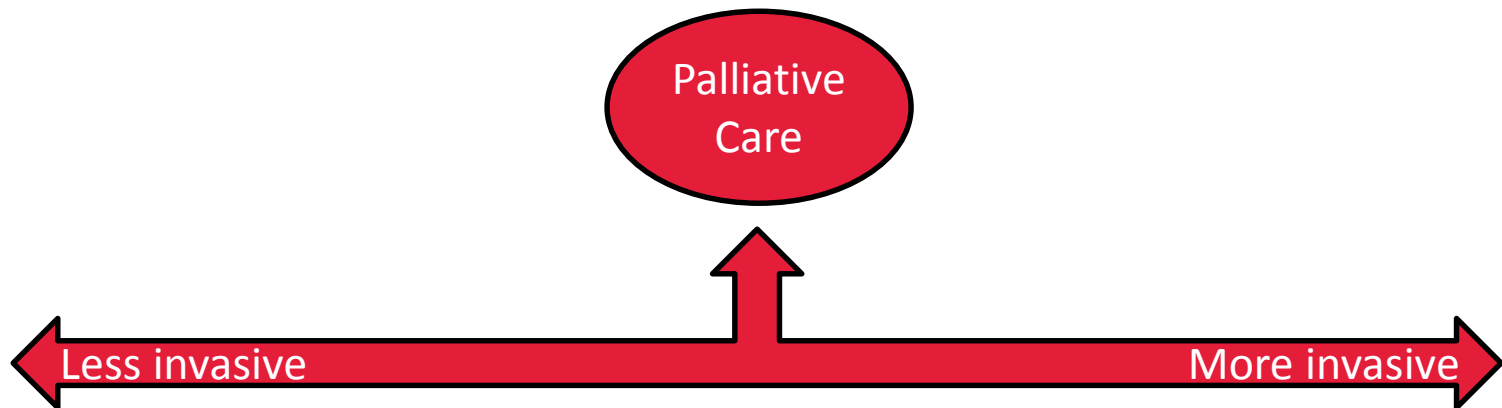
Families should make choices that  
are consistent with their  
personal beliefs and values  
and which work best for them

# Goals of Care

- Essential to identify for the child and family
- Often relate to specific therapy or technology
- Fluid and continually changing
- Center upon (clinical) decision making

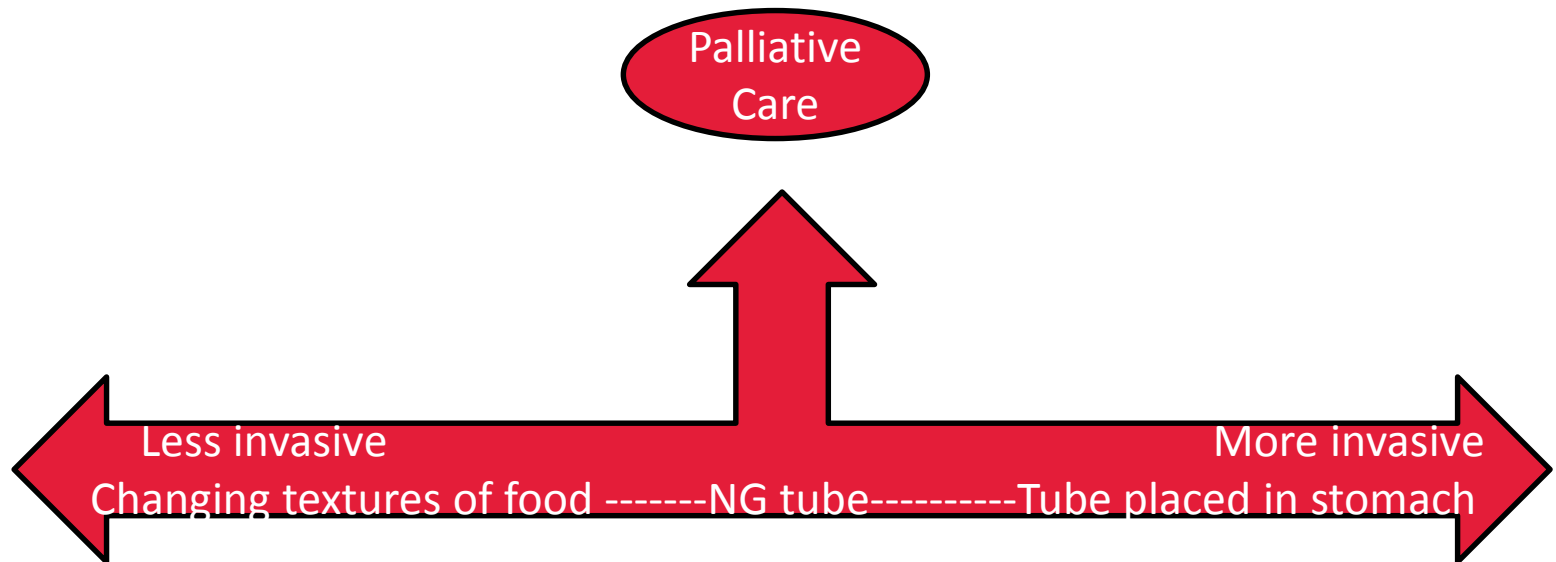
# Respiratory Care

- Non-invasive  
e.g.- CoughAssist™ or BiPAP or a Mechanical Ventilator
- Invasive  
e.g.- Tracheostomy + Mechanical Ventilator



# Nutritional Care

- Tube feedings:
  - Nasogastric (NG) tube
  - Gastrostomy (G) tube
  - G-tube and Nissen fundoplication
  - Gastrostomy-jejunostomy (G-J) tube





# Inherent Challenges

- **Communication**
  - family members
  - specialists from a variety of disciplines
- **Uniformity of Care**
  - duplicating or conflicting messages
- **Providing Care**
  - supporting families during stressful times
  - adapting care to ongoing changes

# Suffering

- The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick.
- Failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself.

*The nature of suffering and the goals of medicine, Cassel EJ NEJM-1982*

# Conclusion

- PPC provides care for a child and family along a physical, psychological, emotional, social and spiritual continuum.
- Children and families living with DMD can benefit from palliative care in a variety of ways.
- Various supportive care interventions exist and it is the role of PPC providers to offer information and support in navigating care options with children and families and the NMD team.

# Acknowledgments

- Interdisciplinary NMD team members at Columbia University Medical Center, Children's Hospital Boston, and The Children's Hospital of Philadelphia
- Parent Project Muscular Dystrophy
- CHILDREN, ADOLESCENTS, AND FAMILIES LIVING WITH NMD

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