



## **A Vision of Hope:**

# **Integration of Palliative Care in Chronic Pediatric Disease** ©2011

*“Hope does not lie in a way out, but in a way through.” ~Robert Frost*

## **Duchenne Muscular Dystrophy: Facilitator’s Guide**

**JOHNS HOPKINS**

**BERMAN INSTITUTE  
OF BIOETHICS**

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*“The most precious gift we can offer others is our presence.” ~Thich Nhat Hanh*

## Dedication

This curriculum is focused on Duchenne Muscular Dystrophy and other forms of neuromuscular disease in honor of Mattie J.T. Stepanek, young poet and peacemaker who lived with a rare form of muscular dystrophy and all the other children around the world with neuromuscular conditions. Mattie's messages of love, hope and peace have stirred the hearts and souls of millions worldwide. The author of 7 books, Mattie shared hope through his 'HeartSongs' poetry, and collaborated with Former President Jimmy Carter on an essay book, *Just Peace*. (<http://www.mattieonline.com/>).

Mattie died in 2004 just before his fourteenth birthday. Mattie's mother, Jeni, carries Mattie's message through her own writing, speaking and advocacy initiatives. Mattie's legacy for a better world for all children has inspired our work to improve the lives of children, like Mattie, who live with life threatening neuromuscular diseases. Mattie's generous spirit carries the work of this project beyond what we thought was possible.

### **Facing the Future**

*Every journey begins  
With but a small step.  
And every day is a chance  
For a new, small step  
In the right direction.  
Just follow your Heartsong.*

**by Mattie Stepanek**

*"Although the world is full of suffering, it is also full of the overcoming of it." –Helen Keller*

## Acknowledgments

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Vision of Hope logo created by: Charlotte M. Fremaux

*“I do not believe that sheer suffering teaches. If suffering alone taught, all the world would be wise, since everyone suffers. To suffering must be added mourning, understanding, patience, love, openness and the willingness to remain vulnerable.” ~Anne Morrow Lindbergh*



## Staff and Team Participants

### **Investigators**

Cynda Hylton Rushton, PhD, RN, FAAN; Co-Principal Investigator  
Gail Geller, ScD, MHS; Co-Principal Investigator  
Mary Catherine Beach, MD, MPH; Co-Investigator  
Carlton Haywood, Jr., PhD; Co-Investigator

### **Project Coordinators**

Janet Pniewski, BSN  
Jackie Williams Reade, PhD  
Emily Jones, MA  
Meredith Caldwell

### **Film Team**

Raphe Reggie  
Florentina Costache

### **Outreach Team**

Alan Regenber  
Leah Ramsay

### **Vision of Hope Neuromuscular Advisory Board**

Annie Kennedy, VP, Advocacy; Muscular Dystrophy Association  
Ross Hays, MD; Children's Hospital, Seattle  
Benjamin Cumbo, student; George Washington University  
Vance Taylor, Principal; Catalyst Partners, LLD

*“The most beautiful people we have known are those who have known defeat, known suffering, known struggle, known loss, and have found their way out of the depths. These persons have an appreciation, a sensitivity and an understanding of life that fills them with compassion, gentleness, and a deep loving concern. Beautiful people do not just happen.” ~Elisabeth Kubler-Ross*

### Purpose of the Curriculum

The Vision of Hope-DMD curriculum was motivated by a commitment to integrate the principles of pediatric palliative care (PPC) into the care of individuals living with Duchenne Muscular Dystrophy (DMD). Although our focus is on DMD, these materials may be applicable to other pediatric neuromuscular diseases that are life-threatening and life-limiting. To this end we will refer to both NMD and DMD as a specific type of neuromuscular condition throughout the curriculum. PPC can be described as a holistic, interdisciplinary model of care that incorporates emotional, spiritual, developmental, and physical dimensions. The Vision of Hope Project builds on the curriculum developed by the Initiative for Pediatric Palliative Care (IPPC) to help facilitate the learning of practices in providing comprehensive and integrated care for adolescents and their families.

The purpose of the curriculum is to provide institutions with evidence-based curricular materials based upon the IPPC model in order to integrate PPC concepts that will improve the quality of care for patients with DMD throughout their care continuum. The curriculum is designed to provide a training sequence of several PPC principles relevant to interdisciplinary team members. Curriculum objectives include exploring knowledge, skills, and attitudes related to patient and family care for a variety of disciplines and any level of PPC knowledge and experience.

### Development of the Curriculum

The Vision of Hope curriculum was developed by a team of experts in pediatric neuromuscular disease, palliative care, and medical education, with input from an External Advisory Board. It was originally piloted in a 2.5 day retreat-style and subsequent 60-90-minute in-service trainings at selected children's hospitals throughout the eastern US. Throughout this process, the curriculum has been modified based on feedback from these trainings. The development of the curriculum took place from January 2010 – January 2011 and included the following steps:

- Establishment of an Advisory Board to guide the development of the curriculum plan.
- Participants included representatives of the Muscular Dystrophy Association (MDA), IPPC Curriculum development experts, and adults living with muscular dystrophy.
- Definition of goals and scope for the Curriculum
- Development of an instructional design for the Curriculum that included general and interdisciplinary-specific breadth of components
- Development of general and specific learning objectives based on IPPC, PPC standards and the identified sequence/depth of instruction intended to achieve the learning objectives
- Assembly of the Curriculum
- Review of the draft curriculum with staff and Advisory Board
- Pilot parts of curriculum with interdisciplinary trainings at home institution
- Revise curriculum for both 2.5 day retreat and 60-90 minute in-service

It is the intention of the Vision of Hope faculty and staff and Advisory Board to structure the Curriculum so that it is flexible and includes a broad coverage of various interdisciplinary aspects of PPC. This approach should provide institutions the opportunity to make the most appropriate use of all of the instructional resources that are available to them. These materials can be used individually or in training sessions for interdisciplinary health care professionals across multiple units who care for children, adolescents, and young adults with DMD.

### **Separate Modules**

The curriculum is presented as separate modules that consist of learning objectives, sample agendas, PowerPoint presentations, film segments, discussion questions, interactive activities, resource lists, and evaluation tools. The materials can be adapted to the needs of individuals and training session participants, to your time frame, and to your training format. The materials can be used in their entirety or individual elements can be selected, modified, and used as needed. You may wish to review resource materials listed for each topic for additional background to help you prepare for delivering training sessions or designing individual sessions. In general, an interactive small group format is most effective for learning about these topics. However, these materials may also be used in a didactic, large group setting.

### **Three Different Formats**

We propose 3 different formats for training—in-service, workshop or 2 ½-day retreat - that can be adapted to the goals and schedules of the participating institutions. For example, the in-service format is meant to align with grand rounds, noon seminars or other standard formats for training, and delivered in 60-90 minute formats. Similarly, the workshop can be delivered in either a 4-hour or 8-hour format. An institution may want to bring together members of the inpatient services with clinic and allied health professionals or they may choose to bring together clinicians from other institutions in regional format particularly for the longer workshop or 2 ½ day retreat model.



## Overview of Modules

The Vision of Hope: Duchenne Muscular Dystrophy curriculum is divided into twelve modules which each include learning objectives, a short, documentary film or a PowerPoint presentation, suggested handouts, and related resources for additional information. The films provided are intended to be used as “triggers” to elicit reflection and discussion during the training session. The films can be used as a stand-alone training tool by providing introductory comments and guiding discussion at the end, or you may also include PowerPoint presentations, lecture, and interactive activities depending upon your preference and time allowed. The concepts portrayed in the films are intended to elicit new thinking and responses from the audience in order to better understand patients and families and to consider personal knowledge, skills, and abilities and those of the team as a whole in response to the issues raised. The concepts are not meant to establish a standard of care or to suggest that the experiences of the patients and families in the films reflect the desired model for care.

<b>Module 1: Introduction to Pediatric Palliative Care</b>
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This section is intended as an overall introduction to the training and can be used in conjunction with any of the modules. It provides a brief overview of pediatric palliative care and how it relates to Duchenne Muscular Dystrophy (DMD).
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<b>Module 2: Overview of Duchenne Muscular Dystrophy</b>
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Use this module to gain a broad understanding of DMD before beginning the Vision of Hope: Duchenne Muscular Dystrophy curriculum.
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<b>Module 3: Many Faces of Hope (Film #1)</b>
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This module explores the different types of hope experienced by patients, physicians, and family members. Participants will brainstorm creative methods of encouraging hope in their practice.
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<b>Module 4: Paradox of Promise</b>
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Use this short module to supplement the “Many Faces of Hope” module. Paradox of Promise explores the effects of the promise of a cure alongside various types of hope experienced by all those affected by DMD.
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<b>Module 5: Listen to Me (Film #2)</b>
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“Listen to Me” examines the important complexities of communication among patients, doctors, and family members affected by DMD, including the role of adolescent decision-making, the limitations of informed consent and the boundaries of parental and clinician authority.
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<b>Module 6: Unexamined Distress (Film #3)</b>
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Use this module to investigate the forms of distress encountered in patients with DMD – both those that are frequently addressed and those that are often ignored.
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<b>Module 7: Ethical Challenges in Duchenne Muscular Dystrophy</b>
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This module explores the ethical dilemmas faced by professionals from different disciplines who care for children and adolescents with DMD.
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<b>Module 8: Transitions</b>
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“Transitions” provides a glimpse into the difficulties presented by the complex transition
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between childhood and adulthood for adolescents with DMD.

**Module 9: An Uncertain Future (Film #4)**

This module raises the challenges associated with acknowledging and discussing death with children and their families, one of the toughest responsibilities of clinicians caring for adolescents with DMD.

**Module 10: Ethical Landscape and Decision-Making Tool**

This module surfaces the complexity of sharing the moral burden of decision making with patients and parents in the palliative care setting, and offers a tool for assisting in this process.

**Module 11: On the Edge (Film #5)**

This module explores the lived experience of a life-threatening event for an adolescent, his family and his clinicians. The challenges of uncertainty, disease progression and perspective-taking during and after a 7-week stay in the pediatric intensive care unit are highlighted.

**Module 12: Moral Angst: The Heartache of Healers (Film #6)**

This module is designed to explore the internal responses (moral, emotional and spiritual) of clinicians who care for children with DMD as they confront intense suffering and moral angst. Often unrecognized, these responses have a profound impact on the clinicians themselves, their interactions with patients, families and their colleagues.

**Interactive Activities**

The following are interactive activities included in this curriculum that can be used at your discretion, depending on time and the goals of your training.

- Interactive Exercises
  - Quality of Life
  - Listening
  - Images of Hope
  - Ben's Story
- Team Meeting Exercise
- Team Meeting Handout
- Closing Session (for retreat or 1-day option)

## Determining Your Format

The content included in this curriculum is specially designed for presentation for inter-professional learning. It is also useful for individuals who may want to learn about the content in a self-paced format. Individuals can tailor their learning experience in a sequence that best meets their needs. When the curriculum invites reflection, an individual can pause for his/her own reflection of the question or issue.

If you are using the curricula in an inter-professional format, thinking through the resources and challenges at your institution and the desired outcome of the curricular activities is vital. The inter-professional curriculum reflects relevant issues and challenges that face patients, family members, and the healthcare team. The curriculum is composed of topics that will challenge and produce increased knowledge, attitude, and skill regarding pediatric palliative care issues such as: quality of life, communication, trust, hope, and pain management. The concepts portrayed in the films are not typical curriculum subjects found in hospital institutions, but are crucial aspects of pediatric palliative care and quality patient care. In order for your training to be successful, it is important to think through what aspects of training would be of most importance and interest for your institution. You may want to consider using systematic assessment tools to understand the needs in your community and to inform your decisions about format, goals and results you hope to achieve.

### Points to Remember

Conduct a Participant/Institution Needs Assessment (see below) to assist in formulating your training agenda. Being aware of the resources, challenges, and needs of your participants and institution can help you develop an appropriate agenda.

Focus on your primary goals for the training. Review each module and accompanying learning objectives, exercises, resources, and PowerPoint presentations to determine which elements best fit with your proposed outcomes.

Leave time for discussion. The films are poignant and jam-packed with potential discussion points so it is recommended that you leave a significant amount of time for group discussion. Try not to rush since the primary impact of this curriculum is the depth of emotion and empathy that can surface if time allows. Also, leave time for evaluations at the end of the session if you choose to do this.

We encourage you to review the following questions to assist you in determining the best training format for your institution:

#### Who

- Who is your intended audience?

- Will it be presented to people with a broad range of experiences or focused on one profession or expertise?
- Will it include an inter-professional team that is drawn from specialty clinics or inpatient units, or is it a hospital-wide training?
- Do you want to include palliative care specialists?
- Do you want to create a regional training that involves other institutions across the continuum of care?
- Whose leadership and endorsement do you need to make this a successful project?

## Why

- What are you trying to accomplish? What is your central aim/purpose?
  - Raise awareness?
  - Build skills and capacity among clinicians?
  - Foster relationships?
  - **Others?**
- To what extent is there alignment with other personal, professional, or organizational values and priorities?
  - How might this training be leveraged to accomplish other important goals?
- Why would participants want to attend?
  - What would make this training relevant and useful?
  - How do you align your vision with their interests?

## What

- What shifts in behavior, processes or practices are you seeking to change?
- What will people be doing differently as a result of participating in this training?
- What topics are most important to emphasize?
- What format will work best in your institution?
  - Facilitated small group discussion, large group didactic?
  - Do you want a small, intimate setting for discussion or a large room to bring in the capacity of participants?
- What will make your training effective?
  - What will be necessary to sustain the learning after the training?
- What are the complexities of what you are trying to accomplish?
  - What are some of the barriers you need to consider?
  - What resources do you have to support your efforts?

## Where

- Where will this training take place (depends on number of people you want to invite, the number of people you expect, and the associated costs)?
  - During a regular training session, 1 day workshop?
  - 2 ½ day retreat?
  - In the hospital? Training center? Off site location?
  - What location, date, and time is most conducive for your target audience?
  - What equipment and technical assistance is needed and available?

## When

- When is an appropriate time of day/month/year to plan this training?
  - In terms of institutional culture?
  - What other trainings and required compliance activities may compete with this training?

#### **How**

- How will the training best serve your intended audience?
- How should you format the training to get your best response and achieve your desired results?
- How will you know if you have been successful?

#### **Additional Institutional Assessment Resources:**

Levetown M, Dokken D, Heller, K.S., et al. for The Initiative for Pediatric Palliative Care (IPPC). A Pediatric Palliative Care Institutional Self-Assessment Tool (ISAT). Newton, MA: Education Development Center, Inc. 2002. For information, contact: M. Z. Solomon, EDC, 55 Chapel Street, Newton MA, 02458-1060. Also available at [www.ippcweb.org](http://www.ippcweb.org) or [www.pediatricpalliativecare.org](http://www.pediatricpalliativecare.org).

## Sample Agendas

Sample Agendas are provided to assist in determining appropriate length and content of training options.

### 2.5 Day Retreat Module

#### Day 1

10:00 AM	Faculty/Facilitator Training
12:00 PM	Registration and Pre-Evaluation Forms
1:15 PM	Lunch   Family Meeting
2:30 PM	Plenary: Welcome, Setting the Context, & Listening
3:30 PM	Small Group Session 1a: Opening Activity   Quality of Life
4:30 PM	Break
4:45 PM	Plenary: QOL as Palliative Care
5:45 PM	Small Group Session 1b: Quality of Life & DMD  Film 1: Many Faces of Hope
7:15 PM	Break
7:30 PM	Dinner   Team Meeting 1
8:30 PM	Faculty-Facilitator Meeting

#### Day 2

7:30 AM	Morning Reflection
7:45 AM	Breakfast
8:45 AM	Small Group Session 2: Film 2: Listen to Me
10:15 AM	Break
10:30 AM	Panel: Involving Adolescents in Decision-Making
12:00 PM	Lunch   Family Meeting
1:00 PM	Plenary: Ethical Framework
2:15 PM	Small Group Session 3: Film 3: Unexamined Distress
3:45 PM	Break
4:00 PM	Small Group Session 4: Film 4: An Uncertain Future
5:30 PM	Break
5:45 PM	Team Meeting 2   Faculty-Facilitator Meeting
7:00 PM	Dinner
8:00 PM	Art Activity: Caregiver Well-Being

#### Day 3

7:45 AM	Morning Reflection
8:00 AM	Breakfast
9:00 AM	Plenary: Transitions
11:00 AM	Break
11:15 AM	Team Meeting 3
12:15 PM	Poster Viewing
12:30 PM	Lunch   Family Meeting
1:30 PM	Small Group Session 5: Closing and Evaluation
2:45 PM	Closing Plenary
4:00 PM	Faculty-Facilitator Meeting

## Sample Agendas (cont.)

### 1 Day/8 hour Module

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8:00 AM	Faculty/Facilitator Training
9:00 AM	Registration and Pre-Evaluation Forms
9:15 AM	Plenary: Welcome, Setting the Context, & Listening
10:00 AM	Film 1
10:15 AM	Group discussion
11:00 AM	Break
11:15 AM	Film 2
11:30 AM	Group Discussion
12:15 PM	Lunch/Break/PPT Presentation
1:00 PM	Film 3
1:15 PM	Group Discussion
2:00 PM	Break
2:15 PM	Film 4
2:30 PM	Group Discussion
3:30 PM	Closing/De-brief
4:30 PM	Closing Evaluation
4:45 PM	End

### 1.5 Hour Module

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9:00 AM	Registration and Pre-Evaluation Forms
9:10 AM	Plenary: Welcome & Setting the Context
9:20 AM	Film 1
9:30 AM	Group discussion
9:45 AM	Closing/De-brief
9:55 AM	Closing Evaluation

## Evaluation of the Training

### **Impact Evaluation**

We do not require you to conduct an **impact** evaluation of these curriculum materials. However, if you would like to do so, please contact us. We will work with you to navigate the various methods of survey and data collection.

### **Process Evaluation**

Although not required, we **strongly request** completion of the **process** evaluation by the facilitator or point person in charge of conducting these trainings. Providing feedback in this way will assist us in improving the Vision of Hope curriculum. The Process Evaluation can be found below and filled out on our website. Please fill out a process evaluation for each version of the training you conduct.



## Process Evaluation

Please fill out a short questionnaire for each training session you implement. Your feedback will assist us in improving the Vision of Hope curriculum.

Your e-mail: \_\_\_\_\_

### Which format of the training did you use?

- In-service (one time only)
- In-service (in a series)
- ½ day Workshop
- Full day Workshop
- Intensive Retreat
- Other: Please describe \_\_\_\_\_

How many hours did the training last? \_\_\_\_\_

Approximately how many individuals participated in this training? \_\_\_\_\_

Was the training voluntary or mandatory? \_\_\_\_\_

Please tell us about your attendees.

### Which departments were represented?

- Pediatric Neurology
- Palliative Care
- Others: Please list \_\_\_\_\_

### Which disciplines/roles were represented?

- Physicians
- Nurses
- Allied health (PT, OT, respiratory therapy)
- Psychology/social work
- Clergy/chaplains
- Others: Please list \_\_\_\_\_

How would you rate your institution's training in Palliative Care? (Have you had PC training in the past?)

### Which curriculum components did you use? Check all that apply.

- Introduction to Pediatric Palliative Care
- Overview of Duchenne Muscular Dystrophy
- Many Faces of Hope (Film #1)
- Paradox of Promise
- Listen to Me (Film #2)

- Unexamined Distress (Film #3)
- Ethical Challenges in Duchenne Muscular Dystrophy
- Transitions (Film #4)
- An Uncertain Future (Film #5)
- Ethical Landscape and Decision-Making Tool
- On the Edge (Film #5)
- Moral Angst: The Heartache of Healers (Film #6)
- Interactive Activities (Quality of Life exercise, Listening exercise, etc.)
- Team Planning Worksheets
- Reading Resources
- Closing Session
- Impact Evaluation

**In your opinion, did the curriculum meet your expectations for delivering the content you anticipated?**

If yes, please tell us which components worked best. If no, please tell us which components did not work well.

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**What recommendations would you give in order to improve the curriculum?**

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**Did you conduct an impact evaluation of your training?**

If no, why not? If yes, which evaluation strategy did you use?

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**Would you be willing to have us contact you for a brief summary of the results?**

- Yes
- No

## Learning Objectives

Throughout this curriculum, participants will:

1. Develop an understanding of pediatric palliative care principles and their relevance in the context of pediatric neuromuscular disease (NMD) with a particular focus on Duchenne Muscular Dystrophy (DMD).
2. Strengthen their understanding of the value and purpose of an interdisciplinary team approach to the integration of pediatric palliative care principles and practices in the context of DMD.
3. Explore creative strategies for enhancing the comprehensive and holistic care of children and families affected by DMD.
4. Evolve strategies for encouraging reflective practice among participants.
5. Become knowledgeable about the range of educational and clinical resources currently available in pediatric palliative care and DMD.
6. Explore networking opportunities with other professionals and family members to address mutual needs and interests with regard to improving the quality of life for children and families affected by DMD.

*“The most beautiful people we have known are those who have known defeat, known suffering, known struggle, known loss, and have found their way out of the depths. These persons have an appreciation, a sensitivity and an understanding of life that fills them with compassion, gentleness, and a deep loving concern. Beautiful people do not just happen.” ~Elisabeth Kubler-Ross*

*To create an atmosphere of safety and trust in order to facilitate conversation in your training session, it is important to set-up expectations for participants to provide positive feedback and support. The following “Responsibilities for Collaborative Learning” may be provided to frame the training event.*

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### **Responsibilities for Collaborative Learning**

As a participant in the collaborative learning process, we ask that you:

- Contribute to creating an atmosphere of trust and respect. Promote the spirit of collaborative learning among all participants.
- Listen attentively. Create a climate in which participants feel comfortable sharing personal thoughts, reflections, and feelings.
- Be clear and concise when sharing thoughts and ideas. Maintain necessary time boundaries in group discussions.
- Create space for "quiet voices" to have room for expression.
- Be respectful of the personal, professional, and cultural frame of reference of other participants.
- Act according to the guiding ethic that there is rarely only one "right" answer in any discussion. The greatest learning is likely to occur when multiple and different perspectives (medical, nursing, family, psychosocial, spiritual) are shared in respectful dialogue among participants.
- Offer personal thoughts and ideas as one option among several. Acknowledge alternate ways to view the same situation.
- Use discretion in regard to personal information that has been shared.
- Engage fully in all sessions.

*“Let me keep my mind on what matters, which is my work, which is mostly standing still and learning to be astonished.” ~Mary Oliver*

### **General Guidelines for Facilitating Small Groups**

Each small group is organized around the viewing of a film or engaging in an experiential exercise followed by group discussion. At the outset of each small group, it may be helpful for the facilitator to set a few ground rules for the discussions:

- Convey the message to participants that there is no right response, and that the group's discussion will be more valuable if there are a variety of views and perspectives.
- Invite people to engage within their sphere of comfort. It is possible that some of the film and curricular content can evoke positive and negative feelings. The purpose of the curricula is to surface these within each person's comfort zone. Each person should be mindful of their own needs and boundaries for involvement.
- Participants are invited to notice their responses to the films and discussions by monitoring their bodies, emotions and thoughts as clues for further investigation individually and collectively.
- Remind participants that all opinions should be treated in a respectful manner, and effort should be made to include as many voices as possible. (If one or two individuals begin to dominate the discussion, make a comment about the value of hearing from as many people as possible.)
- Explain that if individuals choose to share on a personal level, their comments should not be repeated in other settings.
- Strongly encourage participants to arrive on time and stay for the duration of the seminar. Late arrivals and disruptions in the group will negatively affect the educational experience.

#### **About the Films:**

- Clarify that the film segment is not a case study to be analyzed or interpreted, but rather family stories that are provided to stimulate group reflection and discussion about clinical and organizational practice.
- The film segments include positive as well as critical comments about health care professionals. It is important to establish an atmosphere in which "mistakes" or negative behaviors on the part of practitioners are viewed as constructive learning opportunities for all participants, and not as a judgment about any single professional discipline or behavior.

- These films, while created at Johns Hopkins Hospital, are not about care at Johns Hopkins. These are films about (non-clinical) aspects of patient care (e.g., quality of life, communication, ethics) provided to young people with DMD and their families. The films are not meant to suggest a standard of care but rather to explore some of the prominent issues that arise from conversations with patients and families.
- Our hope is that the themes that arise during the training will be common across spectrums of care for adolescents with these diseases. We recognize that the stories in these films do not necessarily reflect the perspectives and experiences of all patients and families. We chose these particular patients and families to elicit certain emotional responses and to explore specific aspects of pediatric palliative care. We invite you to watch these as they are meant to be: films to help clinicians see things from the perspective of a select group of patients and families. Notice if you find yourself wanting to debate the justification for the care these patients are receiving. If you find yourself going in this direction, pause and redirect your focus back to questions that are associated with each module.

### **Materials:**

Facilitator's Guide

Participant handouts (all Participant handouts will be in their folder)

1 Copy of additional articles

**Please review the** Facilitator's Guide in its entirety.

### **Prepare:**

In preparation for facilitating this workshop, review these materials. Give careful attention to the questions you feel are the most important messages conveyed in each film. You may not be able to get through all of the suggested questions below; use the energy of the group as a guide about the direction of content and the needs of the group.

### **Related References:**

Familiarize yourself with the professional literature included in the Related References handout. Refer to these items when appropriate in group discussion. Each participant will receive a Related References list to additional resources which they can obtain on-line through our Vision of Hope blog (this information is contained on the resource list.) Please remind group members of the references list and encourage them to review additional resources on their own time.

### **Basic Outline of Small Group Sessions:**

1. Introductions, checking-in, or de-briefing plenary (~5 - 10 minutes)
2. Show trigger film (~7 minutes)
3. Create a space for reflection—Invite participants to look inside themselves by being quiet and writing about their personal reflections on each film (~2 minutes)
4. Discussion (~60 - 75 minutes)

5. Application to self and home institution (~5-15 minutes)

**Leading the Session:** Begin the session by conveying the following introductory concepts:

*In this seminar, we are going to explore.... We will watch a film segment that presents.... The videotape is approximately 7-9 minutes long. The remainder of the session will be devoted to discussion organized around focused questions.*

Review the learning objectives with participants.

Play the videotape segment.

As you proceed with the discussion questions, read each one aloud and then invite discussion.

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### **Preparing to Lead/Planning your Training Module**

#### **Preparing to Lead:**

##### **Print:**

- This Facilitator's Guide in its entirety, including the participant handouts that appear at the end.

##### **Review:**

- The "General Guidelines for Facilitating Seminars," which appear below.
- This Facilitator's Guide in its entirety, including attachments.
- The corresponding film and/or PowerPoint segment

##### **Arrange for:**

- A registration process to determine how many people will attend the seminar.
- A room large enough for the number of registered participants, set up around a table or in such a way that participants are facing each other.
- A DVD player, television monitor, flipchart, and markers. Check to determine that the equipment is working properly.

##### **Obtain:**

- A copy for each participant of the handouts and resources that appear at the end of this module
- "Seminar Learning Objectives and Discussion Questions"

##### **Prepare:**

- In preparation for facilitating this workshop, give yourself ample time to view the film, review these materials, and think about whether the material should be adapted in any way for the particular audience with whom you are working.

- Give careful attention to what you feel are the most important messages conveyed by the film and/or PowerPoint presentation.

### **Leading the Session:**

Begin the session by conveying the following introductory concepts. Many facilitators prefer to put these ideas into their own words. Or, if you prefer, you may read the following:

*In this training...*

- Distribute the “Learning Objectives and Discussion Questions” handout.
- Review the learning objectives with participants.
- Play the film or PowerPoint segment.
- As you proceed with the discussion questions, read each one aloud and then invite discussion. (Questions are in bold text; notes to the facilitator are indented.)



## **In-Service Curriculum**

**Vision of Hope: Integrating Pediatric Palliative Care into Chronic Disease  
Duchenne Muscular Dystrophy**

**Many Faces of Hope**

What are the similarities and differences in how patients, family members and clinicians view hope and cure in the context of neuromuscular conditions such as Duchenne Muscular Dystrophy (DMD)?

What would be included in broadening a vision of hope for patients with DMD, beyond a strict focus on hope for a cure?

**Listen to Me**

Based on the film, what does “listen to me” mean for adolescent patients, parents, and clinicians?

This film depicts different viewpoints about treatment decisions such as spinal surgery. How might greater attention to advance care planning help to create a shared vision among adolescents, parents, and clinicians, and mitigate value conflicts?

**Unexamined Distress**

What are physical and emotional challenges/burdens that may often go overlooked or unexamined for these patients, parents, and siblings?

How might a palliative care approach help clinicians to respond differently to the suffering experienced by adolescents living with DMD?

### **An Uncertain Future**

As a clinician, how do you acknowledge and plan for an uncertain future while maintaining hope?

What aspects of palliative care might enhance the care of patients with DMD as their disease progresses?

### **General Discussion**

Given our discussion today, what are some specific ways that a palliative care approach could enhance the quality of life and the quality of care for adolescent patients living with DMD?

Regarding what we have discussed during today's session, what change would you like to see/make in your own practice?

## **2.5 Day Retreat Curriculum**

# Module 1

## Introduction to Pediatric Palliative Care

### Description

This section is intended as an introduction to the training and can be used in conjunction with any of the modules. It provides a brief overview of pediatric palliative care and how it relates to Duchenne Muscular Dystrophy.

### Time Estimate

35 minutes

### Structure

10 minutes Introduction

23 minutes Show Video: Palliative Care from the Leading Edge of the Wedge

10 minutes Group Discussion

### Learning Objectives

- Understand the basics of palliative care
- Begin to explore the various roles of palliative care in the care of someone with DMD.

**Show Video: Palliative Care from the Leading Edge of the Wedge (22 minutes)**

**Group Discussion (10 minutes)**

- Did you hear anything new related to the definition of palliative care?
- What are key PC components that can help in “quality of life” for an adolescent with DMD, their parents, family members, and professional caregivers?
- What is the role of hope in palliative care?

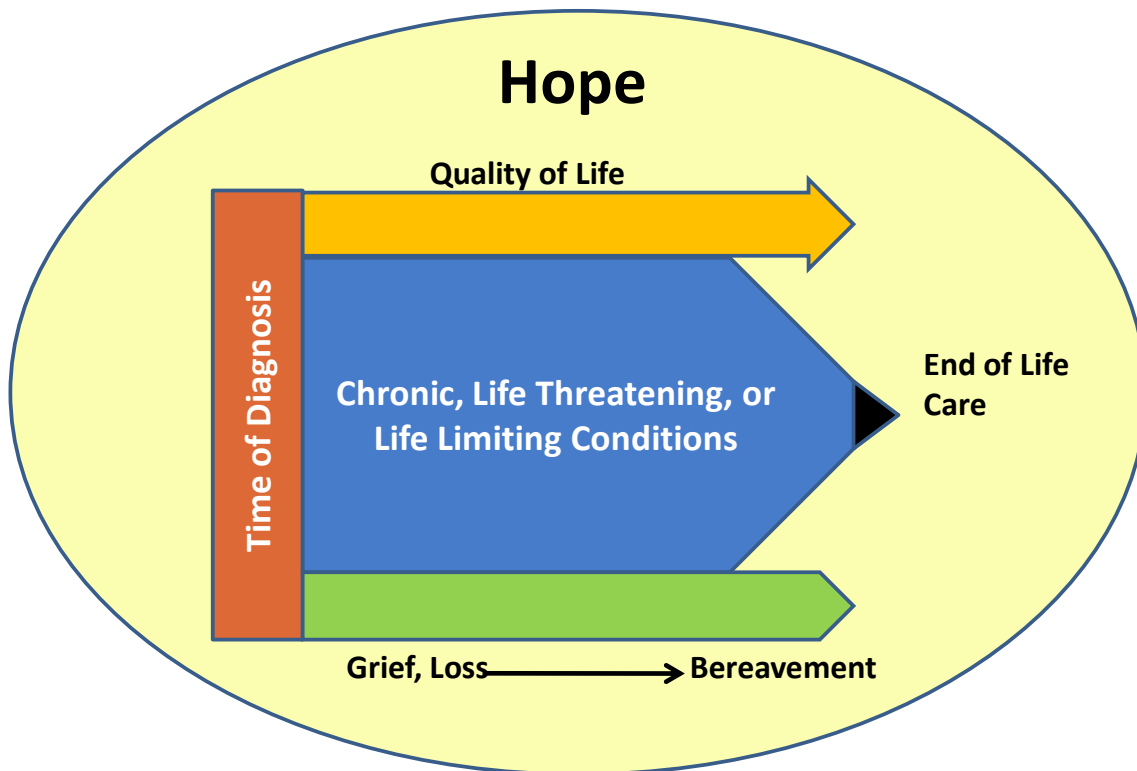
# Palliative Care

“The art and science of patient and family-centered care aimed at attending to suffering, promoting healing and improving quality of life.” ~ Javier Kane, MD

## Components of Palliative Care

- Quality of life
- Pain and Symptom Management
- Communication
- Ethical Decision making
- Advance Care Planning
- Grief & Bereavement

## A Model of Palliative Care in Chronic Life-Threatening Conditions



## Module 2

# Overview of Duchenne Muscular Dystrophy

### Description

Use this module to gain a broad understanding of DMD before beginning the Vision of Hope: Duchenne Muscular Dystrophy curriculum.

### Time Estimate

70 minutes

### Structure

10 minutes	Introduction
10 minutes	Show Video: Overview of Duchenne Muscular Dystrophy
38 minutes	Show Video: Genetics of Duchenne Muscular Dystrophy
10 minutes	Debrief and Questions

### Learning Objectives

- Explore the causes, symptoms, progression, treatment, and care for individuals with DMD.

**Show Video: Overview of Duchenne Muscular Dystrophy (10 minutes)**

**Show Video: Genetics of Duchenne Muscular Dystrophy (38 minutes)**

# Module 3

## Many Faces of Hope

### Description

This module explores the different types of hope experienced by patients, physicians, and family members. Participants will brainstorm creative methods of encouraging hope in their practice.

### Time Estimate

45 minutes – 1 hour

### Structure

5 minutes	Introduction
8 minutes	Show Film 1: Many Faces of Hope
2 minutes	Individual Reflection (Optional)
15-45 minutes	Group Discussion
5 minutes	Application to Self and Home Institution

### Themes

- Reflections on Palliative Care and Quality of Life
- Hope
- Tension between Hope and Cure

### Learning Objectives

- Explore the role of palliative care in discussing quality of life for patients and family members
- Understand differences and similarities in thinking about hope and cure for patients and family members
- Identify constructive ways to navigate varying understandings of hope and cure

### Show Film 1: Many Faces of Hope (~8 min)

### Individual Reflection (2 min)

Give 2 minutes for individual reflection on the film. Ask participants to write responses to the following questions:

- What are your initial responses to this film? What surprised you?
- What did you take away from the film?
- What are your thoughts about what Quality of Life means for patients in the film?

### Group Discussion (15-45 minutes)



## Visions of Hope

Explore the questions below with members of the small group by drawing the following matrix on the flip chart and filling in the boxes with group member's responses.

HOPE	Patients	Families	Clinicians
<b>Film Example Statements:</b>	<i>"I focus on what I <u>can</u> do."</i>	<i>"I looked all over the world for a cure."</i>	<i>"Regaining 10% of what they had would mean the world to them."</i>
<b>Group Reactions/responses:</b>			

- From the film, each member (clinician, patient, family member) seems to have different ideas about what hope means or different things they are hoping for... What are they?
- How do we navigate when we have different visions of hope?
  - One way of understanding the differences in how we view hope is based on Keene and Serwint's research (Keene Reeder and Serwint, 2009) in which they explored the varying views of hope according to parents and clinicians. The study found that parents identified their role as bearers of hope which in turn was a cornerstone of decision making. Health care professionals tended to view hope as related to a positive outcome and reported difficulty in maintaining hope in the face of the actual prognosis. All participants noted the changing nature of hope and its implications for care. The tension between maintaining hope and accepting the reality of the prognosis may lessen by acknowledging that parents see their role as bearers of hope. Supporting families through the changing nature of hope may allow health care professionals to partner with parents while maintaining honest communication. How does this insight impact the way you work with families around the issue of hope?

In the film, Dustin says: *"Dr. Crawford told me that even though I'm in a wheelchair, I can do anything I want to. That made a world of difference."*

- What do you think your role is in the offering of hope to patients and families? (Prompts: *Hope for better quality of life, cure, college, future, etc.*)
- How do these hopes compare with your own hopes for your patients?

## Hope and Cure

In the film, Dr. Crawford says: “Sometimes hope can be a cudgel that parents are pounding themselves and everyone else with saying, ‘We can’t give up because of the hope that you know the MDA or other people are gonna come up with a miracle.’ And it’s like, ‘Yeah, but in the meantime we’ve got some real suffering going on and how much are we going to make these kids suffer as a consequence?’”

Explore the following questions with small group members:

- What categories of treatment do you think patients and families hope for? (Prompts: cure for the disease, relief of certain symptoms, addressing issues related to quality of life or emotional/physical pain –
- In what ways do your values about hope affect your assessments regarding treatment, including cure for patients with DMD?
- How do we navigate when we have different visions of treatment?
- In what ways does the tension between multiple visions of hope and cure impact QOL for patients, family members, and physicians?

In the film, Dustin’s mom says “It makes me mad” when referring to messages she’s received regarding a possible cure.

- How do you/we manage expectations regarding hope and cure through our communication with patients and families?
- How do we assess how our message is being received by patient families?
- If your team is involved in clinical trials, how do you manage keeping up hope/energy for participation while also helping to ensure that families have realistic expectations for trial outcomes?
- What role can palliative care efforts play in responding to the tension between hope and cure?

### **Application to Self and Home Institution (5 min)**

- How could you add to your practice ways to encourage hope?
- Regarding what we have discussed during this group, what change would you like to see/make at your home institution?

### **References:**

Keene Reder, EA & Serwint, J. “Until the Last Breath: Exploring the Concept of Hope for Parents and Health Care Professionals During a Child’s Serious Illness,” *Archives of Pediatric and Adolescent Medicine* 163(7) July 2009.

## **Appendix Module 4: Paradox of Promise**

### **Description**

Use this short module to supplement the “Many Faces of Hope” module. Paradox of Promise explores the effects of the promise of a cure alongside various types of hope experienced by all those affected by Duchenne Muscular Dystrophy.

### **Time Estimate**

20 minutes

### **Structure**

5 minutes	Introduction
10 minutes	Show Video: Paradox of Promise
5 minutes	Debrief

### **Show Video: Paradox of Promise (10 minutes)**

- Reflect on the concerns raised in the video. How might you address these in your work with patients with DMD?

### **Debrief**

# Module 5

## Listen to Me

### Description

“Listen to Me” examines the important complexities of communication among patients, doctors, and family members affected by Duchenne Muscular Dystrophy, including the role of adolescent decision-making, informed consent and the boundaries of parental and clinician authority.

### Time Estimate

~45 minutes – 1 hour

### Structure

5 minutes	Introduction
8 minutes	Show Film 2: Listen to Me
2 minutes	Individual Reflection (Optional)
15-45 minutes	Group Discussion
5 minutes	Application to Self and Home Institution

### Themes

- Communication
- Decision-making
- Boundaries of parental and clinician authority

### Learning Objectives

- Recognize the importance of empowering adolescents and parents to make choices regarding day-to-day as well as long-term concerns regarding medical treatment.
- Acknowledge that caring individuals may differ in their assessment of what is in the child’s best interest, because such assessments are not simply matters of fact, but opinions based on experiences and personal values.
- Recognize the significance and complexity of practitioners sharing the moral burden of decision making with parents in the palliative care setting.

*(Facilitator Note: One of the major facilitation challenges for this session is managing the tension between “getting through the session” in terms of covering all the material vs. allowing group process to direct the flow of the session. Another is managing group discussion when members have strong feelings or opinions. If you find that the discussion veers too far off course, you might choose to make comments as a participant to re-focus the conversation.)*

## Introduction:

The goal of this session is not to debate the effectiveness of spinal surgery as a treatment for scoliosis in patients with DMD. Rather, the discussion about spinal surgery is used to explore the boundaries of informed consent—particularly the unintended consequences of a treatment—with patients and families. Alert participants that informational resources are available, but that the focus on the discussion will be on the issues that arise from their experiences with decision making and informed consent.

**(Facilitator Note:** *The following are resources regarding the timing and implications of spinal fusion surgery available from the Muscular Dystrophy Association’s website:*

- <http://www.mdausa.org/publications/quest/q41scoliosis.html>
- <http://www.mdausa.org/publications/Quest/q94checklist.html>
- <http://www.mdausa.org/publications/Quest/q94ahead.html>
- <http://www.mdausa.org/publications/Quest/q94medicalperspective.html>
- <http://www.mdausa.org/publications/Quest/q94wheel.html>

### Show Film #2: Listen to Me (~8 min)

#### Individual Reflection (3 minutes)

Give 3 minutes for individual reflection on the film. Ask participants to write responses to the following questions:

- What are your initial responses to this film? What surprised you?
- What are your thoughts about what being listened to means for patients, parents, and clinicians in the film?

**(Facilitator Note:** *This film is not intended to suggest that clinicians fail to listen to patients, but rather to point out the ways that we may not be hearing each other clearly or missing opportunities to improve our communication with each other.)*

#### Group Discussion (15-45 min)

- What does “listen to me” mean for patient? Family members? Professional caregivers?

**(Facilitator Note:** *Solicit responses from participants - be sure to invite quiet people to contribute)*

### Shared Decision-Making, Different Concerns

Notice that in Film 2, each individual says something different about the spinal fusion surgery:

Doctor: “I push pretty hard - I can’t bear to see these kids the way they were”

Patient: “I used to be able to do... I didn’t know I wasn’t going to be able to...”

Parent: “They didn’t tell us this was going to happen...”

Ask participants to consider:

- What concerns do you think needed to be heard from each individual? Doctor, patient, parent...

**(Facilitator Note:** Each individual was concerned about a certain Impact on their quality of life – doctor wanted to confirm that the patient and family understood the long-term consequences of not doing the surgery; patient wanted to hear what will this mean on a day-to-day basis regarding what matters to me – playing video games, opening doors; Parent wanted to hear about the practical care-giving aspects – feeding, toileting, and the meaning of those things to a parent as they watch child suffer.)

#### Spinal fusion surgery impact on QOL

Patient	Family	Clinician
Day-to-day function Limitations: video games, dress myself Pain	Practical care-giving Couldn’t feed himself w/out special implements	Long-term cons of scoliosis; suffering without surgery What will happen without surgery

- Ask parent in the group:
  - What do you think this parent was concerned about regarding spinal fusion surgery?

**(Facilitator Note:** If answers focus on parent and clinician interaction, ask “What about the physical and emotional impact of these decisions on you, as a parent?”)

- How does deciding to have the surgery align with your perception of being a good parent?

#### Honoring all voices

Jo (mother of Ben) says in the film: “Parents know their child better than the doctors know. The doctors might know the disease, but they don’t always know the disease pertaining to the child. A good doctor, in my opinion, is someone who listens to the parents.”

- How do you honor what parents know about their child and their family while making medical decisions?

- Is it possible for parents to represent the best interests of their dependent children and make decisions that conflict with medical advice?
- What does “shared decision-making” mean in this scenario?
- How much should we push patients and family members, in general? When is it ok to push? How do we know when to push or not push?

**(Facilitator Note:** “When clinicians feel as if parents are not listening to their advice or parents do not feel like their concerns are being heard, a counter-productive cycle can begin. Let’s explore how we respond to that...”)

Jo says: “When I got to look at Ben’s medical records years later, the things that were written about me in those medical records were not very flattering– over-reactive, overly emotional, demanding.”

- What arises for you when you think about families you cared for who you might have perceived as over-reactive, overly emotional, or demanding?

**(Facilitator Note:** Invite participants to reflect on what they noticed about their thoughts, feelings or body sensations—e.g. do they feel tightness anywhere? What is the feeling tone? What thoughts are prominent?)

- When parents start to feel “demanding” to you, what do you start to think about yourself? What kinds of feelings do you associate with those interactions? (Prompts: Incompetence, not trustworthy, stressed by time... More anxious? Insecure? Questioning your abilities? Questioning the scientific knowledge in general? Feeling like a failure? Not being a “good” clinician?)
- In those situations in which you have perceived families behaving this way, what do you think they were needing?
- **Ask parent in the group:** Have you ever been in that situation? Have you ever felt you were being seen in a negative light when you were trying to do the “right” thing or be a “good” parent? What were you wanting? What would have helped in those situations? What was NOT helpful?
- How do we acknowledge someone trying to be a “good parent” when we feel they may be “demanding” or displaying behaviors that bother or annoy us?
- How do we, as professionals, not “turn off” regarding parent concerns when our job is to constantly address and dismiss concerns? (Prompts: Problem-solving, listening, reassurance, acknowledgement of suffering, asking questions, calling the social worker; reconcile these different perspectives/needs when each individual is trying to be a “good” doctor, “good” patient, “good” parent...)
- What do clinicians need in these situations? A good place to acknowledge their suffering and distress in a compassionate way.

**(Facilitator Note:** *Pause for a moment to reflect on what is arising for people during this section. Invite people to notice their responses and to let them go before you continue to the next section.*)

### **Shared Decision-Making – Pushing the Limits**

In the film, Dr. Crawford says: “Everybody’s got to talk to everybody. Everybody has to have the ability - that means the resources and the time and the support, to be able to talk to each other. And then we also have to have the humility and forgiveness in letting other people make mistakes, because all the time I forget this or mess up that and I know the moms do and certainly the kids mess up and doctors and therapists do, too.”

- To what extent does your institution’s team communicate about the complexity of treatment decisions?
- What helps you to you listen to what the parent is saying to you when it is at odds with your advice?
- When parents make decisions that are at odds with your advice, what do you typically do in that situation? (*Prompts: Give more information, postpone intervention, let go of your agenda...*)
- What would help you to be able to remain in the relationship with the parent in the midst of conflict?
- At what point are you able you let go of your own concerns/agenda?
- How do you balance letting go of your concerns and wanting to prevent mistakes or cause harm?

### **Application to Self and Home Institution (5 minutes)**

- Regarding what we have discussed during this group, what change would you like to see/make at your home institution?
- What would facilitate those changes? What are some barriers?



# Module 6

## Unexamined Distress

### Description

Use this module to investigate the forms of distress encountered in patients with Duchenne Muscular Dystrophy – both those that are frequently addressed and those that are often ignored.

### Time Estimate

~45 minutes – 1 hour

### Structure

5 minutes	Introduction
8 minutes	Show Film 3: Unexamined Distress
2 minutes	Individual Reflection (Optional)
15-45 minutes	Group Discussion
5 minutes	Application to Self and Home Institution

### Themes

- Pain and Suffering

### Learning Objectives

- Identify the range of challenges that are commonly discussed as well as those that are not as prominent in the care of children with DMD
- Identify how palliative care can address physical and emotional pain experienced by patients and their family members

#### Show Film #3: Unexamined Distress (~8 min)

#### Individual Reflection (2 min)

- What are your initial responses to this film? What surprised you? What did you take away from the film?
- What areas of distress do you most often ask about? Which areas of distress do you avoid asking about?
- What are your own areas of distress that go unaddressed?

#### Group Discussion

## Physical and Emotional Pain

In the film, Dr. Crawford says: “It’s clear that they (patients) have reasons to hurt and they also have reasons to be terrified of the world. And that’s gotta hurt. Both in the physiologic sense and in the more psychic sense.”

- What are the physical and emotional challenges that are typically talked about and acknowledged with patients? Parents/family? Professional caregivers?
- How are physical and emotional pain discussed differently?
- Sometimes patients and family members have difficulty talking about their emotional pain due to the burden of the physical pain. How do you and your team address emotional pain of patients and family members?
- What fears do you have about exploring these issues?

## Unexamined Distress

	<b>Physical</b>	<b>Emotional</b>	<b>Other</b>
<b>Patients</b> <b>Ben</b> <b>Dustin</b>	Example Statements: <i>Pain like being stabbed</i> <i>Sleeplessness</i> <i>Immobility</i>	Example Statements: <i>Isolation</i> <i>“I feel empty inside because I can’t do much”</i> <i>“Can’t do things for myself”</i> <i>Dependence</i>	Example Statements: <i>Discrimination: disability bias; social isolation; cognitive impairment</i>
<b>Family</b> <b>Tim</b> <b>Jo</b> <b>Grace</b> <b>Megan (sibling)</b>	Example Responses: <i>Waking from sleep, no matter how tired you are</i>	Example Responses: <i>You can’t do anything right</i> <i>“Do it without complaining”</i> <i>Burden – mixed opportunity</i> <i>Sibling - invisible</i>	
<b>Clinicians</b> <b>Tom Crawford</b>			

- What are physical and emotional challenges/burdens that may often go overlooked or **unexamined** for patient, parents, and siblings? (Prompts: Depression, isolation, anger, grief, perception of cognitive ability, and others.)
- Think of a patient who has different needs than the patients in the film. What needs might you be missing in their care?
- What are the consequences of not addressing these unexamined burdens?
- What could be done to make these areas of concern part of routine assessment and care?
- How might discrimination or unexamined assumptions show up for these patients and families when addressing their physical and emotional pain? (Prompts: Perception of decreased cognitive ability of adolescent, lack of decision making capacity based on age, disability equates with lowered expectations for life, normal developmental needs are unimportant when a person is physically disabled)
- What is the impact of DMD on the family? How do we acknowledge and address this impact?

### **Application to Self and Home Institution (5 min)**

- What can be done better in your institution to raise awareness about these issues and to improve care? (Prompts: Educational sessions to raise awareness, involvement in of different disciplines in understanding these issues (i.e. child life, social work, chaplains), new care processes such as involvement of pain service or other discipline in developing treatment plans, etc.)

**(Facilitator Note:** Encourage clinicians to ask questions such as: What gives you joy? Where do you find your strength?)

- Regarding what we have discussed during this group, what change would you like to see/make at your home institution?

# Module 7

## Ethical Challenges in Duchenne Muscular Dystrophy

### Description

This module explores the ethical dilemmas faced by professionals from different disciplines who care for children and adolescents with Duchenne Muscular Dystrophy.

### Time Estimate

25 minutes

### Structure

5 minutes

Introduction

15 minutes

Show Video: Ethical Challenges in Duchenne Muscular Dystrophy

5 minutes

Debrief

**Show Video: Ethical Challenges in Duchenne Muscular Dystrophy (15 minutes)**

**Debrief**

# Module 8

## Transitions

### Description

“Transitions” provides a glimpse into the difficulties presented by the complex transition between childhood and adulthood for adolescents with Duchenne Muscular Dystrophy.

### Time Estimate

25 minutes

### Structure

5 minutes

Introduction

28 minutes

Show Video: Planning for a Lifetime of Happiness, Not Just a Happy Childhood

5 minutes

Debrief

### Learning Objectives

- Understand the importance of emphasizing long-term quality of life with adolescents living with DMD
- Recognize that transition from childhood to adulthood presents similar milestones in those with DMD and those without DMD
- Identify ways that healthcare can effectively equip individuals with DMD with the skills needed to transition to independence

**Show Video: Planning for a Lifetime of Happiness, Not Just a Happy Childhood (28 minutes)**

### Debrief

# Module 9

## An Uncertain Future

### Description

This module raises the challenges associated with acknowledging and discussing death with children and their families, one of the toughest responsibilities of clinicians caring for adolescents with Duchenne Muscular Dystrophy.

### Time Estimate

~45 minutes – 1 hour

### Structure

5 minutes	Introduction
8 minutes	Show Film 4: An Uncertain Future
2 minutes	Individual Reflection (Optional)
15-45 minutes	Group Discussion
5 minutes	Application to Self and Home Institution

### Themes

- Pain and Suffering
- Decision-making
- Communication

### Learning Objectives

- Identify a range of challenges that practitioners face in regard to communicating openly about the anticipated death of a child or adolescent, and ways that such challenges may be addressed.
- Recognize the importance of respecting adolescents by disclosing information about the nature and severity of their illness to them.
- Understand the emotional challenges inherent in bearing witness to the experience of children, adolescents, and families in these difficult conversations.

### Introduction (5 min)

This session raises one of the toughest challenges practitioners have in pediatric palliative care, i.e., dealing directly with children who are dying and who want/need to talk about their own dying. The session challenges participants to reflect upon their own experience with these difficult conversations.

**(Facilitator Note:** For some participants, it might be more comfortable to critique the physician on the videotape rather than to relate what they are observing back to their own practice. The facilitator must be prepared to actively encourage participants to explore their own practice and feelings. There may be points in the discussion where you will choose to support/assist them in this process.)

Group discussion will likely also raise important issues about intimacy between practitioners and children/families, leading to discussion about professional boundaries and the challenge practitioners face to be authentic, intimate, and “professional” simultaneously.

**(Facilitator Note:** These are challenging personal/professional issues not often discussed in professional settings. The facilitator must be prepared to frame and explore these issues with group members. There may be points in the discussion where you will choose to support/assist them in this process.)

During this session, participants will be referring to the handout on DMD Trajectories. This session focuses on the issues that arise in recognizing that DMD is a life-limiting disease.

**(Facilitator Note:** Invite participants to notice their own responses to the film - thoughts, feelings, body sensations. Because this is an area that clinicians and families may not have explored together, invite everyone to be generous to themselves and each other during this session.)

#### **Show Film #4: An Uncertain Future (~8 min)**

#### **Individual Reflection (2 min)**

- What are your initial responses to this film? What surprised you? What did you take away from the film?
- What did you notice about your thoughts, feelings, body sensations? What do these tell you about yourself?

#### **Group Discussion (15-45 min)**

## Different Perspectives

	Patients	Families	Clinicians
Film Example Statements	<p><i>"I'm afraid of dying"</i></p> <p><i>"I believe in reincarnation"</i></p>	<p><i>"If I talk to him re: life-threatening part, will he give up?"</i></p> <p><i>"Wheelchair signaled beginning of the end"</i></p> <p><i>"My boy will be taken from me"</i></p> <p><i>"Every day I have with him is special"</i></p>	<p><i>"It's possible to hold two realities in one's head"</i></p> <p><i>"He's living "now"'"</i></p>
Group Responses/Reactions			

- What differences did you see in talking about the future from the perspectives of patient, parents/family members, and professional caregiver?  
(Prompts: *What is the perspective of each? What do each of them think the other one knows (Parent, patient, caregiver)? What do they know themselves?*)
- What are the implications of having those different perspectives? (Prompts: *Impact on family relationships, treatment decisions, treatment adherence, or attitudes*)
- What is your role as a professional caregiver in a situation like this when family members have different views regarding hope and cure?

## Thinking about Living and Dying

Dr. Crawford says: *"You know, it's possible to hold two realities in your head at the same time. One is the hope and one is the reality of what's going on."*

- What is your response to this quote? Does it resonate for you?
- How does this quote relate to the definition of palliative care discussed in the plenary session?

From Film #1 - Dr. Crawford says: *"I think trying to be a human being in the condition where there's nothing medically can be done, that's where the human spirit is the most intense. Where it's expressed the most."*

- What is your response to this quote? In what way does this quote resonate with you?



- What determines a clinician’s capacity and willingness to be present at times like these?
- What is the clinician’s role in the patient/family discussions about death?
- It is difficult to give news with serious consequences or that evokes strong emotions. As a clinician, how comfortable do you feel about your ability to give difficult news in a way that patients/families are able to engage in dialogue about the issues with you?
- How can we talk about death in a way that is not disempowering and hopeless?
- How can we balance truth-telling and hope in the communication process?
- What is the role of clinicians in informing, educating, or encouraging parents regarding options for the child’s life that may not be being actively pursued or expected? (*Prompts: school, college, social activities, etc.*)
- How can we encourage patients and parents to live their lives as fully as they can?

### **To Tell the Truth**

- What is the clinician’s role in the patient/family discussions about the trajectory of the illness?
- How do you, as a clinician, educate the child and/or family about the disease and possible trajectory?

**(Facilitator Note:** Refer to DMD Trajectory handout at end of this guide. Invite participants to reflect on when there are opportunities to discuss these issues.)

- What are some possible reasons that parents might refrain from telling their child his/her prognosis?
- Ethically speaking, what do you see as at stake?
- What are the harms that could be caused by not telling patients the truth about their condition?
- What are the benefits that full disclosure might bring?
- Are there any downsides to full disclosure?
- How do you balance what they need to know vs. don’t need to know?
- What is not being communicated with patients, families, and other clinicians? What is left unsaid?

### **Application to Self and Home Institution (5 min)**

- Regarding what we have discussed during this group, what have you learned about your own relationship to end of life care?
- Regarding what we have discussed during this group, what change would you like to see/make at your home institution?

**(Facilitator Note:** This session may evoke deeper emotional responses. Take time at the end of the session to gain closure and to honor the participants’ willingness to be vulnerable and to explore these issues together.)

# Module 10

## Ethical Landscape/DMT

### Description

This module surfaces the complexity of sharing the moral burden of decision making with patients and parents in the palliative care setting, and offers a tool that can assist in this process.

### Time Estimate

~45 minutes – 1 hour

### Structure

5 minutes	Introduction
16-30 minutes	Ethical Landscape Presentation
20 minutes	Case Study (Optional)
10 minutes	Debrief
5 minutes	Application to Self and Home Institution

### Themes

- Pain and Suffering
- Decision-making
- Communication

### Learning Objectives

- Become familiar with the decision-making tool and identify potential areas for application.
- Learn how to more effectively navigate making decisions involving morally-sensitive issues

**Show Video: The Decision-Making Communication Tool (16 min)**

**Case Study: Duchenne Muscular Dystrophy (20 min)**

We recommend the case study found at the back of this Guide.

**De-brief Plenary: Ethical Framework for Decision Making (10 min)**

- What new insights did you gain about ethical decision-making?
- How might you apply the decision making tool to your clinical practice?
- What new insights did you gain regarding responding to ethical conflicts?
- What lingering questions do you have?

## **Application to Self and Home Institution**

- Regarding what we have discussed during this group, what change would you like to see/make at your home institution?

# Module 11

## On the Edge

### Description

This module explores the lived experience of a life-threatening event for an adolescent, his family and his clinicians. The challenges of uncertainty, disease progression and perspective-taking during and after a 7-week stay in the pediatric intensive care unit are highlighted.

### Time Estimate

~45 minutes – 1 hour

### Structure

5 minutes	Introduction
16 minutes	Show Film 5: On the Edge
2 minutes	Individual Reflection (Optional)
15-45 minutes	Group Discussion
5 minutes	Application to Self and Home Institution

### Themes

- Exploring/Challenging Assumptions
- Values and Decision Making/Perspective Taking
  - Impact of condition on siblings, family cohesion, marriage and parental well being
  - Adolescent's role in decision making
- Communication and Continuity of Care
- Being a Good Parent

### Learning Objectives

- Identify the challenges surrounding actual and anticipated progression of disease including the potential of death, and opportunities for enhanced communication and advanced care planning.
- Uncover the hidden assumptions that clinicians make about each other and the patients and families they care for.
- Develop personal capacities for perspective taking with patients, families and colleagues.
- Recognize and address the ethical challenges in weighing the benefits and burdens of various medical technologies and their unintended consequences for patients and families.

**Show Film #6: On the Edge (16 minutes)**

**Individual Reflection (2 minutes)**

- What stands out for you in this film?
- What connections do you make to your own experience and why?

### Group Discussion (15-45 minutes)

- As you reflect on the film:
  - What resonated with you?
  - Did anything surprise you?
  - Was there anything that made you uncomfortable? If so, what contributed to making you uncomfortable?
- What do you imagine Ben was experiencing during his initial decompensation?
- What struck you about Jo, Tim, and Megan’s initial experience of Ben’s life-threatening event (LTE)? *(Prompts: Explore the impact of not knowing whether Ben would survive the trip to the hospital on all members of the family; explore the role of uncertainty and fear in Tim and Jo’s communication (or lack thereof) with each other that created silence and isolation; explore the fears and uncertainties that Ben and Megan were experiencing.)*

### Exploring/Challenging Assumptions

One of the common features of an admission of a patient with a chronic condition to the ICU is that the ICU clinicians rarely know much about the patient’s history, disease trajectory, family context, or prior decisions. Incomplete information can create gaps in understanding and interpersonal conflicts.

- What assumptions are you making about any of the characters in the film (Ben (patient), Jo (mother), Tim (father), Megan (sister), Dr. Crawford, Dr. McGinley, Beth Wieczorek (nurse practitioner)? Be as specific as possible. *(Prompt: Explore both positive and negative assumptions—list them.)*
- What do you notice about these assumptions? Reflect on other cases where you may have made similar assumptions. What insights can you draw from those experiences and your own reaction to the film? Share your reflections with a partner.
- What assumptions do you think might be made about Ben’s condition and his treatment? *(Prompt: Imagine the kinds of statements that clinicians may make during shift report, handoffs, or rounds that reflect these assumptions.)*

Beth: *“Healthcare providers were shocked by his weight and how thin he was, but really were more shocked that the healthcare workers had not been speaking to the family about this issue prior to that.... It’s very possible those conversations were taking place, but we weren’t aware of that, but still we had a reaction”.*

- If you had seen Ben come into the ICU at his weight of 55 lbs., what kinds of assumptions or judgments might you have made about his weight? *(Prompt: Clinicians may assume: The*

neurologist didn't suggest a G-Tube; the family was in denial about his condition; the parents are neglectful and irresponsible, the parents weren't willing to take on the additional burden of care, etc.)

- How might these judgments/assumptions affect the care of Ben and his family?
- How might they affect collegial trust and communication? (Prompt: How do you imagine that Dr. Crawford and Ben's parents might react to feeling misjudged by the ICU team?)

Dad: "We resisted Dr. Crawford's initial recommendations to start a direct stomach feed because we didn't want to put him under another operation after a couple of other major operations... and I didn't want to go to that next level of care..."

- What is your appraisal of Tim's statement? Notice the tone of your response. Positive, negative, neutral?
- What do you notice about your own responses when others (patients, families, other clinicians) make decisions that are different from your own?
- What are some ways that the tendency to make negative assumptions and judgments can be prevented or overcome? What practices or systems need to be in place to challenge assumptions and judgments? (Prompt: Routine assessment of prior communication with patient/family and other specialties, informal conversation, systematic inquiry in rounds, routine family meetings, forums to explore assumptions and judgments etc.)

### **Values and Decision-Making/Perspective-taking**

This film highlights the importance of understanding the benefits and burdens of caring for a boy with DMD. Perceptions of benefits and burdens vary based on one's perspective.

Each member of Ben's family shares some of how Ben's condition has affected them.

- What is the impact of the condition and technological interventions on each family member?

### **Parent's Perspective**

The technology that saved Ben's life also brought associated costs in quality of life and independence. The feeding tube, for example, has had a positive impact on Ben's weight and overall health (e.g., reduction of pain) but a negative impact on home life burden (i.e., having to manage his feeding tube, he is heavier to lift and carry, etc.). The benefits and burdens of his treatment extend beyond his physical care to the impact on the quality of life of each of his family members—their relationships, home life, school experience, etc.

Mom: "I said thank you for your information, but what you're saying is major life-changing stuff. I have to prepare Ben, his sister, his father, the school, his friends because up until 2 weeks ago, Ben was just

*a kid in a wheelchair and that was bad enough for him. It takes from 5:30 – 7:15 to get him ready for the day...”*

- What insights can you gain from this statement by Ben’s mother?
- What are some other trade-offs in terms of benefits and burdens for Ben and his parents? (Prompt: *Ben has lost arm function so he can’t feed himself anymore. Cough assist and ventilator support requires much more involvement by family members.*)
- What might some of the tradeoffs be in terms of family cohesion, marital relationship, and parent wellbeing? (Prompt: *Consider the impact of the parents rarely seeing each other during the hospitalization because they live so far away and one of them always had to be home to care for the other child and home responsibilities. Consider the impact of the hospitalization and discharge with new technology on family stress.*)
- To what extent should clinicians proactively recognize and respond to the impact of hospitalization and chronic condition on parents and family?

### **Ben’s Perspective (Adolescent Boys Living with DMD)**

- What do you think Ben is thinking and feeling about his illness, his prognosis, and his experience with the health care system as a result of his ICU admission? (Prompt: *Angry, sad, disappointed, scared, anxious, isolated, helpless, ashamed, trusting, grateful*)
- To what extent do clinicians attend to the thoughts and feelings of children and adolescents with Duchene Muscular Dystrophy when they are hospitalized? What role does or should age/maturity play in how we attend to the needs of hospitalized adolescents? (Prompt: *As Ben watched his O<sub>2</sub> stats drop on the monitor, his anxiety increased because of his awareness of the tension present for the medical team regarding the drop in oxygen. No one (except Jo) seemed to notice that his anxiety contributed to his breathing difficulties.*)
- Whose role or responsibility is it to understand a child’s personal thoughts and emotions? (Prompt: *everyone? Nurses, social workers, child life specialists, doctors, psychologists?*)
- What would help clinicians to be able to recognize and explore a child’s personal thoughts and emotions? (Prompt: *Routine assessment, taking time to understand and inquire into the experience of the patient, explaining what is happening, giving the patient some control over their environment etc.*)
- To what extent would orienting patients like Ben to the technology, sights and sounds in the ICU influence his anxiety? (Prompt: *Explore how to overcome rote explanations in order to individualize information to the unique needs of the patient.*)

Ben says: *“It would be nice to be involved in something that has to do with me because I know more about my body than anyone else does... I just felt like I couldn’t trust anyone. I thought I was the only one who could help myself.”*

- What kind of role does or should Ben have in decision-making about his care?

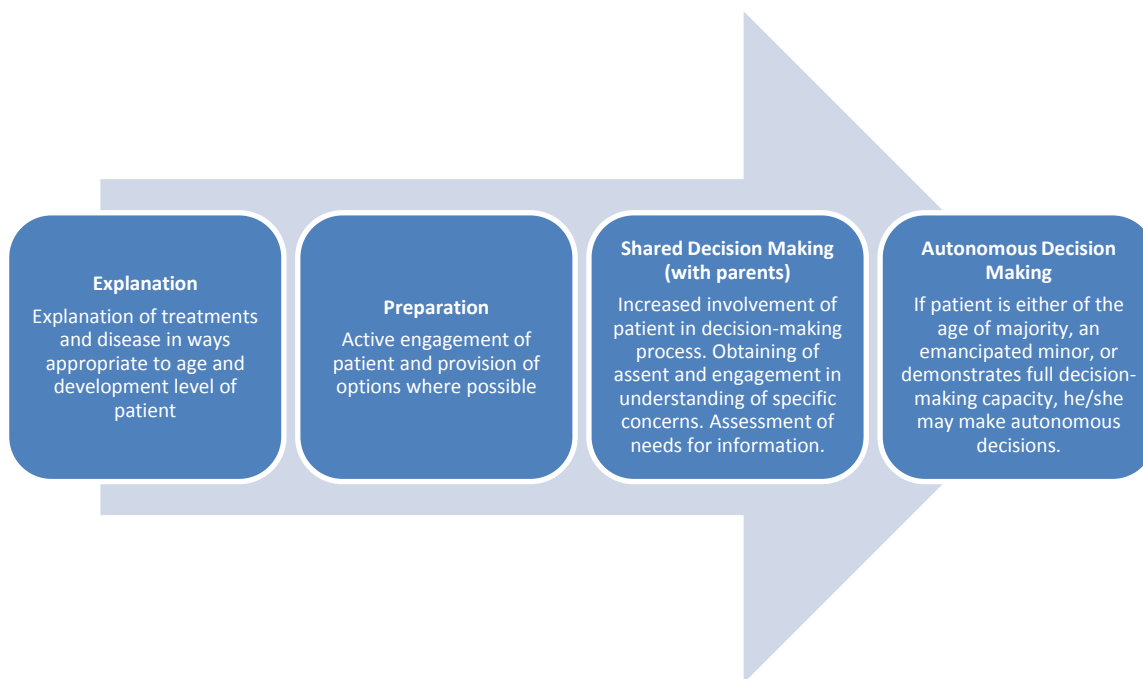
## Assessing Decision Making Capacity

- Given what you observed about Ben, to what extent does he have decision-making capacity? How would you assess this?

**(Facilitator Note:** Refer here to article on assessment of DMD by Mark Hughes, which can be found here: <http://journal.publications.chestnet.org/article.aspx?articleid=1086272>)

- What are some ways that we can involve Ben more fully in communication and decision-making about his care? (Prompt: Explore the missed opportunities to engage Ben and other boys like him more fully.)
- Given the child's developmental and cognitive capacity, they may participate in a variety of ways. On the continuum below, consider where there are opportunities for involving Ben more fully.

**With increasing age and/or cognitive capacity:**



## Impact of Cognitive Impairment

Considering that cognitive impairment can accompany DMD, the capacity for adolescent decision-making can vary.



- How does or should cognitive impairment affect adolescent's role in decision-making and advanced care planning?
- Even normal development can be stunted in terms of independence and decision-making. Achieving independence and autonomy for children with chronic illness is complicated because they are reliant upon their parents for basic needs.

Ben: *"To put a lot of things on my parents, I don't really like. It doesn't seem fair on them. It doesn't seem fair on me. It's just a horrible feeling. Kinda frustrating to know that I lost more strength from being in the hospital, I have to have people feed me... It just makes me angry sometimes."*

- To what extent should an adolescent boy's physical and emotional dependence alter his role in decision making? (Prompt: Not at all; he is not independent and his parent's interests should be given more weight; he is not in a position to override his parent's decisions; he should not have a significant role.)

### **Sibling's Perspective**

Siblings of boys with DMD experience their own challenges.

Megan: *"A lot changed when he got home. It was more hectic. I just didn't want to be home so I spent Thanksgiving at a friend's house and away from my family because I didn't want to be with them because they were all about him. I felt left out. They were yelling and it was really just hectic. It was a catastrophe."*

Megan: *"I thought he was going to die."*

Megan: *"I can't do stuff with my siblings. I can't go play sports and throw a ball around with them like my friends can with their siblings."*

- To what extent do clinicians attend to the thoughts and feelings of siblings of children and adolescents with Duchenne Muscular Dystrophy?
- Whose role or responsibility is it to understand a sibling's personal thoughts and emotions? (Prompt: everyone? Nurses, social workers, child life specialists, doctors, psychologists?)
- In what ways should Megan's perspective be taken into account in determining the best course of treatment for Ben? (Prompt: Not at all; should be considered in the context of the whole family; should have significant weight.)

### **Clinician Perspective**

Dr. Crawford: *"DMD is relentlessly progressive. We expect things to be lost every increment of time. Something has to be given away..."*

- What feelings is Dr. Crawford expressing? What are you feeling in response?
- Given this reality, how do you address your own feelings about the reality of the progression of DMD? (Prompt: Explore the effect of cumulative loss on clinicians' effectiveness in working with children and families where the options for benefit are limited by the disease trajectory.)

In response to Ben's life threatening event, Dr. Crawford says: "Ben's parents were not ready for this. They were scared... I don't think you can ever prepare somebody for having your child throw up blood and look deathly ill. There's no such thing as preparing for that."

- To what extent do you think it is possible to prepare patients and/or family members for the kind of life threatening incident described in the film? (Prompt: Explore the difference between preparation for a series of conceivable life threatening events at some point in the future, and being able to accurately predict and prepare for a specific life-threatening event? In Ben's case, it was predictable that he would have a life-threatening event that involved respiratory distress, but it was not as predictable that he would have a life-threatening event that involved throwing up blood. Dr. Crawford may be correct in his assertion that you cannot prepare for the latter but we can provide anticipatory guidance regarding the former.)
- If this is true, what kind of preparation would address both their informational and emotional needs?
- To what extent do clinician's fears and emotional responses:
  - Influence their appraisal of parental readiness to consider the possibility of a LTE and/or the need for more aggressive interventions?
  - Influence their ability to be responsive to the child and family's experience?
  - Influence their reasoning about appropriate goals of care?
- What do you think are appropriate goals of care for Ben? Why?
- How do you weigh the benefits and burdens?

Beth: "Placing an artificial airway will change the child's life, but I don't know that many providers really understand what that change means..."

Dr. Crawford: "I'm not gonna torture kids with too much stuff in order to sustain some minor function into the future. This is the balance, I think, a clinician has to make: what are the discomforts and what burdens am I going to place on his life now in order to sustain what functions and abilities later on. Is the juice worth the squeeze? Where is the balance made most properly?"

Dr. Crawford: "In retrospect, it would have been nice to have it in, but the only way I was going to move it along was to talk directly to him..., but ultimately it's consent and he has to buy in and say I agree with you."

- What underlying meaning, values, or goals of care may lead patients, parents/caregivers, and clinicians to different decisions in care?

Beth: *“The challenge for those of us in the ICU is to know that Ben may end up in the ICU without technology decisions being made and it’s not because they didn’t try, but sometimes it has to be made in a life-threatening, critical situation than what we would like.”*

- How does the urgency to respond to life threatening events in the ICU, impact the weighing of benefits and burdens and ultimately treatment decisions?

## **Continuity and Communication**

One of the particular challenges of an ICU admission for a boy with DMD is recognizing and overcoming barriers to effective communication and facilitating continuity of care.

### **Continuity**

Dad: *“Every shift brought a different nurse, therapist, different team of doctors. We needed some continuity. The continuity was us.”*

Mom: *“It was getting very confusing. One team was saying one thing, one team was saying another... I felt very alone.”*

- What stands out for you in listening to Ben’s mom and dad describe their experience with a lack of continuity?
- What do you think contributes to patients and parents feeling alone or untrusting of healthcare professionals? *(Prompt: Ben’s mother discovered that it was possible to request a family meeting to address her concerns about the lack of continuity and inconsistent communication among the team.)*
- In what ways can clinicians partner more effectively with parents to understand their needs for information, participation in decision making and support?
- What impact does the lack of continuity among the teams and specialists have on you as a clinician?
- How might this lack of continuity for the patient and family affect how they respond to you as a clinician or how they respond to decisions they need to make?

### **Communication**

- What do you find most challenging about communicating with families and children with chronic conditions like DMD, particularly during LTE’s? *(Prompt: Uncertainty about prognosis, parents understanding, goals of care; conflicts between parents and clinicians; lack of time; etc.)*

- Are there differences among the disciplines (physician, nurse, social worker, etc.) in communicating with children and families about LTE's? If so, what is the nature of these differences and what might explain them?
- What do you think enables patients and parents to feel that their perspective and preferences are being shared with practitioners in this kind of situation?
- What do you think contributes to patients and parents feeling that they are being heard, and trusting that healthcare professionals will act in alignment with patient/family preferences?

It is our ethical responsibility as healthcare team members to communicate appropriate benefits and burdens regarding medical decisions with families. One of the challenges conveyed by this film is how to reconcile potentially competing clinician obligations to give information that is balanced in terms of benefits and burdens and also aligned with patient/family goals.

Brian: *“There was never a conversation of, ‘You have to do this, but here are the options.’ Our job is to discuss those options – the benefits to them, but also the downside.”*

- What principles/values should guide our actions in these cases?

### **Being a Good Parent**

Parents of a child with a chronic, life-limiting condition experience the full range of emotions. These emotions, though perhaps heightened during a hospitalization for a life-threatening event, are always present.

Tim (Dad): *“Especially in times when the routine (of caring) gets too hard to bear and I think I’d be happier if it was over and if I didn’t have to do it...”*

- What thoughts and feelings do you think Tim is communicating?

*(Prompt: Sadness, anticipatory grief, anger, guilt, resentment, anticipatory relief etc.)*

- To what extent to any of these thoughts or feelings surprise you? Why or why not?
- Do Tim’s thoughts fit with our assumptions about being a “good dad”?

Mom: *“I felt like I was drowning. I could never judge, ever again, say, ‘How could that mother walk away from that family? How could that father just walk away from that child?’ Because the effects are so deep, the foundations of my family are cracked. The buildings haven’t fallen down yet, but the foundations are cracked. I’m trying really hard to make sure it doesn’t go any further than that. People say to me you’re such a strong woman, I don’t know how you do it. Well that puts a big burden on my shoulders.”*

- To what extent do Jo’s thoughts and feelings surprise you? Why or why not?

- To what extent do Jo’s thoughts fit with our assumptions about being a good mother?
- How did you feel “witnessing” her reaction? What meaning do you attach to her strong emotional expression? (*Prompt: sorry for her? Scared for her? Like you were intruding on her private experience? That she’s not as strong as she appears; she’s decompensating; she’s decompressing her feelings, etc.*)
- To what extent does the last scene of the film alter your thoughts about whether Jo is “a strong woman” or a “good mother”? (*Prompt: What are the consequences of labeling people as “strong” or appraising them as “good” parents?*)
- What do you think Ben and his family would feel that it is important for health care professionals to know about them as a family and as individuals?
- What additional skills and support do clinicians need to be able to know the unique vulnerabilities and needs of their patients and families? (*Prompt: Explore how clinicians might be able to expand their repertoire of skills to partner with families in “healing their cracks” even if we are unable to cure their disease.*)

### **Application to Self and Home Institution (5 minutes)**

- Regarding what we have discussed during this group, what change would you like to see/make at your home institution?

# Module 12

## Moral Angst: The Heartache of Healers

### Description

This module is designed to explore the internal responses (moral, emotional and spiritual) of clinicians who care for children with Duchenne Muscular Dystrophy as they confront intense suffering and moral angst. Often unrecognized, these responses have a profound impact on the clinicians themselves, their interactions with patients, families and their colleagues.

### Time Estimate

~45 minutes – 1 hour

### Structure

5 minutes	Introduction
16 minutes	Show Film 6: Moral Angst: The Heartache of Healers
2 minutes	Individual Reflection (Optional)
15-45 minutes	Group Discussion
5 minutes	Application to Self and Home Institution

### Themes:

- Showing your humanness
- Trust
- Control/powerlessness
- Helplessness
- Collegial betrayal and inter-professional anger.

### Learning Objectives

- Appreciate the importance of moral, emotional, and spiritual reflection for clinician well-being.
- Acknowledge the interplay between clinician well-being and the care of patients and families.
- Identify personal and professional challenges in appropriately caring for patients and family members during times of intense suffering.
- Develop awareness of one's common responses to patient/family suffering.
- Apply selected strategies to cultivate clinician resilience.

**Show Film #6: *Moral Angst: The Heartache of Healers***

## Individual Reflection

- What stands out for you in listening to these professionals discuss their experiences?
- As you think about the participants responses, which comments do you identify with and why?

**(Facilitator note:** Participants can write their responses or reflect silently.)

## Group Discussion

### Show Your Humanness

The physical therapist says: *“Touched by death more than expected...”*

- Have you ever been surprised by your emotions for a patient? What does this mean for you?
- Participants in this film remind us how challenging it can be to stay connected to families during times of intense suffering.
- In reflecting on your own experience, what sensations do you notice in your body? What emotions arise? What thoughts do you associate with your experience? What do you make of these?

Reflect on the following quote by a pediatric neurologist: *“No better way to connect to parents is this humanizing... To show that this is difficult for you – there’s nothing more powerful.”*

- Do you agree? Why or why not?
- What does “being human” mean for you?
- In what ways does exposing your humanness to patients and families support your role as a clinician? In what ways might such exposure undermine your role?
- What are the potential benefits and harms of showing your vulnerability as a clinician?  
(Prompts: Showing vulnerability as a way to connect with patients; appearing invulnerable can disconnect us from our humanness)
- Do you feel that patients want to see your vulnerability or do they want to see you as strong and knowing all the right answers?
- Do you feel it is in the best interest of the patient/family to show your vulnerability? Why or why not?

*“Need balance so you have bedside manner, but competence.”~ Physical Therapist*

- What does this statement mean to you? (Prompt: What does balance mean in this context?)
- What are different ways of being with patients and families? (Prompts: Strong, empathic, vulnerable, distracted, engaged, caring, humble etc.)

- In reflecting on your own practice, do you notice a pattern of your own comfort in showing your humanness to patients and families? If so, share your experience of a specific instance where you shared your humanness or when you did not.

**(Facilitator note:** *this can be done by written reflection if you are alone, in dyads or in small groups.*)

- What does it mean to balance different ways of being with patients and families? What is potentially in conflict? *(Prompts: Balance of vulnerability and confidence)*

Dr. Crawford (Pediatric Neurologist) says: *“I want to make certain we keep human life going in the face of... technical proficiency. We get things done absolutely perfect but we miss the fact that these kids aren’t gaining as a consequence... [when we lose sight of our goal], this technical proficiency is empty.”*

- Can you identify any situations from your own experience where there was a tension between technical proficiency and humanness? What were the consequences for you personally? Professionally? *(Prompts: Dr. Crawford implies that without our humanness, our technical proficiency is meaningless and makes us feel empty—to what degree can you identify with his experience?)*

The nurse practitioner says: *“The most important thing... is honesty, in terms of what you’re thinking, what you’re feeling, openness in terms of having conversations that are sometimes painful should be had, and just staying with the family. Taking the journey with them as they experience their child’s illness and health.”*

- What are some practical ways you stay connected to families during times of intensity?

## **Trust**

*“You can’t take care of patients with long-term medical conditions without trust... “*

- How would you define trust in the patient/provider relationship?
- How do you build trust in your relationship with the families you care for?

Physician says he asks parents: *“Do you trust what I’m saying to you?”*

- Have you had the experience of imagining, or being told, that the patient/family does not trust what you are saying? *Facilitator note: share the experience in a writing reflection, in dyads or small groups.*
- What feelings arise when you think a patient or family do not trust something you did or said? *(Prompts: Anger, resentment, guilt, helplessness, fear, uncertainty, etc.)*



- How do these responses impact the way you feel about yourself? Your work? Your interactions with patients and families? (Prompts: *threatens your competence, questions your certainty, undermines trust*)

*“Important part of trust is... you make mistakes, you share personal thoughts, or be honest and say ‘I don’t know’.”*

- Do you agree with this statement? Why or why not?
- What feelings arise when you imagine saying “I don’t know” to a patient/family? (Prompts: *Fear of judgment/loss of trust or esteem, anxiety about not knowing the answer or being wrong, shame, guilt, etc. On the positive side—authentic, honest, unburdened, calm, etc.*)
- How do these feelings impact the trust between you and your patients?
- To what extent does your ability to tolerate ambiguity and uncertainty impact your ability to trust yourself? Trust others?
- The following section explores in greater depth, common responses to suffering. Although the questions are specific to Muscular Dystrophy, they can be modified for clinicians who care for children with other types of life limiting diseases.
- Recall a time in your care of patients with Muscular Dystrophy who are experiencing a life-threatening event.
  - What did notice about your own response? (Prompts: *typical response might be: “I want to get away from it” (flight), “I get angry” (fight), “I feel numb and disconnected” (freeze), sadness, regret, guilt, etc.*)
  - What do you notice in your body? Areas of tightness, relaxation, discomfort, ease? Locate the area in the body where you notice these sensations.
  - Notice the thought patterns that accompany the memory of your experience. What is the nature and tone of your thoughts? Spacious? Positive, Negative, Painful, etc.?
- What are some ways that you have found to remain connected to yourself and your patient/family during times of intense suffering? (Prompts: *What do you rely on for support during these times?*)
- What are some of the challenges to remain connected within yourself, your team and your institution? (Prompts: *time, cumulative stress, moral distress, burnout, grief, etc.*)

## Helplessness

The nurse practitioner says: *“Working with families who have a child with a life limiting/life threatening conditions takes staff to an emotional place they’re not comfortable with... they feel helpless regarding how to develop meaningful relationship... which are important so we can make difficult decisions.”*

- What does helplessness mean to you?

- Think of a time when you experienced helplessness in the care of patients with Muscular Dystrophy. What feelings do you associate with this memory? What did you notice yourself saying or doing in response to these feelings? (Prompts: anger, shutdown, abandonment, numbness, disrespect, etc)

**(Facilitator note:** share the experience in a writing reflection, in dyads or small groups.)

- How do these feelings impact your relationship with patients/families and colleagues?

A common refrain by clinicians who are feeling helpless is: “Why are we doing this?” “Should we be doing this?”

- When you hear yourself or your colleagues saying these words, what do think underlines these statements? (Prompts: Is your sense of right and wrong or your integrity as a person and a professional being threatened? Is your professional identity as a “good” nurse, doctor or other clinician being undermined? Are you being complicit in what you perceive to be moral wrongdoing?)
- What are some ways you could address these feelings—individually or as a team?

The ICU nurse practitioner suggests that one way to overcome the feeling of helplessness is to better understand a family as they are outside the hospital.

*“We only see child in the hospital, we don’t see them outside the ICU. That onus is on the staff to get to know that family... to talk to the family... when he feels well, what does he do? So you know that what you’re doing has a purpose. It’s not hopeless, it’s not just doing painful things, making the child suffer... It is sometimes doing painful things, but for an end goal, that the child is going to go back to school and have a happy life. It’s difficult that we don’t get to see that.”*

- In your clinical practice, how might you create, or take advantage of, opportunities to gain a broader perspective on the lives of your patients? In what ways might this influence the ways you interact with, and care for, them?

## **Powerlessness**

The physical therapist says: “You’re supposed to stay hopeful, but the disease makes you feel powerless. Watching someone lose their abilities makes you feel powerless.”

- In what ways do you feel powerless when it comes to treating children with DMD?
- What do you do with feelings of powerlessness? How do you cope with those feelings?
- How does your sense of powerlessness change over time?
- How does that changing powerlessness affect your relationship with patients/families?
- In what ways are hope and powerlessness connected?

One answer to overcoming powerlessness is given in the film: *“In order to overcome powerlessness, you derive energy and get satisfaction out of being there for kids and families if there really is no hope... The more you can get involved in this, the more it helps you to, at least, put the powerlessness to a degree that it doesn’t interfere and bother you so much anymore.”*

- Do you agree with this statement?
- What makes it difficult for members of the healthcare team to acknowledge feelings of powerlessness?
- What changes could be made to the medical culture to allow the acknowledgment of powerlessness in medical care?

The pediatric resident says: *“Different levels of being powerless... I am powerless to cure them which is [a difficult thing to cope with]. Showing that vulnerability to the patient and to the family is actually really difficult – to expose that part of yourself to them.”*

- What is the impact of level of training or position in the hierarchy on feelings of powerlessness?
- Reflect on a time when you felt powerless (because of your role) to address a situation that you were involved in. What actions did you take or wished you had taken. What is the residual from this experience on your current practice?
- How do the feelings of powerlessness impact our willingness and ability to speak up when we identify situations that are questionable or harmful?

### **Being in Control/Fear of losing control**

- As a clinician, what does being in “control” mean to you?
- When does being in control serve you or your patients? When does it not serve?

A pediatric neurologist says: *“I like being in control and trying to make things go as well as possible... kids have complications I didn’t expect, disasters I feel responsible for. Those hurt, I feel like I’ve done something wrong. I messed up. The most disquieting sensation I have is that I have somehow screwed up... That is with me a lot of the time... I don’t usually talk about that too much.”*

- Reflect on a time when you thought you made a mistake, “screwed up” or missed something that was clinically important.
- What feelings, thoughts, or body sensations arise in response to Dr. Crawford’s quote? Jot down your responses.
- Where do you notice this memory in your body? (Prompts: Dr. Crawford talks about the tightness in his chest.)
- What feelings do you associate with this memory?
- What is the thought pattern that you associate with this situation? (Prompts: Dr. Crawford talks about “feeling like I did something wrong—like I messed up”.)

- How do you respond to these feelings and thoughts?
- Have ever talked about mistakes you have made with your colleagues? If yes, what was that like? Was it helpful? In what ways? If not, why not? (*Prompts: Never had the opportunity (scheduling issues, cultural sanctions, etc.), had the opportunity but was afraid, too embarrassed to discuss, fear of losing control etc.*)
- What would it take for clinicians to be able to speak about their mistakes and fears about “screwing up” and/or loss of control?

### **Betrayal/Anger among professionals**

In the following quote, one of the pediatric neurologists suggests that he and another clinician had very different approaches and goals for a child’s treatment: *“Working toward a goal with a family, what are the next steps, and then someone else comes in and it happens often in ICU, you are the primary physician, there are other people who take responsibility for the day-to-day care things, I have worked with a family to get to a point and then someone else gets it off track... I’ve felt really angry...”*

- Reflect on any experiences of conflict you have had with other clinicians regarding differences of opinion or approaches to a child’s treatment?
- What feelings or thoughts arise in response to this situation? (*Prompts: Anger, frustration, betrayal, disrespect, helplessness, challenge to my competence (“they don’t think I know what I’m doing”), undermining my relationship with the family, greater understanding, grateful for new insight, etc.*)
- How do these feelings impact your relationship with yourself, patients/families, and colleagues?
- When clinicians have different role responsibilities (such as a long term relationship with a specialist or an ICU clinician) what steps can be taken to recognize and address sources of conflict and potential feelings of anger and betrayal? (*Prompts: Acknowledge everyone’s expertise and role in the patient’s care; create systems to formally engage all stakeholders in developing the patient’s plan of care; create forums to discuss areas of conflict, etc.*)
- Reflect on other experiences involving your colleagues that have generated strong emotional responses. Describe these situations, the feelings they generated and how you addressed them.
- What seemed to help and what did not?
- What could you do differently within yourself and within your team when you feel angry, betrayed, disrespected etc.? (*Prompts: Develop self-awareness, Develop strategies to promote resilience, develop forums to discuss challenging cases, use ethics and mental health consultants, etc.*)
- In reflecting on your overall experience in completing this module, what has it been like for you to discuss the impact caring for patients with DMD has on your personal and professional life?

### **Application to Self and Home Institution (5 minutes)**

- Regarding what we have discussed during this group, what change would you like to see/make at your home institution?

## Exercises

# Listening

Interactive Exercise (60 minutes)

1. The facilitator invites participants to find a partner-preferably someone they do not already know.
2. Have the partners face each other.
3. Determine the order that each person will speak.
4. Each person will have 3 minutes to share his/her responses to a question.
  - a. The question to be explored: “Share a time when you were able to provide care for a patient with DMD that you were proud of.”
5. The first person to speak will share their experience while the other person listens **silently**. There should not be any cross talk or questions during the time the person is speaking. The listener is invited to bring their whole self into the process and listen deeply to the words of the other person.
6. At the end of 3 minutes, the facilitator will signal the end of the time. The person speaking should complete their sentence and both people remain silent.
7. The roles switch and the listener, becomes the speaker and the speaker listens deeply in the same way as their partner.
8. At the end of the second 3 minutes, the partners will thank each other.

## Debrief

### Speakers:

1. What was it like for you to speak about your experience in this way?
2. What did you notice in your body, emotions and thoughts as you told your story?
3. What was it like to be listened to by your partner?
4. What did you notice that suggested to you that they were listening to you?

### Listeners:

1. What was it like for you to listen to your partner?
2. What did you notice in your body, emotions and thoughts as you listened in this way?
3. What did you notice yourself wanting to do or say?
4. What was your experience of being silent?

# Images of Hope

Interactive Exercise (60 minutes)

## Group Activity

### Supplies:

Provide a collection of images (postcard size works well) that evoke different feelings drawing from nature, art, photographs, and other scenes. Provide an ample supply of images so that there are about twice as many images as the people in the group so that there are plenty to choose from.

**Prep:** Arrange chairs in a circle. Place the pre-selected images on the floor in the center of the circle. Invite members to sit in the chairs in the circle. Place one page of flipchart paper on the wall near the circle. Have tape and post-it notes nearby.

- Invite group members to sit quietly for a moment. When everyone is settled, begin with the first person in the circle; invite them to choose an image from those in the center of the circle that represents hope to them. Each person goes in turn until everyone has an image.
- In silence, ask participants to reflect on their chosen image for 1-2 minutes.
- Go around the circle and ask each member to share in 1 sentence share what this image means to them.

**(Facilitator Note:** *Encourage participants to distill their statements to just once sentence. Example: “This image of mountains represents hope to me because...”*)

- After each person has spoken, pause for a moment and ask group members to briefly reflect on what they have heard from each other.
- Pass out Post-it notes to each participant. Ask them to write one word that represents hope to them (can be related to the image or another word).
- Ask each participant to tape their image and their post-it note word (which they share with the group) onto a flip-chart, creating a group collage. The post-it note can be placed on the collage – either on their photo or somewhere of their choosing.
- When everyone has placed their image and post-it note on the group collage, invite everyone to stand together in front of the collage to reflect on the image and what it evokes for them.
- End the session with a moment of gratitude to everyone for their participation in the activity.



# Exploring Quality of Life

Interactive Exercise (60 minutes)

## Format:

10 minutes	Introduction
20 minutes	Group Introductions
3 minutes	Individual Reflections on Quality of Life
7 minutes	Discussion in Pairs
20 minutes	Group Discussion

## Introduction (10 minutes)

- Your role in this session is facilitator. Welcome participants. Explain the rationale for the emphasis on small group learning across boundaries (i.e., family member/clinician, different disciplines and settings of care).
  - (Refer to *Relational Learning* article on Related References sheet in Participant Notebooks. Facilitator's have one copy of this article to offer to small group participants if they did not have a chance to read the article e-mailed to them ahead of time.)
- Explain that this is the first of six sessions in which the small group will meet:
  - Sessions 1b, 2, 3, and 4 will use small group activities from the curriculum.
  - Sessions 1a and 5 will introduce and close the group's work together.
  - (Refer to Retreat Agenda in Participant Notebook)
- Review general guidelines and groundrules for small group work.
  - (Refer to Participant Notebook for "Responsibilities for Collaborative Learning,")
- Discuss self-awareness, reflective practice, creating safety, vulnerability, taking risks.
- Introduce yourself and the facilitator briefly and review your role as faculty, facilitator, debriefers, and guides.
- Review Learning Objectives of this session: (Refer participants to Learning Objectives for this Small Group that can be found in their Participant Notebook)
  - Recognize the range of individual perspectives on what constitutes "quality of life"
  - Explore the role of palliative care in discussing quality of life for patients and family members

- As you facilitate this session, do your best to make family members in your group comfortable taking part in the discussion. Look for opportunities to draw them into the conversation.

### **Group introductions (2 minutes per participant, 20 minutes total)**

- Explain that the remainder of this session will be devoted to exploring basic values regarding quality of life. Ask each person to introduce themselves in the following way: Please state your name, discipline or role (physician, nurse, family member, etc.), and home institution. Then, please respond to the following question. Ask each person to "distill" their comments into 2 minutes (you will need to monitor the time).

“Please respond to the following prompt, keeping your responses to approximately 2 minutes. Question: The most important thing I have learned in caring for children with life limiting conditions, such as muscular dystrophy, is...”

### **Individual Reflections on Quality of Life (3 minutes)**

**Ask each participant to take 3 minutes to individually reflect and write answers to the following questions:**

1. If you were defining “quality of life” for yourself and/or your family, what 5-6 components would be most important?
2. What *values* underlie your definition of quality of life?
3. When you were an *adolescent*, what meant the most to you regarding your quality of life? Now, think of being a patient with DMD. Would you have been able to experience these things?
4. What would they need to be able to achieve your desired quality of life?

### **Group De-briefing and Discussion (25 min)**

1. What is the “essence” of quality of life? Ask participants to list some of their components of Quality of life –use a flip chart to capture the list
2. Facilitator Note: Use some of the following questions to probe meaning of quality of life.
  - What do you notice about the similarities or differences in your responses about quality of life?
  - How do they compare to what you’ve heard from patients and their family members? What key components/values seem to be critical in defining “quality of life” for a child with disabilities, especially those with DMD?
3. What is the role of hope in quality of life?

4. How can you, as a clinician, help adolescent patients increase their quality of life?
5. How can patients, families, and clinicians have productive and comfortable conversations about definitions of quality of life and the implications for treatment?
6. How might discussion of palliative care contribute to those conversations?

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# Exploring Grief, Meaning, and Self-Care Art Activity

(60 minutes)

## Background

All participants will engage for 30 minutes in an open-ended art exploration around the theme of grief, meaning and self care. After this process, participants will process their experiences and thoughts as facilitated by faculty leaders.

## Exploration of Themes (45 minutes)

Ask participants to share their artwork -- as a product and as a process -- using the following questions to facilitate discussion:

- 1) What was your experience in the art process?
- 2) What images arose in your art process?
- 3) What ideas or feelings did you experience symbolically or concretely in your art process?
- 4) What ideas or feelings do you experience now looking at your artwork around the themes of grief, meaning and self care?
- 5) How does a nonverbal process like art-making inform us regarding the themes of grief, meaning and self care?
- 6) What are the implications of these ideas for communication and partnership with children and families affected by life-threatening pediatric neuromuscular disease?

Note that there are no correct answers to the processing in this discussion. Participants can be encouraged to share their artwork with the group and discuss their experience in both creating the piece and exploring it relative to the themes of this session. Suggestions for facilitation will be discussed in onsite faculty meeting.

## Overall Debriefing (15 minutes)

Ask participants, "How might the kind of learning from this session happen in settings -- both formal and informal -- within your own institutions (e.g., educational activities, rounds, nursing report, lunchtime conversations, family meetings, staff meetings)?"

# Reflections on Ben's Story

30 minutes

Have participants read the following story and respond to the questions below:

OPPORTUNITIES FROM A WHEELCHAIR BY BEN RIVERS ©Ben Rivers, 2010

Imagine a life where people literally do everything for you. It sounds great doesn't it? Well, if I want a drink, someone gets it for me and they even hold the cup! If I want to play a video game, someone puts the disc into the console for me. I have people who bathe and dress me and even clean my teeth for me! When I'm hungry someone gets me food (I don't make it myself) and someone always opens the door for me.

By now you are probably thinking, "Wow, he's lucky" and that I am either a famous person with lots of assistants, an affluent person who can afford all these 'servants' or just a lazy person. Well you would be wrong. I'm not famous (not yet anyway), I'm not lazy (I would love to be able to do everything for myself), nor am I wealthy (my parents are my 'servants'). I do however; have a legitimate reason for all these helpers and all this help. I have a medical condition called Duchenne Muscular Dystrophy or DMD.

I was diagnosed during the week of my fifth birthday and it came as a great shock to my parents and family. DMD is a genetic condition carried by the mother and passed to her son. DMD does not recognize race, color, social status or nationality. I am half English. My mom is an English emigrant who came to this country to marry my dad in 1992. She is not a carrier of DMD so in my case the doctors say, it was spontaneous mutation. A fault occurred on one of my DNA strands which stops my body from producing the muscle protein dystrophin.

I used to be able to walk and run but in the third grade I began to use my power wheelchair which made me happy because it was getting to be very hard work for me to get around.

There have been times when I felt that my life is barren because I have to rely on people to do so much for me, but in fact my life is wonderful! I have everything I need to make my life easier and happier although I am waiting for someone to contrive a device that could help my parents lift me. Taking care of me can sometimes be very hard work for them.

I am a member of the MDA (Jerry's Kids) which is an organization that helps kids like me to get things I need. Every year in June, the MDA has a summer camp that I get to go to and I have so much fun there! I stay for a week and I get to be with kids who are just like me. Everything at camp is free for the campers. All the activities like crabbing, boating, swimming, horse-riding, motorcycle rides etc and even my room and board are free. It's amazing! The MDA can only do this though thanks to kind people who endow monetary gifts each year through the Shamrock Campaign at local stores such as Lowes, Taco Bell, Burger King and KFC.

Every month I attend a teen group where we get together and play games, watch movies or go out to dinner. I always have a lot of fun and laugh a lot when I am there.

I am also an ambassador for the MDA which means I get to go to different places and meet lots of people and thank them for everything they do to support Jerry's Kids and the MDA.

I have also been asked to be in a medical documentary movie that will be shown to doctors all over this country and maybe the world. I will be going to the MDA clinic where they will film me with my doctors and then they are coming to my house to film my life at home. This is a great opportunity for me and I think it will be very helpful for doctors to see what it is really like to live with my condition.

So what does the future hold? Well, I plan on graduating high school with the idea that my vocation will be in video game designing. Who knows though, I may even become the proprietor of my own video game store.

In the meantime, I'm concentrating on enjoying my life, my home, my friends and my family and all the love, fun and kindness that they lavish on me.

### **Discussion Questions:**

- What insights do you take away from Ben's story?
- In what ways does hope play a role in Ben's life?
- How might these insights impact your own clinical practice?

# Closing Activity

(50 minutes)

35 minutes Group Activity/Discussion  
10 minutes Overall Debriefing

In this session you will guide the small group members to complete their experience together. For many participants, the experience of learning in a small group setting may have been quite different from other professional learning experiences. This session is an opportunity for people to reflect on their experience and say their “good-byes” since this will be the final small group session.

**Materials: Shells, dish, retreat evaluations**

## **Introduction and De-Briefing of Art Activity and Transition Plenary (15 minutes)**

- What did you notice about your responses to the art activity? What did you learn about yourself and others?
- What new insights did you gain from the transitions plenary? What opportunities do you see to enhance the experiences of adolescents in their various transitions?

## **Group Activity/Discussion (35 minutes)**

- Thank participants for their involvement in the group.
- Make a few remarks about your own experience in the group and what it was like for you to serve as faculty and facilitator.
- Ask each participant to share what it was like to participate-what surprised and/or inspired them from the retreat. (Hopefully all will do so.)
- Ask each person to consider what others can count on them for when they go back to their home institution regarding palliative care. Ask them to write a word that reflects this commitment on a post-it note. Ask them to bring the post-it note into the final session.
- Finally, place the shells in a dish and send them around to each group member. Invite them to take a shell from the dish and tell them it will be a tangible reminder of the time here-the people they met, the vision shared, the creative ideas that arose.
- Instruct them to take a shell and respond to the following:
  - How will you practice differently as a result of being here?

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## **Appendices/ Supplemental Materials**



## DMD Case Study

A frail 12 year old boy with DMD has worsening curvature of the spine with worse pulmonary function, with an overall decline in his health and functional status.

He has a history of depression and weight loss, however, has responded well to Zoloft in the past when taken consistently. He presents with normal cognitive functioning, attending public school with the assistance of an aide and performing at the appropriate grade level. His surgical history includes multiple orthopedic surgeries which he and his parents report have resulted in long and painful recovery periods. He experiences, what he reports as excruciating intermittent hip pain, however has refused further surgery. He is wheelchair bound, requiring assistance for all activities of daily living.

He was recently airlifted to the emergency room in respiratory failure, requiring intubation and mechanically assisted ventilation. He was diagnosed and treated for aspiration pneumonia and an intestinal pseudoobstruction. While hospitalized, he experienced profound weight loss resulting in PEG placement for nutritional support. He also experienced high levels of anxiety, reportedly related to feelings of air hunger and suffocation while on B-Pap.

After a month long hospitalization with slow recovery, he was released with orders for additional supportive care equipment to provide continuous tube feeds and Bi-Pap to support respiratory function at home. He has a younger sister, who is compassionate and attempts to get involved in his care.

Spinal fusion surgery is an option for improving his quality of life.

1b) Now imagine that this family has very different socioeconomic circumstances. His parents are migrant workers which means they are constantly moving and can't comply with rehab. He has no medical insurance and their home is not ADA accessible. The health care team is concerned about possible post-op noncompliance and complications because of his parents' SES and lack of continuity with respect to his healthcare team.

## Opportunities for Integration of Palliative Care into Pediatric Neuromuscular Disease

Phase of Trajectory	Integration Opportunities
Peri-Diagnostic Phase	Communicating a new vision of hope and a commitment to companioning families throughout the process
	Establishing realistic timelines and expectations for the diagnostic process
	Eliciting parental preferences for communication, decision-making and continuity of care
	Framing the diagnosis as living with the disease rather than focusing on dying
	Anticipating and acknowledging parental grief*
	Disclosing clinicians' objections to offering or implementing certain treatment options (including enrollment in clinical trial)
	Acknowledging the uncertainty in velocity of progression and severity throughout the disease process
	Appreciating the unique significance of the genetic aspect of the diagnosis on family dynamics such as parental guilt related to mode of transmission, communication of familial risks and family planning decisions.
	Beginning advance care planning by anticipating decision points along the trajectory and assessing families' priorities for quality of life, and expectations and limits of treatment
	Reframing definition of a "normal" child and honoring the range of bonding attitudes and behaviors
	Encouraging parents/families to begin "meaning-making" activities such as taking pictures, family gatherings, celebrating milestones
	Anticipating technology and therapy needs based on goals of care and values regarding quality of life
	Assessing pain and symptoms to establish patient baseline
Changes in Functional Status	Discussing goals and preferences for treatment (resuscitation, ventilation, oxygen, feeding tubes, etc.) <b>at regular intervals and appropriate times</b> as the disease progresses <ul style="list-style-type: none"> <li>- with parents</li> <li>- with affected children and adolescents who have cognitive and developmental capacities</li> </ul>
	Re-defining the morally permissible boundaries of treatment including aggressive technological interventions such as tracheostomy, mechanical ventilation, G-tube, etc.
	Re-visiting previous decisions in light of new information and experience, and offering options to continue care or redirect it to focus on palliation or end-of-life care
	Instituting measures to enhance quality of life such as <ul style="list-style-type: none"> <li>-optimizing interaction, mobility, positioning</li> <li>-maximizing educational, social and community integration/access</li> </ul>
	Determining eligibility for services such as home nursing care, medical equipment, hospice, etc.

	Frequent monitoring of pain and symptoms including joint and muscle pain, discomfort associated with mobility and positioning, gastrointestinal discomfort due to reflux, dyspnea, etc.
	Honoring child's resilience and adaptive patterns
	Anticipating grief responses at each loss of function and referring to appropriate specialist.
	Exploring family needs for respite, psychosocial and spiritual support
Life-Threatening Events (many of the items listed above are ongoing)	Clarifying the meaning of life-threatening events such as progressive respiratory failure, inability to feed orally, infections, pneumonia, etc., acknowledging the likelihood of death and offering psychosocial and spiritual support to: - parents - affected children and adolescents
	Assessing whether prior preferences for life-sustaining therapies have changed and, if so, document changes in goals of care including use of intensive care, transfer to hospital, home hospice, etc., and, if appropriate, executing DNR or Allow Natural Death orders or other limitations of care and communicating these decisions to relevant entities and personnel including EMS, local hospital, etc.
	Considering if or when to involve ethics consultants or committees if disputes arise
	Re-assessing symptoms, functional status, and comfort
	Re-introducing opportunities for "meaning-making" to - parents - affected children and adolescents
Terminal Phase (many of the items listed above are ongoing)	Acknowledging the uncertainty and variability in the dying process and offering grief counseling and support
	Anticipating fears and concerns regarding terminal events and care at the end of life/time of death including managing breathing, comfort, impact of analgesia on awareness and interaction - of parents - of affected children and adolescents who have cognitive/ developmental capacities
	Completing important life closure activities - among family members and - with affected child/adolescent
	Exploring preferences for location of death – home, hospital, hospice, other.
	Assisting with plans for funeral, burial, cremation and care of the body at the time of death
Death and Bereavement	Assessing family needs and preferences for bereavement services
	Making referrals for spiritual, emotional and psychological support for the entire family
	Providing opportunities for post-death meeting with the interdisciplinary team to review new findings, autopsy, lingering questions, revisit genetic testing recommendations
	Offering involvement of health care team members in remembrance and memorial services
	Providing bereavement support for 1-2 years after the child's death

# **Team Meeting #1**

**Facilitated by Faculty/Facilitator**  
(60 minutes)

When using a longer version of the curriculum and one of your goals is to leverage the training for organizational change, we have included opportunities for inter-professional teams to work together. The following are suggested formats for those team meetings to help structure a process aimed at creating an actionable plan to leverage change.

Vision of Hope faculty and facilitators will serve as facilitators for the first team planning session, with a focus on concrete challenges in applying and implementing what has been learned at the workshop back at home institutions. Note that your group will be comprised of one institutional team and parent(s).

## **Overview of purpose of team meetings**

The outcome of this process at the end of the retreat is for each institutional group to develop a commitment statement that reflects their guiding values, principles, and commitments to improving the lives of children with DMD and other pediatric NMDs and a beginning action plan for integrating palliative care into pediatric DMD care.

During this initial team planning session, direct participants to the *Next Steps* worksheet in their Participant Guide. Explain that, throughout the retreat, references will be made to instituting change “back-home.” The worksheet is a tool for participants to use in organizing their ideas.

Facilitator will guide the discussion. Ask for a volunteer to be the scribe for the group’s discussions. Identify a person(s) from the group who will be responsible for the follow up and implementation of the groups’ plan after the meeting.

## **Introductions:**

Introduce each person in the following way:

Name, discipline, role in the care of children with DMD, and one thing they would like to see changed to improve their care. (Brevity is beautiful—each person should limit their introduction to 2-3 minutes.

## **Group Question:**

What is most important to you in the care that you provide to patients with DMD?

Have each person in the group say a word or sentence that answers this question. Have the scribe write these words or phrases down and read them after each person has spoken.

## **Current Status of Institution:**

Invite people in the group to consider what they are currently doing in their own institution in integrating palliative and end of life care into the care of patients with DMD.

Make a list of things that are currently being done in the areas of education, clinical practice, protocols, policies, inclusion of parents and family members, etc regarding palliative care.

**Goals of Institution:**

Invite people to consider potential goals for their institution based on the thoughts of the participants and institutional culture and receptivity regarding palliative care integration with DMD.

**These goals should be related to the themes of palliative care: Quality of Life, Decision-Making, Communication, Symptom Management, Psychosocial Support, etc.**

**Example goals might include the following:**

- 1. Develop ways to initiate educational activities at my own institution about the needs of children with life-threatening neuromuscular diseases and the role of palliative care.*
- 2. Develop ways to better integrate family members as teachers and consultants in those educational activities as well as in other initiatives to enhance care for children and families affected by life-threatening neuromuscular diseases.*
- 3. Continue to collaborate with colleagues within my own institution as well as regionally, nationally, and internationally to improve education and practice for children living with life-threatening neuromuscular diseases and their families.*

**Invite the group to write down 1-3 possible goals for themselves on their Team Meeting #1 worksheet (in participant guide).**

Goal 1:

Goal 2:

Goal 3:

- Ask participants to keep thinking about ways to address these goals as they continue to attend the retreat and jot them down as they will continue this conversation during Team Meetings #2 and #3.

## **Team Meeting #2**

**Not facilitated by Faculty/Facilitators**  
**(60 minutes)**

The outcome of this process at the end of the retreat is for each institutional group to develop a commitment statement that reflects their guiding values, principles, and commitments to improving the lives of children with DMD and other pediatric NMDs and a beginning action plan for integrating palliative care into pediatric DMD care.

The person(s) identified from Team Meeting #1 as being responsible for the follow up and implementation of the groups' plan after the meeting can facilitate this meeting.

### **Work on Institutional/Organizational Next Steps**

- Invite people to reflect on the goals for your institution discussed in Team Meeting #1 regarding palliative care integration with pediatric DMD care.
- Clarify the 1-3 goals your team will focus on upon returning to your home institution and write them below.
- Ask each team member to share ideas they have written down on their worksheets or have thought of throughout the retreat to address these goals and write them under the corresponding goal below.
- Keep in mind potential challenges/obstacles and suggest strategies for addressing the challenges/obstacles
- At the end of this session, each team should have a provisional list of goals that will be refined for final presentation in Team meeting #3.

# Goals of Institution

Goal 1:

*Steps for implementation:*

1.

2.

3.

Goal 2:

*Steps for implementation:*

1.

2.

3.

Goal 3:

*Steps for implementation:*

1.

2.

3.

# Team Meeting #3

Facilitated by Faculty/Facilitator  
(60 minutes)

During this session, participants will refer to their *Next Steps* worksheet which they have previously filled out and discussed with their fellow team members.

## **Introduction** (5 minutes)

- Explain that you will facilitate the session but will look to the group for their active participation.
- Remind participants that, throughout the workshop, references have been made to instituting change “back-home.” This breakout session will focus on this through discussion of their *Next Steps* worksheets.

## **Work on Institutional/Organizational Next Steps** (20 minutes)

- Remind participants of the three areas on the *Next Steps* worksheet and their 1-3 goals they created in Team Meeting #1.
- Ask each team to share ideas they wrote down on their worksheets or have thought of throughout the retreat.
- Ask each team to consolidate these ideas into their 1-3 goals and identify potential challenges/obstacles in implementation.

## **Sharing Next Steps: Commitment Statement and Action Plan** (20 minutes)

### **Commitment Statement**

- Ask team to create a commitment statement that shares their intention as a team for when they return to their home institution. The commitment statement should include overarching ideas, values and guiding commitments the team will maintain in their work when they return home.
- Ask participants to suggest statements that reflect their commitments to improving the care of children with DMD through better communication, ethical decision making, quality of life, and end of life care. Reflect on what will you DO and how will you BE as a result of your work together over the last 3 days?

### **Action Plan**

- Ask team members to review the 1 – 3 goals and related action steps identified in Team Meetings 1 and 2 that they are willing to implement following the retreat to advance the integration of palliative and DMD care. Consider what is feasible and realistic for the next 6 months. Be sure to include ways to celebrate their successes.

## **Poster Creation** (15 minutes)

- Ask the team to create a poster that reflects commitment statement and action plan.
- Each team will be given templates, a flip chart, and pens to develop their poster.



- Bring poster to main room for display.

# Next Steps Worksheet

Throughout the duration of the retreat, we want you to think about specific ways in which you can extend your own learning to colleagues and others. We hope that all of you will take advantage of the new connections you have made at the retreat to network together over the coming months to improve care for children with neuromuscular diseases and their families.

The following outline allows you to organize your ideas and think about how to follow up on your ideas when you return to your home institution. During the Team Planning Sessions at the retreat, you will share your ideas about next steps with other participants and receive input from your colleagues.

## Action Steps

**Please list 2 – 3 specific actions/steps** identified in response to the goals you created in Team Meeting #1 that **you are willing to implement following the retreat to advance the integration of palliative and DMD care in the following areas.**

### Goal 1:

Action Step #1

Action Step #2

Action Step #3

### Goal 2:

Action Step #1

Action Step #2

Action Step #3

### Goal 3:

Action Step #1

Action Step #2

Action Step #3

# Commitment Statement and Action Plan

Institution: \_\_\_\_\_

**Commitment Statement/Oath:**

**Goal #1:**

Action Step #1

Action Step #2

Action Step #3

**Goal #2**

Action Step #1

Action Step #2

Action Step #3

**Goal #3**

Action Step #1

Action Step #2

Action Step #3

# Resources and References

## Duchenne Muscular Dystrophy

- Bushby, K., Finkel, R., Birnkrant, D. J., Case, L. E., Clemens, P. R., Cripe, L., ... & Constantin, C. (2010). Diagnosis and management of Duchenne muscular dystrophy, part 1: Diagnosis, and pharmacological and psychosocial management. *The Lancet Neurology*, 9(1), 77-93.
- Erby, L. H., Rushton, C., & Geller, G. (2006, June). "My Son Is Still Walking": Stages of receptivity to discussions of advance care planning among parents of sons with Duchenne Muscular Dystrophy. In *Seminars in Pediatric Neurology* (Vol. 13, No. 2, pp. 132-140). WB Saunders.
- Geller, G., Harrison, K. L., & Rushton, C. H. (2012). Ethical challenges in the care of children and families affected by life-limiting neuromuscular diseases. *Journal of Developmental & Behavioral Pediatrics*, 33 (7), 548-561.
- Kohler, M., Clarenbach, C. F., Böni, L., Brack, T., Russi, E. W., & Bloch, K. E. (2005). Quality of life, physical disability, and respiratory impairment in Duchenne muscular dystrophy. *American Journal of Respiratory and Critical Care Medicine*, 172(8), 1032-1036.
- The Muscular Dystrophy Association
- Parent Project Muscular Dystrophy
- Parker, D., Maddocks, I., & Stern, L. M. (1999). The role of palliative care in advanced muscular dystrophy and spinal muscular atrophy. *Journal of Paediatrics and Child Health*, 35(3), 245-250.
- Poysky, J. (2007). Behavior patterns in Duchenne Muscular Dystrophy: Report on the Parent Project Muscular Dystrophy behavior workshop 8–9 of December 2006, Philadelphia, USA. *Neuromuscular Disorders*, 17(11), 986-994.
- Rushton, C. H. (2012). Integrating palliative care in life-limiting pediatric neuromuscular conditions: The case of SMA-type 1 and Duchenne Muscular Dystrophy. *Journal of Palliative Care & Medicine*.
- Rushton, C. H., & Geller, G. (2010). Life-threatening neuromuscular disorders: Interest in palliative care for children and their families. *Médecine Palliative: Soins de Support-Accompagnement-Éthique*, 9(6), e1-e6.
- Webb, C. L. (2005). Parents' perspectives on coping with Duchenne Muscular Dystrophy. *Child: Care, Health and Development*, 31(4), 385-396.
- Yates, K., Festa, M., Gillis, J., Waters, K., & North, K. (2004). Outcome of children with neuromuscular disease admitted to paediatric intensive care. *Archives of Disease in Childhood*, 89(2), 170-175.

## Palliative Care and Other

- The Conversation Project
- The Conversation Project: Conversation Starter Kit
- The Education Development Center, Inc.
- Hays, R. M., Valentine, J., Haynes, G., Geyer, J. R., Villareale, N., McKinstry, B., ... & Churchill, S. S. (2006). The Seattle Pediatric Palliative Care Project: Effects on family satisfaction and health-related quality of life. *Journal of Palliative Medicine*, 9(3), 716-728.
- Himmelstein, B. P., Hilden, J. M., Boldt, A. M., & Weissman, D. (2004). Pediatric palliative care. *New England Journal of Medicine*, 350(17), 1752-1762.
- The Initiative for Pediatric Palliative Care

- IPPC: Family Members as part of the Interdisciplinary Team
- IPPC: Families as Educators: Guidance for Implementation
- Kuttner, L. (2010). *A child in pain: What health professionals can do to help*. Bethel (CT): Crown House Publishing Limited.
- Martin House Children's Hospice
- National Hospice and Palliative Care Organization
- Riddle, C. A. (2013). Defining disability: Metaphysical not political. *Medicine, Health Care and Philosophy*, 16(3), 377-384.

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