

# Taking Care of You

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

# Parent Response to Pediatric Disease

- Avoidance and Acceptance
  - Leads to a pattern of withdrawal
- Approach and Attack
  - Supports a sustain pattern of acceptance and commitment

Parent functioning is important!

# Review of literature in Pediatric Psychology

## Parent functioning is important!

- Child and parent report often not consistent
- Parent under-report child functioning and over-report problem
- Parent function impacts child function

# Family Coping

- Manage own anxiety
  - Self-care
  - Creating structure and routine

# A few points about medical trauma

- Pediatric medical traumatic stress refers to reactions that children and their families may have to pain, injury, and serious illness;
- Or, to "invasive" medical procedures or treatments that are sometimes frightening.

# Impacts of Medical Trauma

- Parent self-report of trauma is typically higher than child self-report
- Parental trauma leads to:
  - hypervigilance
  - over-protection
  - pre-occupation
  - not taking care of themselves

# Medical Trauma is common

12-53% family with medically ill children  
experience significant trauma

# A few points about medical trauma

- Patient fearful of upcoming procedure or hospitalization
- Parents have same fear, to greater extent
- Parental concerns may extend beyond completion of current treatments

# Anger

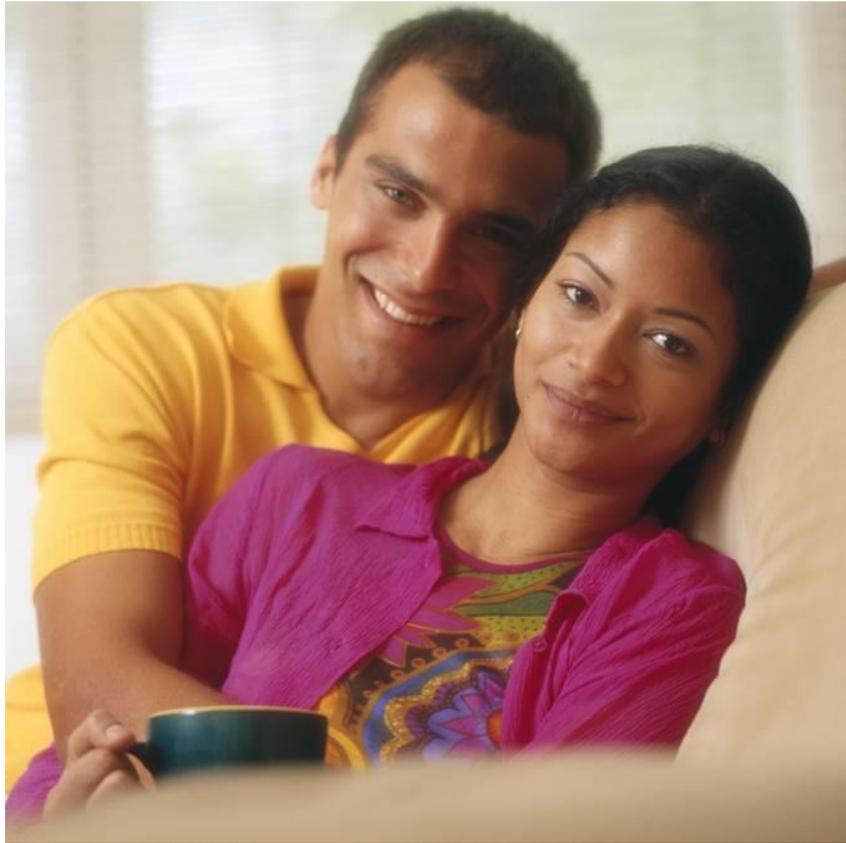
- A common experience
- Often one of the first, and usually strongest early emotions after receiving medical news that leaves you with broken dreams.
- "Why him?" "Why us?" "Why me?"

# Anger

- Anger can be consuming, over-whelming.
  - Don't let it mask other feelings
    - Uncertainty
    - Guilt
  - Your hostility is a sign that your anger is misdirected
  - Anger Management: good self care
    - Exercise, diet, & sleep
    - Stress management (relaxation, mindfulness, hobbies)
    - Invest time in friendships
    - Go to do good deeds
    - Deliberately find gratitude

# Marital Functioning

- Divorce is common . . . for everyone.
- Recognize that not all families are traditional.
- But, there is significant risk for strain in a marriage in the context of managing a complicated disease like DMD.
- Risk for divorce in the context of facing pediatric health diseases is increased.



**BE A DYNAMIC DUO**

## In our own way . . .

- Each parent may approach and respond to the diagnosis in very different ways from each other.
  - “out of sync”
- What to do?
  - The disease can divide you.
  - Know this. Expect this.

Discuss.  
Dialogue.  
Debate.  
Deliberate.  
Disciple.  
Discern.  
Diverge.  
Distract.  
Decide.  
Disintegrate.  
Divorce.  
Deliver.

In your own way . . .  
Reflecting on on the 12 D's of  
being a “Dynamic Duo” while  
confronting Duchenne

# What are we (psychology) doing?

- “You raise an important point about Duchenne Muscular Dystrophy. I think that there has been remarkably little work done with these neuromuscular diseases. I ran a group for the MD Association many years ago but was always surprised at how little support these kids get from their hospitals. Sometimes schools step up but formal psychosocial programs in hospitals seem absent.”

- A leading Pediatric Psychologist, 2018