

Talking to family, friends and school

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

Talk . . . Do talk too much.

- Disclosing and discussing the diagnosis with family members is critical
- Doing this as soon as you can be ready is likely going to be most helpful to most children and families, and in most contexts.

Family and Parent Friends Adjustment

- Coping with other people's reactions/questions
 - Anger, fear, denial, and (even) relief
 - Managing “information seekers”
- Managing your own feelings
 - Guilt
 - Grief
- Concerns leading to overprotection
 - This will thwart development.

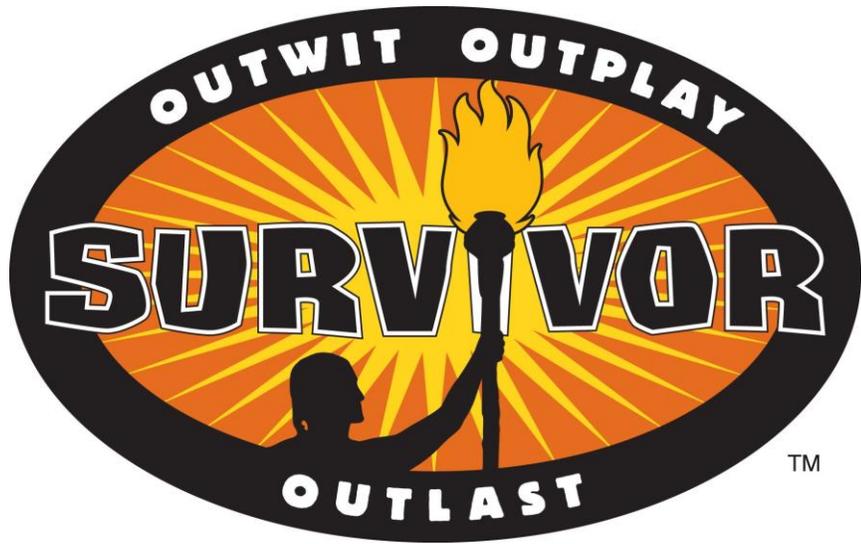
Sibling Supports

- Siblings feel responsible for protecting and defending the affected child
- May also receive teasing
 - “stigmatization by association”
- May have difficulty expressing own needs because they may feel they are not as important
- Equality among siblings

Family and Parent Friends Coping

- Teach child about condition from early age
 - Become an expert, invite others to as well.
 - Seek support from care team, outside agencies, and any relevant source.
- Model and teach responses to disease-related questions
 - Parents demonstrate healthy attitudes and behaviors
 - Helpful terminology
 - Help others find and use the right words

Healthcare professionals can help families by providing education about the child's condition and providing language to help families communicate about differences.



SCHOOL

Patient Adjustment Impacting Social Inclusion

- Self-consciousness about appearance
 - Stigmatization by peers
- Teasing or bullying
 - 28% of children in grades 6-12 experience bullying
- Signs that child is being bullied:
 - Fear of going to school, somatic complaints, bad dreams, trouble sleeping

Patient Adjustment

- Activity limitation
- Emotional reaction and adjustment
 - Body image
 - Potential anxiety and avoidance related to social situations
- Pain

Patient Coping

- Screeners for emotional/behavioral functioning
- Assess and promote peer relations
- Stress and Pain management training
- Encourage inclusion in as much “school” as possible, including extra-curricular activities

Self Image

Our internal view of ourselves

→ influenced by how others perceive us too

Interventions:

- Target improving self-view
 - Identify interests and “I can”
- Emphasize “sameness”
- Enhance skills for dealing with social stigmatization

School - Itself

- Seeking information promotes predictability and control
- Monitor school and social functioning
 - Proactive vs. reactive
 - Talk to school prior to problem
 - Identify your advocates - help determine need to additional accommodations
 - Determine need for education plans (504, IEP)
 - Seek (outside) advocacy if needed.

Cognitive Concerns for Patients with DMD

- Some evidence for distinctive cognitive profiles that will complicate learning across the curriculum.
- Notable learning differences:
 - Executive Function deficits
 - Difficulty in shifting tasks/sets, multitasking and switching tasks
 - Inhibiting responses
 - Planning, directing and intending goal directed behavior
 - Verbal working memory deficits

Psychosocial Concerns for Patients with DMD

- Other common emotional concerns could complicate educational management.
- Anxiety and depression common among children and adolescents with chronic illness
- Obsessive Compulsive Disorder
 - Known to be common among youth diagnosed with DMD
- ADHD
 - Also known as a common comorbidity

Emotional Functioning

(Anxiety and Depression)

Promoting healthy emotional functioning positively impacts success in other areas

Intervention:

- Cognitive-Behavioral Therapy
 - Identify links between thoughts-feelings-behaviors
 - Improve self-talk about appearance and function - modify negative thoughts, distortions, focus on function
 - Decrease avoidance behaviors that reinforce negative perceptions
- Stress management/relaxation training

Impacts of Care

- Burden of clinical trial participation
 - Time
 - Cost
 - Stress
 - Emotional whiplash
- Absenteeism
- Social isolation and learned helplessness

Friendships

- Important factor in social and cognitive development
- Help to “stop the world from shrinking”
- Diversify support for your child
- Improve quality of life
- Disclosure – actually – “self-disclosure” is likely key, sometimes, often, but not always.

Disease Disclosure to Friends

- Disclosure – actually – “self-disclosure” is likely key.
- To who?
 - Sometimes, often, but not always
 - We all have different types of friendships.
- When?
 - As soon as possible, or “at the right time”.

Peer Relationships

- Functions of Friendships
 - help with social concepts and skills
 - vehicle for self-expression
 - Become more **psychologically** based during school years
- Developmental Patterns in Friendship
 - Children's friendships are complex and multifaceted
 - **School age children have a handful of friends, more selective**

Friendship Development

- Under 6 years:
 - based on physical and geographical factors;
 - more self-directed
- 7 to 9 years:
 - begin to be based on reciprocity and awareness of other's feelings;
 - social actions and evaluations of others
- 9 to 12 years:
 - based on genuine give & take;
 - seen as people who help each other;
 - mutual evaluations & trust
- 11 and 12 years:
 - stable, continuing relationships based on trust;
 - can observe relationships from perspective of a third party.

Peer Groups

- *Peer groups* –
 - Rejected children at risk for learning and emotional problems.
- In early middle childhood, groups are relatively informal
- At ages 10 to 12, peer groups become more formal and are usually gender-segregated
- Peers often conform to the expectations of their peer group.

Peer Groups

- Children have to figure out what it means to be a member of their peer
- Popularity in one's peer group is important
 - Popular children generally have good emotional control and can cooperate and share
 - Children who are overly aggressive, timid, or different in some way are usually less popular

Social Challenges & Skill Deficits

Some children with visible differences experience anxiety in social situations:

- afraid others will notice their difference and treat them poorly.
- Vicious cycle...children avoid social situations and subsequently don't learn how to interact with other children or handle questions about their appearance difference
- leads to more anxiety and avoidance.

Social Skills Training

- **Body Language**
 - Good posture, eye contact
- **Staring**
 - Smiling, assertiveness
- **Questions and motivations**
 - Curiosity vs. cruelty
- **Responses**
 - One-liner – “Be the expert on you”
 - Explain-Reassure-Deflect
- **Initiating and maintaining conversations**
 - Role plays
 - Open vs. close-ended questions
 - Reflective listening