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Psychosocial Considerations in Duchenne Muscular Dystrophy

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Psychological / Psychosocial Concerns

- **Impact on child with DMD**
 - Development and Learning
 - Emotional: anxiety, depression, anger
 - Social
- **What to look for, how to intervene**
- **General recommendations / testing**
- **Impact on family members**
 - Parents
 - Siblings

DMD

- **Medical issues**
 - DMD impact
 - Medications
 - Medical procedures, frequent doctor visits
 - Physical functioning
- **Stress / trouble coping**
 - Classmates, peers
 - School (learning related)
 - Family: parents, siblings, others
- **Understanding diagnosis**

Recommendations for Child / Adolescent

- **Monitor neurodevelopmental functioning**
 - Increased rate of certain disorders
 - ADHD, learning difficulties, intellectual disability, anxiety, Autism Spectrum Disorder
 - Earlier intervention is warranted: screening for symptoms, testing for diagnoses, treatment plan for home and school

Recommendations for Child / Adolescent

- **School / learning**
 - Monitor academic functioning
 - Psychological or Neuropsychological testing
 - Accommodations and modifications in school, IEP
- **Social**
 - Help with confidence and strategies
 - Formal social skills interventions if needed

What to look for

- **Learning issues**

- Language delays, trouble with language based tasks
- Memory difficulties
- Trouble in specific academic areas: reading, written expression, mathematics

- **Possible “red flags”**

- Homework becomes “a battle”
- School refusals
- Worries/fears about certain subjects, tests, assignments
- Easily upset or frustrated relative to other areas

How to help

- **Learning issues**

- School can often conduct psychoeducational testing to address learning issues
- Formal neuropsychological testing may be helpful
 - Areas of strength and areas of need
 - Identify ways child will learn best
 - Identify ways to support any specific needs or weaker areas
- May need help addressing any behavioral or emotional issues related to learning struggles

What to look for

- **Social difficulties**
 - Difficulty interacting with others
 - Lack of interest vs lack of skills/knowledge
 - Frequently being teased or bullied

- **Possible “red flags”**
 - Getting into disagreements or fights with peers
 - May get along okay with younger children or adults, but not children their same-age
 - Preferring to play independently, not interested in others’ activities or games

How to help

- **May benefit from formal assessment**
- **Social skills training for lack of skills/knowledge**
 - Schools can offer (e.g., “lunch bunch”)
 - Community providers may offer groups too
- **Peer support**

General recommendations

- **Routines are important!**
 - Morning, bedtime, after school, homework
- **Consistency**
 - Across settings, across caregivers
- **Communication with**
 - Teacher
 - Therapists
 - Other caregivers / parent
 - Child
 - Siblings
 - Medical team

General recommendations

- **Clear expectations**

- Break down tasks into steps, one at a time
- State commands/requests positively
- Ensure understanding
- Follow through on consequences – both positive and negative
- Reinforce appropriate behavior, ignore the negative behaviors if you can

What is “testing”?

- **Psychological or neuropsychological testing looks at a child’s level of functioning in specific areas**
 - Cognitive ability (IQ)
 - Memory
 - Attention/concentration
 - Language
 - Executive functioning
 - Adaptive behavior
 - Social-emotional and behavioral functioning

- **Used to help plan services or treatment**

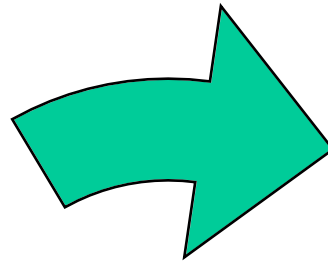
Impact on family - parents

- **Parent well-being and health is**
 - Influenced by child behavior and caregiving demands
 - Related to parent self-perception and family functioning
 - Affects child functioning

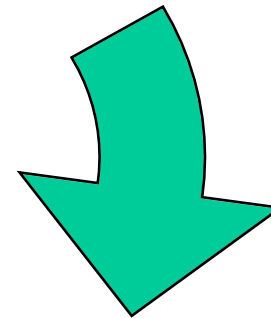
- **Parents are models for their children – they will watch how parents cope and how they manage stress!**

The circular relationship

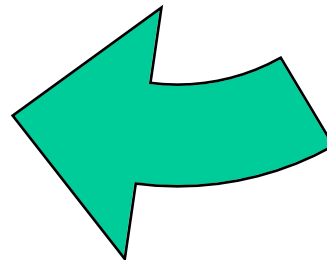
Stressful, non-supportive or emotionally distressing family relationships



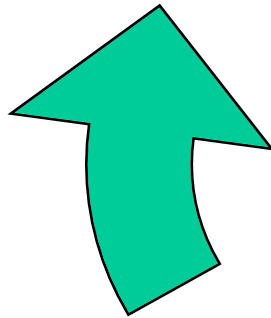
behavior and emotional issues in the child



diminished sense of competence as a parent



behavior and emotional issues in the child



Myths about self-care

- **It's selfish.**
- **People will think I'm weak.**
- **I can't afford the time.**
- **I don't have enough money to spend it on something like that.**

Methods of self-care

- **Take a walk**
- **Talk to a friend**
- **Go to bed early**
- **Play a game**
- **Go out for coffee (or take five minutes at home)**
- **Think about things you are grateful for**
- **Look at old photos**
- **Seek and accept help when you need it!**

Impact on family - siblings

■ Why Siblings?

- By some estimates, 7 million people in the United States have a sibling with special needs/disabilities.
- Probably first generation where children with special needs are more regularly outliving their parents.
- Siblings are likely to have the longest-lasting relationship with a child with disabilities...they will be there long after the parents, special ed teachers, and medical doctors are no longer involved.
- First studies found some negative effects, more recent have found some benefits as well

Siblings of children with special needs

- **May seem more mature than same-age peers**
- **Develop an understanding of the challenges others go through**
- **Demonstrate increased frequency of pro-social behaviors**
- **May develop a deep sense of loyalty to and caring for family members**
- **Can show an increased tolerance for people who are different**

How To Help Siblings

- **Keep expectations realistic for sibs**
- **They have a right to their own lives, friends, and interests**
- **Acknowledge that they may have mixed emotions or feelings about their brother/sister and that's okay**
- **Make sure standards and expectations apply across the board – for all children in the family**
- **Limit care-giving responsibilities**
- **Provide information about disability on a level they can understand...if and when they want it**

How To Help Siblings

- **Find support for them if needed:**
 - Sibling support groups – give kids an opportunity to meet and interact with other children in their situation
 - Therapy for more significant difficulties/issues

What Siblings Would Like Parents and Service Providers To Know (Sibling Support Project)

- **The right to one's own life.**
- **Acknowledge sibling's concerns**
- **Expectations for typically-developing siblings**
- **Expect typical behavior from typically-developing siblings**
- **Expectations for the family member with special needs**
- **The right to a safe environment**
- **Opportunities to meet peers**
- **Opportunities to obtain information**
- **Sib's concerns about the future**
- **Celebrate every child's achievements and milestones**
- **Parent's perspective is more important than the actual disability**

Mental Health

- **“Mental health is defined as a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community.”**

World Health Organization

Mental health...signs to look for

- Eating or sleeping too much or too little
- Pulling away from people and usual activities
- Having low or no energy
- Feeling numb or like nothing matters
- Having unexplained aches and pains
- Feeling helpless or hopeless
- Smoking, drinking, or using drugs more than usual

Mental health...signs to look for

- **Feeling unusually confused, forgetful, on edge, angry, upset, worried, or scared**
- **Yelling or fighting with family and friends**
- **Experiencing severe mood swings that cause problems in relationships**
- **Hearing voices or believing things that are not true**
- **Thinking of harming yourself or others**
- **Inability to perform daily tasks like taking care of your kids or getting to work or school**

- 1. Connect with others**
- 2. Do what you enjoy**
- 3. Share your interests**
- 4. Help out**
- 5. Take care of yourself**
- 6. Challenge yourself**
- 7. Manage stress**
- 8. Rest & refresh**
- 9. Live in the present**
- 10. Ask for help**

Questions?

- **Contact info**

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