Psychosocial Care in Duchenne Muscular Dystrophy

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The Big Picture

• Most boys with DMD will show steady developmental progress in the acquisition of cognitive, emotional, and social skills, even with loss of motor skills.

• Assume that boys with DMD will lead fulfilling lives and pursue areas of interest and expertise, as well as have social relationships

• When developmental progress follows a different path, there are resources to help along the journey.
Monitor Overall Development

• Cognitive Skills
  – Memory
  – Language
  – Problem-Solving

• Emotional and Behavioral Regulation Skills
  – Attention
  – Resilience in the face of change or the unexpected
  – Regulation of mood

• Social Skills
  – Initiation and maintenance of peer relationships
  – Understanding of others emotions
  – Play skills
Coping with a Chronic Medical Illness

• Information provided should be appropriate to developmental stage and the individual

• Should involve the family
  – Siblings
  – Parents
  – Extended family

• Community Resources
  – DMD Community
  – Local Community, including schools
Brain Development

• Dystrophin plays a bigger role in muscle development and function, but isoforms are also found in brain

• Depending on the nature of the genetic mutation, there can be changes in brain development
  – Smaller total brain volume
  – Smaller gray matter volume
  – Changes in the structure of white matter pathways

• Higher prevalence of neurodevelopmental conditions in those without Dp140 (exons 45-79) and Dp71 (exons 63-79)
• Higher expression of dystrophin in regions important for learning, memory, emotional regulation, decision-making, and integrating information
Common Neurodevelopmental Conditions in DMD

- Intellectual Disability (~30%)
- Learning Disabilities (25-40%)
- Attention Deficit Hyperactivity Disorder (ADHD, 32%)
- Autism spectrum disorder (ASD, 15%)
- Anxiety (27%)
- Obsessive compulsive disorder (OCD, 5%)
Intellectual Disability

• Child makes steady developmental progress

• Skills uniformly fall below age-based expectations

• Important to support the development of functional living skills
Learning Disability

- Many aspects of functioning, including overall cognitive abilities, are within normal limits for age

- Certain academic skills are harder to learn than others
  - Reading (e.g., dyslexia)
  - Writing (e.g., dysgraphia)
  - Math (e.g., dyscalculia)

- Early signs can be more general
  - Needing more time to shift to new activities
  - Needing more time to complete written and oral work

- May need specialized academic supports
Attention Deficit Hyperactivity Disorder

• Inattentive Symptoms
  – Can focus on preferred activities
  – Hard time focusing on nonpreferred activities, especially if too easy or too challenging

• Hyperactivity
  – Restlessness
  – “can’t sit still”

• Impulsivity
  – “acts without thinking”

• Treatment Options: Medication and Psychotherapy (Cognitive Behavioral Therapy)
Autism Spectrum Disorder

• Difficulties relating to other children
  – Prefer to play alone
  – Play tends to be repetitive and scripted
  – May play with toys in unusual ways
  – Shows reduced awareness or understanding of others’ emotional experiences

• Prefers to follow routine, may have difficulty adjusting to change

• Sensory sensitivities

• Treatment: Behavioral Therapy (ABA), social skills training, specialized academic programs
Anxiety

• All children worry, and this can be common in kids with health-related concerns

• Anxiety:
  – Frequency is high
  – Intensity is high
  – Interferes with daily functioning

• Types of Anxiety Disorders
  – Social anxiety
  – Obsessive compulsive disorder

• Treatment: Medication and Psychotherapy (Cognitive Behavioral Therapy)
Clinical Resources

• Neuromuscular Team
  – Clinical Care Coordinator
  – Psychologist (therapy, assessment)
  – Psychiatrist (medication)
  – Social Worker

• Available for the whole family, including the patient

• Possible Referrals
  – Neuropsychologist
  – State/Local Organizations
Who Is a Neuropsychologist?

• Doctorate in Clinical Psychology

• Specialized Pre- and Post-doctoral Training:
  – Normal and abnormal development
  – Broad clinical neuroscience knowledge
  – Assessment of psychological functioning
  – Assessment of brain-behavior relationships

• Board Certification in Clinical Neuropsychology
What Happens during a Neuropsychological Evaluation?
Neuropsychological Evaluation Report

• Comprehensive description of your child’s cognitive, emotional, social, and academic skills

• Diagnostic Impressions
  – May include diagnoses of psychiatric or neurodevelopmental conditions

• Recommendations
  – Psychosocial Interventions
  – Educational Interventions
  – Timeline for Follow-up (usually 2-3 years)

• Quantification of skills allows for tracking over time
Interventions

- Medical
- Psychiatric/Psychological Care
- Community Resources
- School-based Supports
- Social Supports
- Family Supports
Emotional and Behavioral Interventions

• Psychotherapy
  – Caregiver support
  – Family therapy (parents, siblings, affected child)
  – Individual therapy
  – Specialized therapy

• Psychopharmacology
  – Stimulants for ADHD
  – Mood stabilizers

• Monitor in Relation to Medical Interventions (e.g., steroid treatment)
Social Interventions

- Peer education
- Social skills training
- Support groups
- Participation in group activities
  - Modified/adapted sports
  - Special summer camps
Infants and Toddlers

- Early Intervention Services
  - Physical Therapy
  - Occupational Therapy
  - Speech and Language Therapy

- Government funded based on Individuals with Disabilities Education Act (IDEA)

- In your community and sometimes your home

- Eligibility until age 3
Preschool-Aged Children

• Integrated preschool settings
  – Through the public school system
  – Often allow for continuation of EI services
  – Integration with other children who may or may not have special needs
  – Placement and services defined through an IEP

• Private Preschools
  – Need for tailored individualized supports
  – Will sometimes work with private services funded through insurance
Elementary-Age Children

• Primary Factors:
  – Medical (Physical) Factors
  – Cognitive (Learning) factors
  – Social and emotional factors

• Three Components to Consider:
  – Placement
  – Accommodations
    • Adjustments made to the classroom environment to allow the child to fully participate
  – Services
    • To help a child learn skills so that they can access the curriculum
Elementary-Age Children

• Two Types of Special Education Plans:
  – 504 Plan
  – Individualized Education Program

• Plans can be adjusted over time as needs change
  – Most school districts will meet with you annually

• Can remain in place until the end of high school and then 504 plans can transfer to college
Working with Schools: Developing a 504 Plan

• American Disabilities Act (ADA), Section 504:
  – No one with a disability can be excluded from participating in a federally funded activity, including schooling

• Specifies **accommodations** or modifications that will be needed for the student to have an opportunity to perform at the same level as their peers

• Eligibility based on presence of a “disability” that impacts his/her ability to access the school environment
Working with Schools: Developing a 504 Plan

- Wheelchair ramps
- Specialized desks or slant boards
- Access to a scribe or voice recognition software
- Extra set of books at home
- Extra time on tests
- No penalty for breaks to address the medical condition, even during timed standardized exams
- Access to a tutor in the event of extended absence
- No penalty for tardiness
- Access to assistive technology
Working with Schools: Developing an IEP

- IEP = individualized education program
- Individuals with Disabilities Education Act (IDEA)
- Specifies services and accommodations to allow a child to access the academic curriculum, including a provider and frequency of the service
- Eligibility determined based on the presence of a “disability” and evidence that the child is unable to access the curriculum and/or making sufficient progress
- Includes goals and benchmarks to assess progress
Working with Schools: Developing an IEP

- Occupational therapy
- Physical therapy
- Speech and language therapy
- School-based counseling or social skills training
- Applied behavior analysis (ABA)
- Specialized classroom placement
- Specialized instruction in reading, math, or writing
Adolescence to Early Adulthood

• Gradual transition of care responsibilities

• Should be developmentally appropriate

• Should occur through childhood and adolescence
Transition Topics

• Educational and Vocational Goals
• Peer Support
• Dating and Relationships
• Housing
• Transportation
• Financial