



# 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

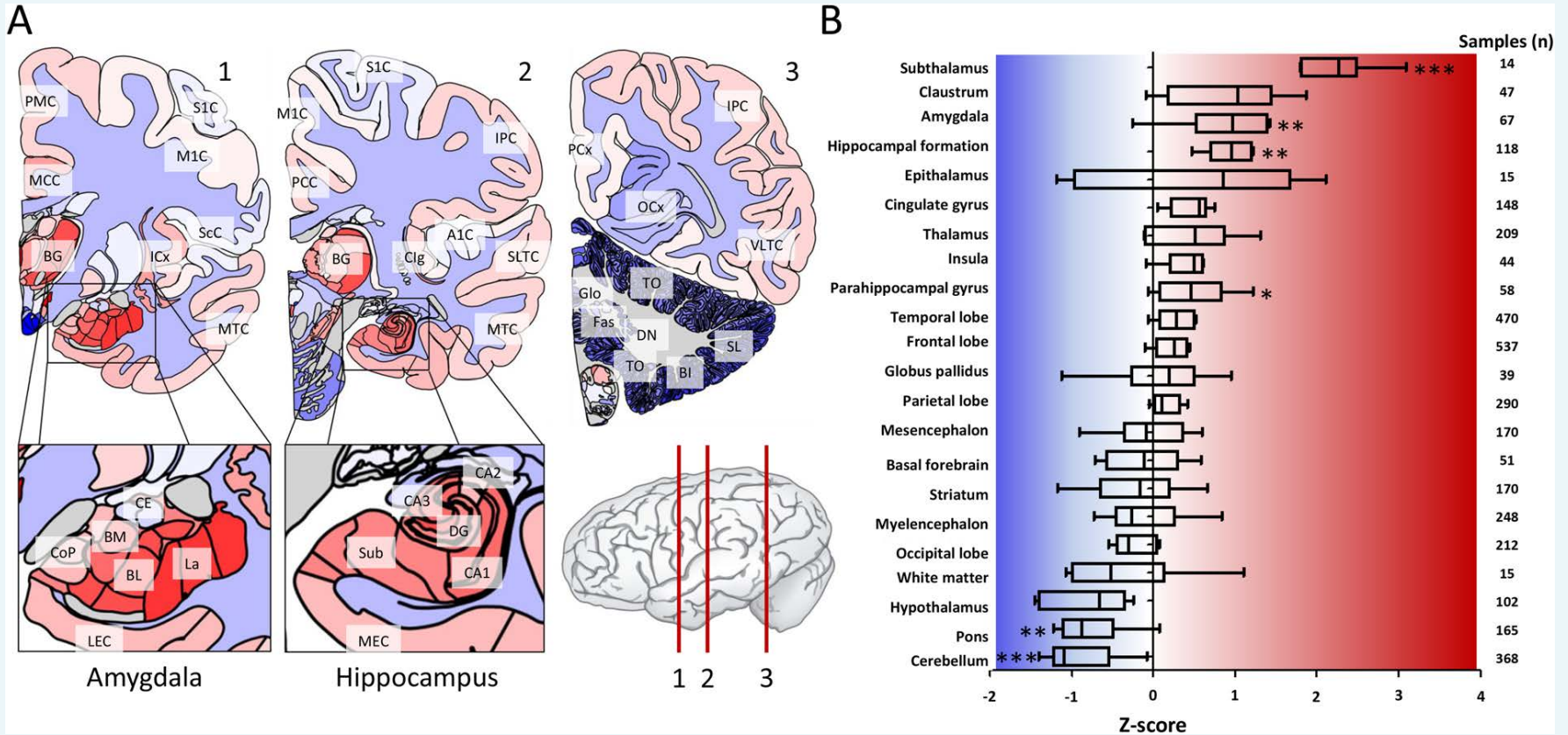
- Cognitive Skills
  - Memory
  - Language
  - Problem-Solving
- Emotional and Behavioral Regulation Skills
  - Attention
  - Resilience in the face of change or the unexpected
  - Regulation of mood
- Social Skills
  - Initiation and maintenance of peer relationships
  - Understanding of others emotions
  - 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?

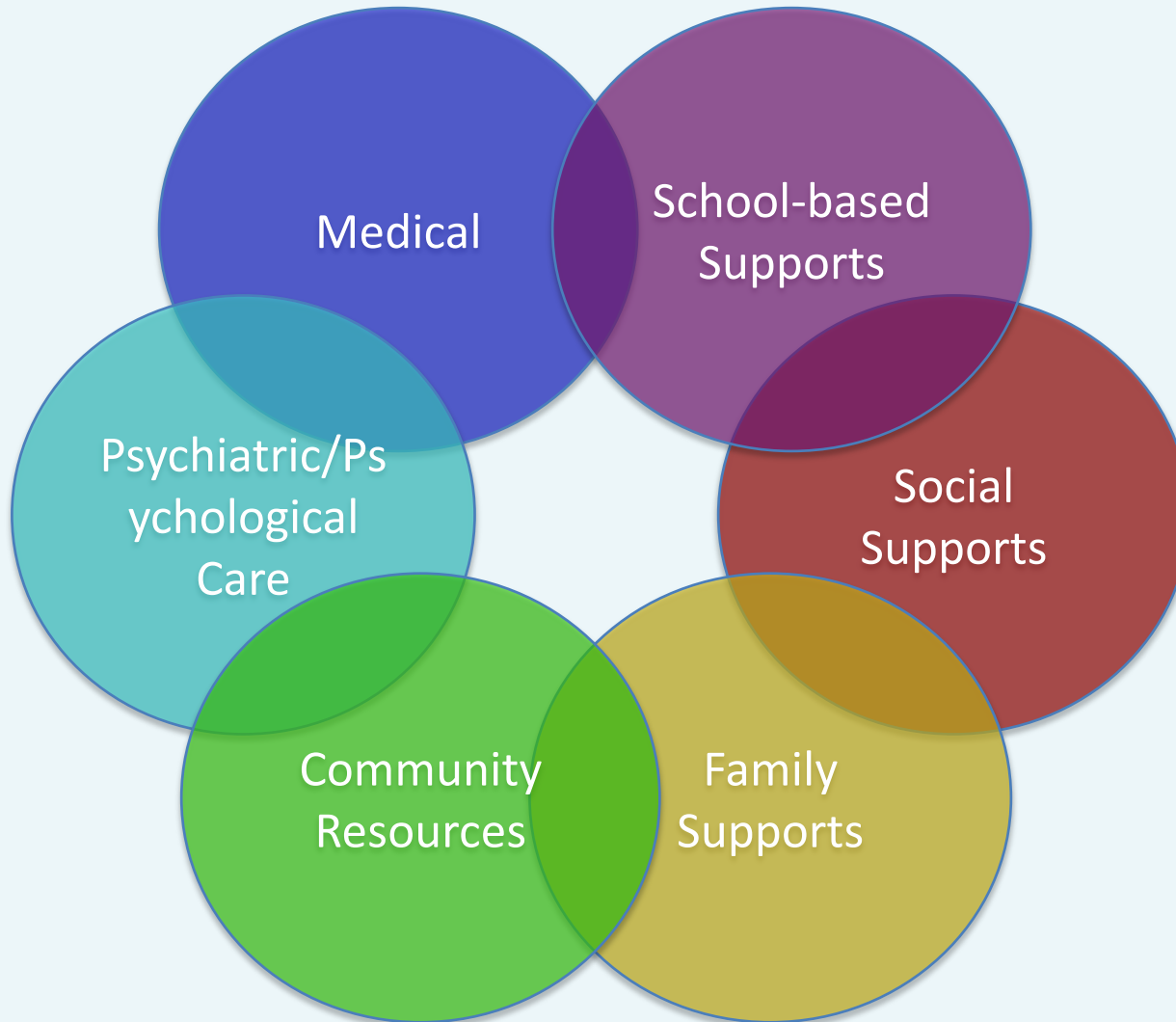


# Neuropsychological Evaluation Report

- 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



# 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



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