



Duchenne Muscular Dystrophy: Psychosocial Considerations

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AUGUST 2022**

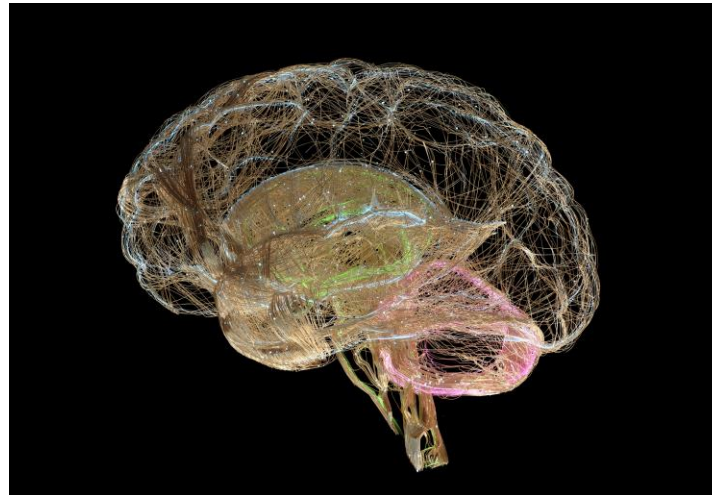
Discussion Topics

- Why is psychosocial care important to consider and include as a routine part of healthcare?
- What is psychosocial care?
- How do my child's caregivers, medical providers, and community providers work together to support psychosocial care goals?



Mental Health is Important!

- Medical needs and physical health are one important component of care. Emotional, social, and cognitive health are also key components that promote well-being, independence, and daily life.
- Neurodevelopmental disorders occur at a higher rate in individuals with DMD.
- Individuals with DMD and their family members have higher risk of anxiety, depression, and/or psychological stress.



- Aspects of Mental Health and Neuropsychological Functioning:
 - Intellectual Functioning
 - Attention and Executive Functioning Skills
 - Memory
 - Language
 - Academic Skills
 - Fine motor Skills
 - Mood
 - Behavior
 - Social Skills
 - Adaptive Skills



Aspects of Psychosocial Care

Care Coordination

Mental Health Screening

Neuropsychological Assessment

Aspects of Psychosocial Care

Psychological Interventions

Pharmacological Interventions

School and Community Planning /
Resources

Developmental Considerations

- **Childhood**

- Neuropsychological evaluations to address concerns / needs & as baseline
- Connect with mental health, school, and community services / supports
- Parent and child education about DMD and psychosocial considerations
- Start to promote child's self-advocacy / independence & social networks



- **Adolescence / Young Adulthood:** All the above PLUS

- Emphasize adolescent's self-advocacy, participation, and independence
- Set goals for future education, vocational training, and daily living
- Connect with palliative care professionals

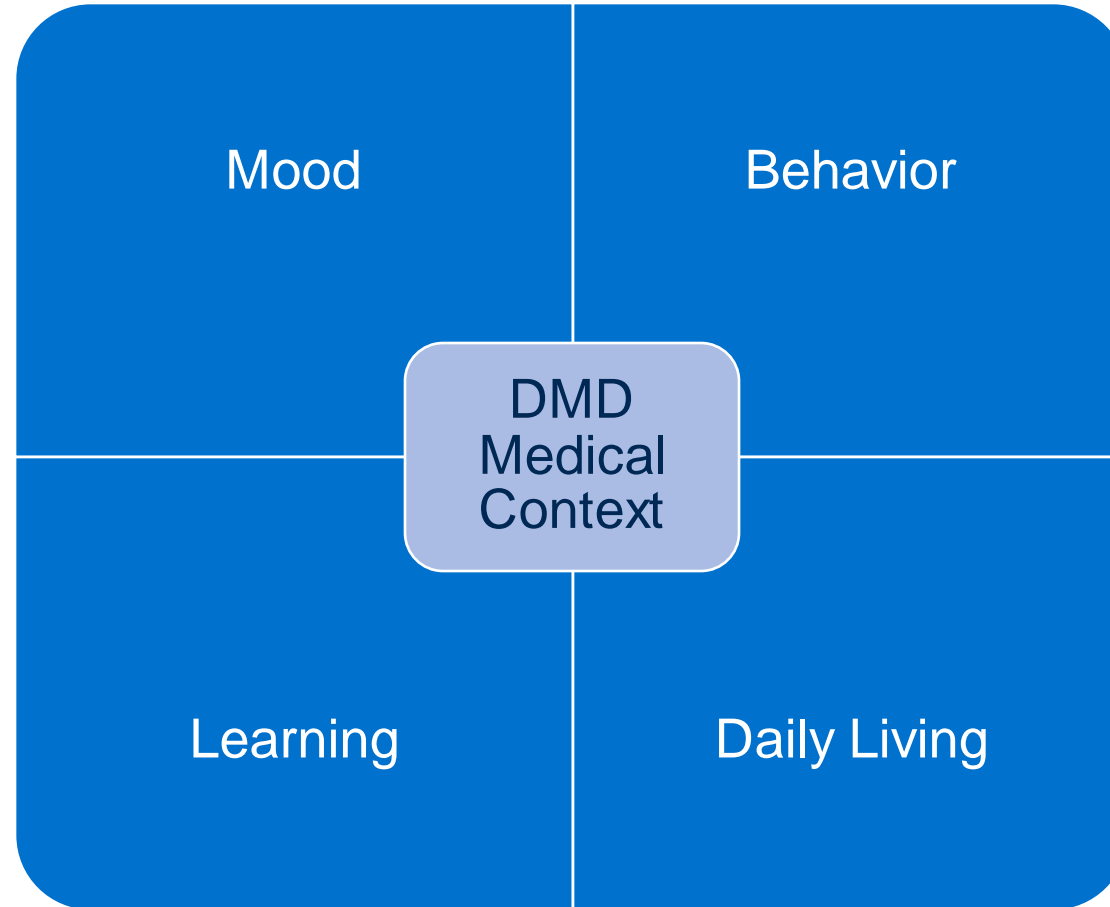


- **Adulthood:** All the above PLUS

- Considering adjustments to accommodate job requirements
- Considering adult home and community health-care services / daily living supports



A Brief Note on Neuropsychological Functioning



How does the psychosocial team work together?



Sharing neuropsychological evaluation results and recommendations with school team and medical providers.



Sharing resources about community and social services / supports across home and clinical settings.



Proactively planning, anticipating needs, and communicating across team members.



Frequent “touch-base” meetings with key psychosocial providers (e.g., school staff, therapist, social worker, etc.).



**Spectrum
Health**

Questions?

Thank you!