PSYCHOSOCIAL CARE GUIDELINES (2018)

- Team including a mental health professional
- Routine screening of mental health and quality of life
- Provide cognitive-behavioral interventions for concerns identified
- Refer for neuropsychological evaluation
  - Concerns with: cognitive function, attention, learning, etc
  - If evaluated, repeat every 2-3 years OR near transition points
- Transitioning planning
  - General (normative) independence, power of attorney, advanced directives, adult medical care services

(Birnkrant et al., 2018; Kazak, 2006)
COGNITIVE, EMOTIONAL, & BEHAVIORAL SYMPTOMS

- Evidence for changes in dystrophin in brain areas associated with learning, behavior, and emotions. Steroids can exacerbate.
- Increased risk compared to general population, but risk ≠ will have.
- Many young men are doing well overall outside of need for physical supports

**Attention/Executive Functioning & Learning**
- Distractible & Impulsive
- Verbal working memory
- Decoding Fluency (reading)
- Reading Comprehension
- Larger tasks/demands
- Multi-tasking
- Flexibility in thinking
- Activities out of routine

**Language**
- Efficiency/Reliability
- Word finding
- Elaborating thoughts
- Too much verbal may be overwhelming (slower, lower, less words)

**Other (Related) Concerns**
- Anxiety [Mood]
- Endurance
- Task avoidance / noncompliance
- Regulation of arousal, motivation, emotions
- Tantrums or aggression
- General hyperarousal

(Banihani et al., 2015; Hendriksen & Vles, 2006; Lambert et al., 2019; Lee et al., 2018; Pane et al., 2012; Ricotti et al., 2016)
POSSIBLE PSYCHOSOCIAL SUPPORTS PROVIDED

- Recognizing and managing emotions. Planned breaks, regardless of activity
- Behavior management; Strategies/supports for attention and organization
- Evidence-based (cognitive-behavioral) strategies for mood or anxiety
- Medical Regimen help
  - Problem-solving, Goal-setting, Contingency management, Exposures (BiPAP), motivation enhancement or self-talk strategies
- Disease Coping
  - General adjustment, disclosure, declines in function, social and decreased structure after school completion, logistics or resources
- Self-advocacy & transition (independence promotion)
- Finding local therapy options (as needed) for significant concerns
  - Help improve symptoms, quality of life, family functioning