

Muscular Dystrophy & Mental Health

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Yale SCHOOL OF MEDICINE

Let's start with introductions

What is a Pediatric Psychologist/Health Psychologist?

- Bachelor's (BA/BS) degree (4 years)
- Doctorate (PhD/PsyD) in Clinical Psychology (5-7 years)
 - Expertise in child psychology AND health (pediatric) psychology
- 1 year of residency (direct patient care)
- 1-2 years of post-doctoral fellowship specializing in pediatric psychology
- Specialty, intersection of health and behavior



Who is in the crowd?

Adult with a Neuromuscular Disease **(A)**

Kid or Teen with a Neuromuscular Disease **(B)**

Parent or Caregiver of someone with a Neuromuscular Disease **(C)**

Other **(D)**

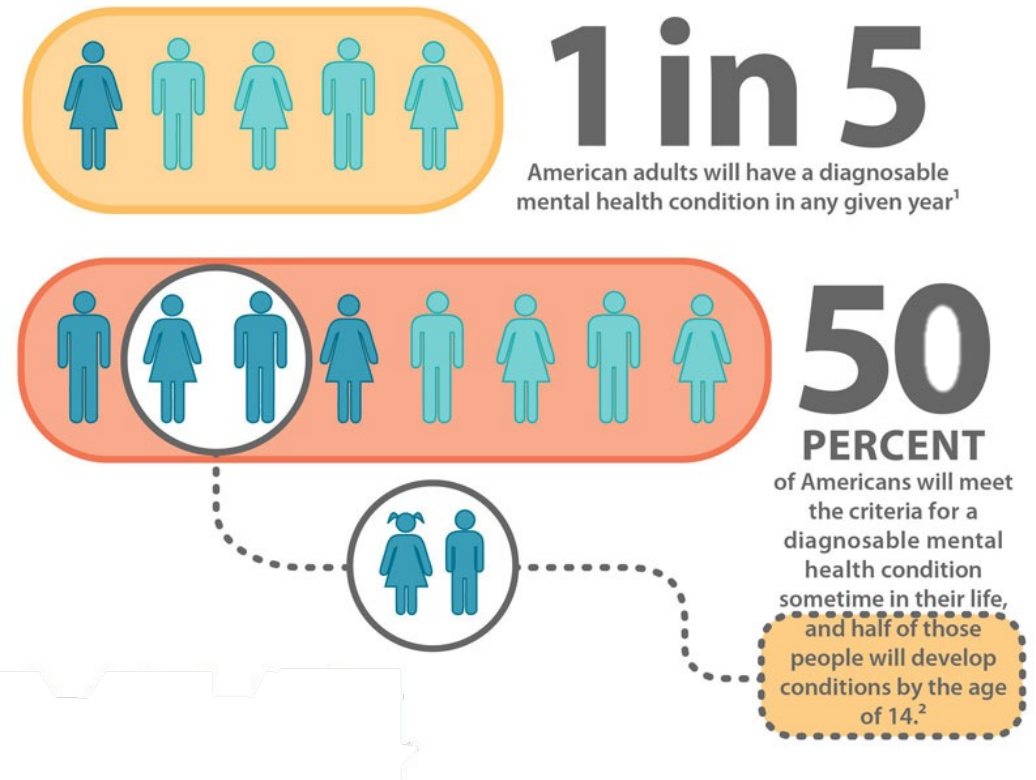
Things we'll talk about today



- Ways chronic illness affects mental health (and vice versa)
- Recognize signs and symptoms of some common mental health challenges
- Learn ways to address mental health challenges and how to find help

What does the research tell us?

- Many people experience mental health challenges
- More likely if you have:
 - Learning/cognitive differences and/or
 - Chronic health conditions
- Neuromuscular disorders:
 - DMD: Higher rates of Autism Spectrum Disorder (14.8%), Intellectual Disability (36.2%), Anxiety/Depression (23.4%)
 - Disease trajectory affects quality of life in youth with neuromuscular disorders



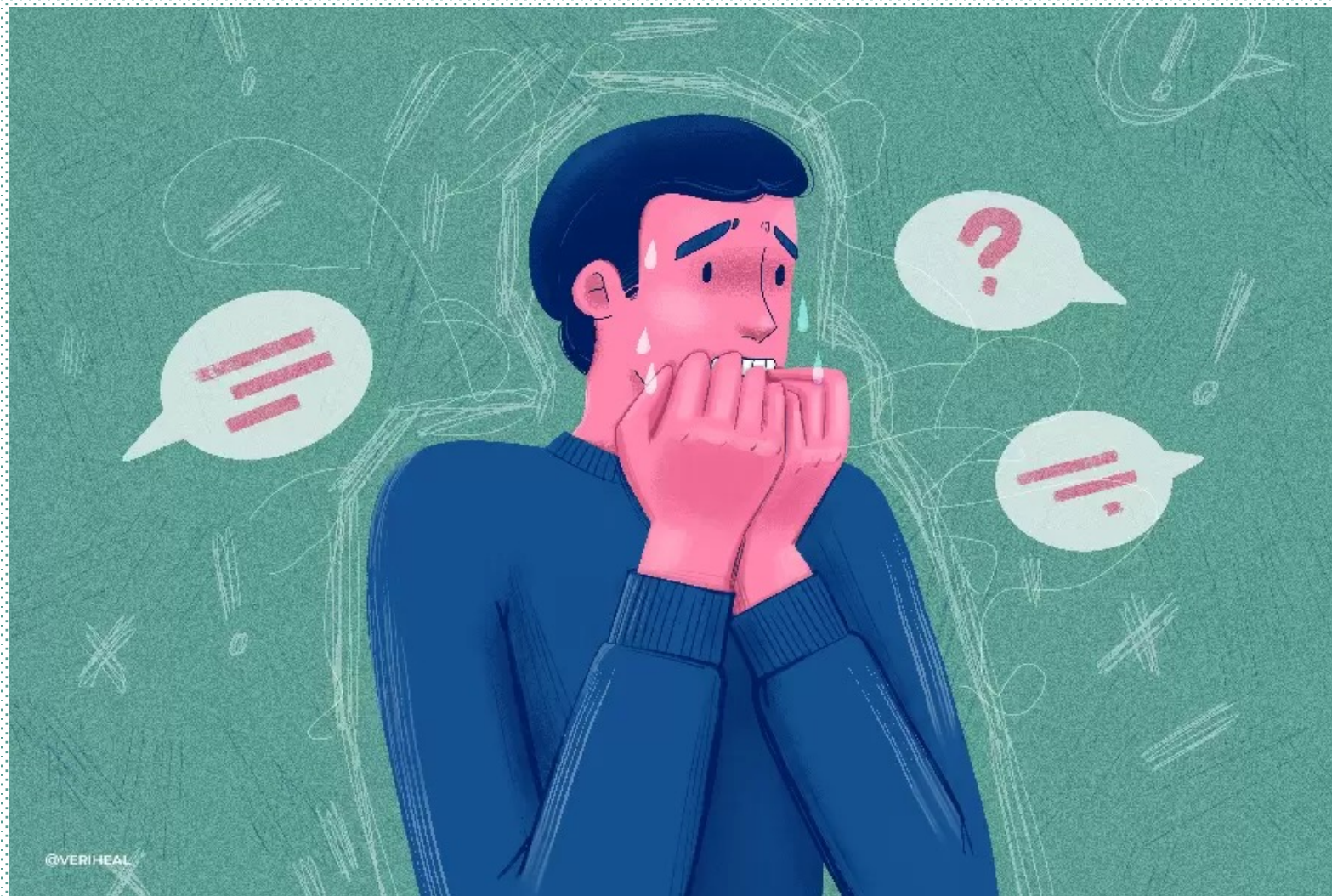
What have you felt?

Nobody has responded yet.

Hang tight! Responses are coming in.

Recognizing the signs

Anxiety



Panic Attacks



Physical symptoms include:



Chest pain.



Difficulty breathing.



Trembling or shaking.



Racing heart.



Sweating.



Nausea.

You may feel:



Intense terror.



A choking or smothering sensation.



Depression



Adjustment difficulties

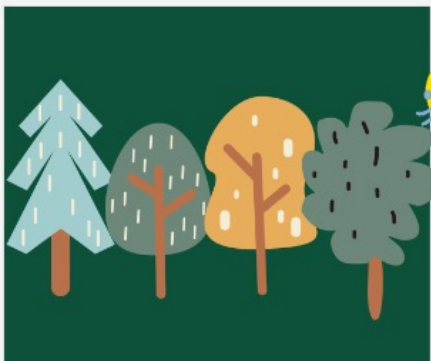


What to do? Where to go for help?

- Depends on what's needed!
 - Things to do on your own
 - Talk with your MDA/NMD Clinic team
 - Seek treatment provider
- Finding a:
 - Pediatric or Health Psychologist (PhD/PsyD)
 - General Psychologist (PsyD/PhD)
 - Psychiatrist (MD/DO) or Prescriber (APRN/NP)
 - Therapist or Counselor (LCSW, LMFT, LPC)



Self Care

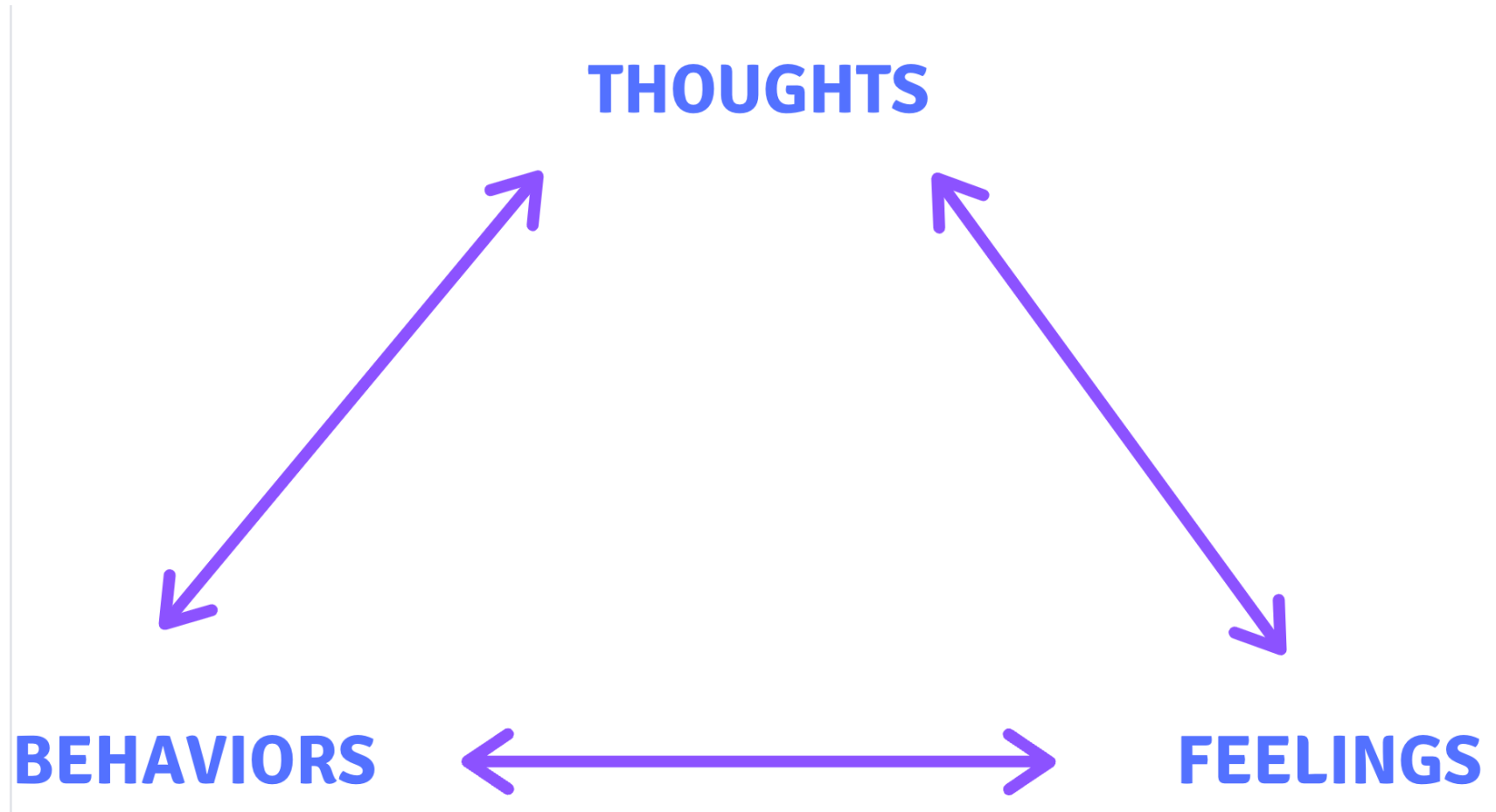


What to look for?

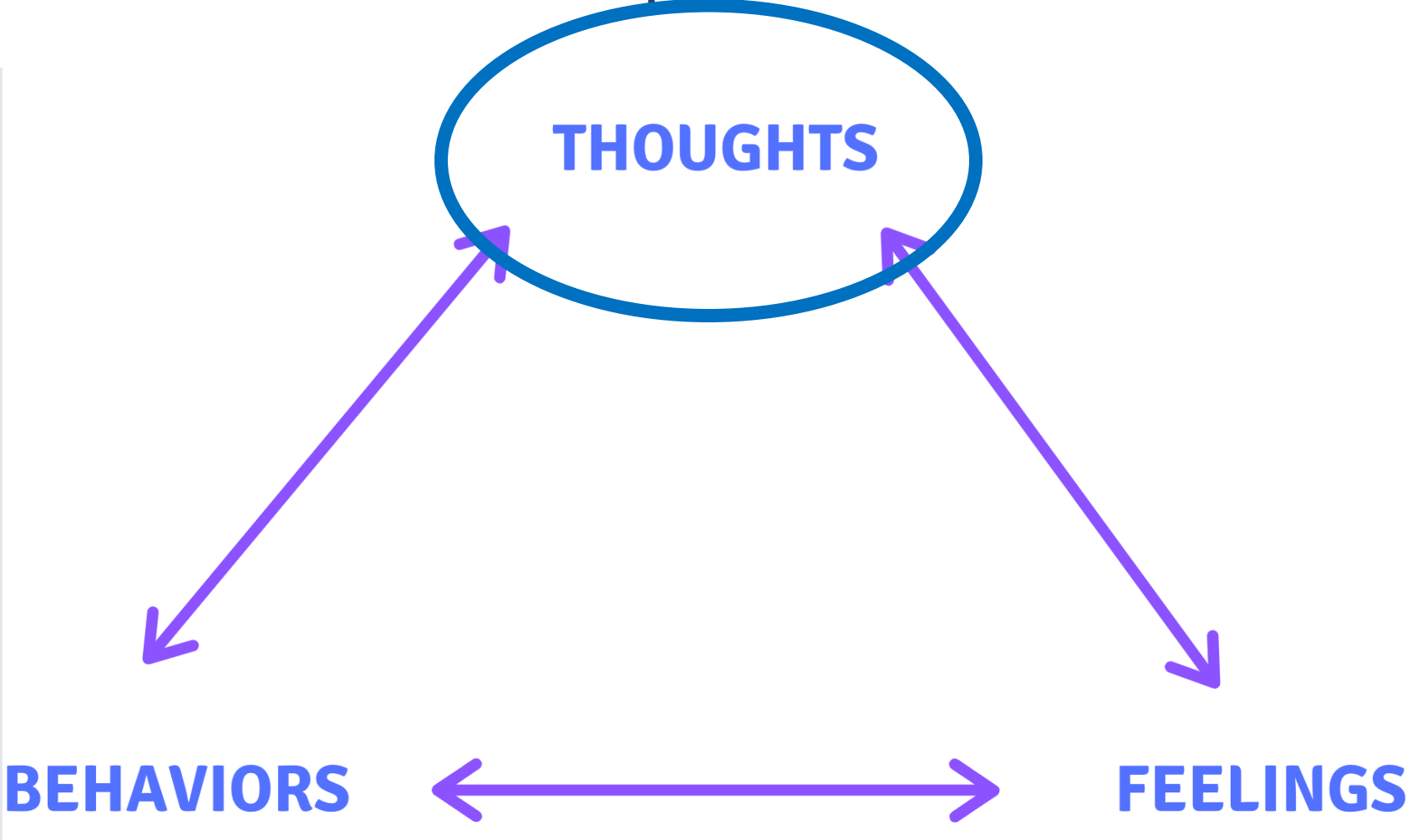
- Supportive therapy
- Cognitive Behavioral Therapy
- Mindfulness
- Acceptance and Commitment Therapy
- Health-focused intervention



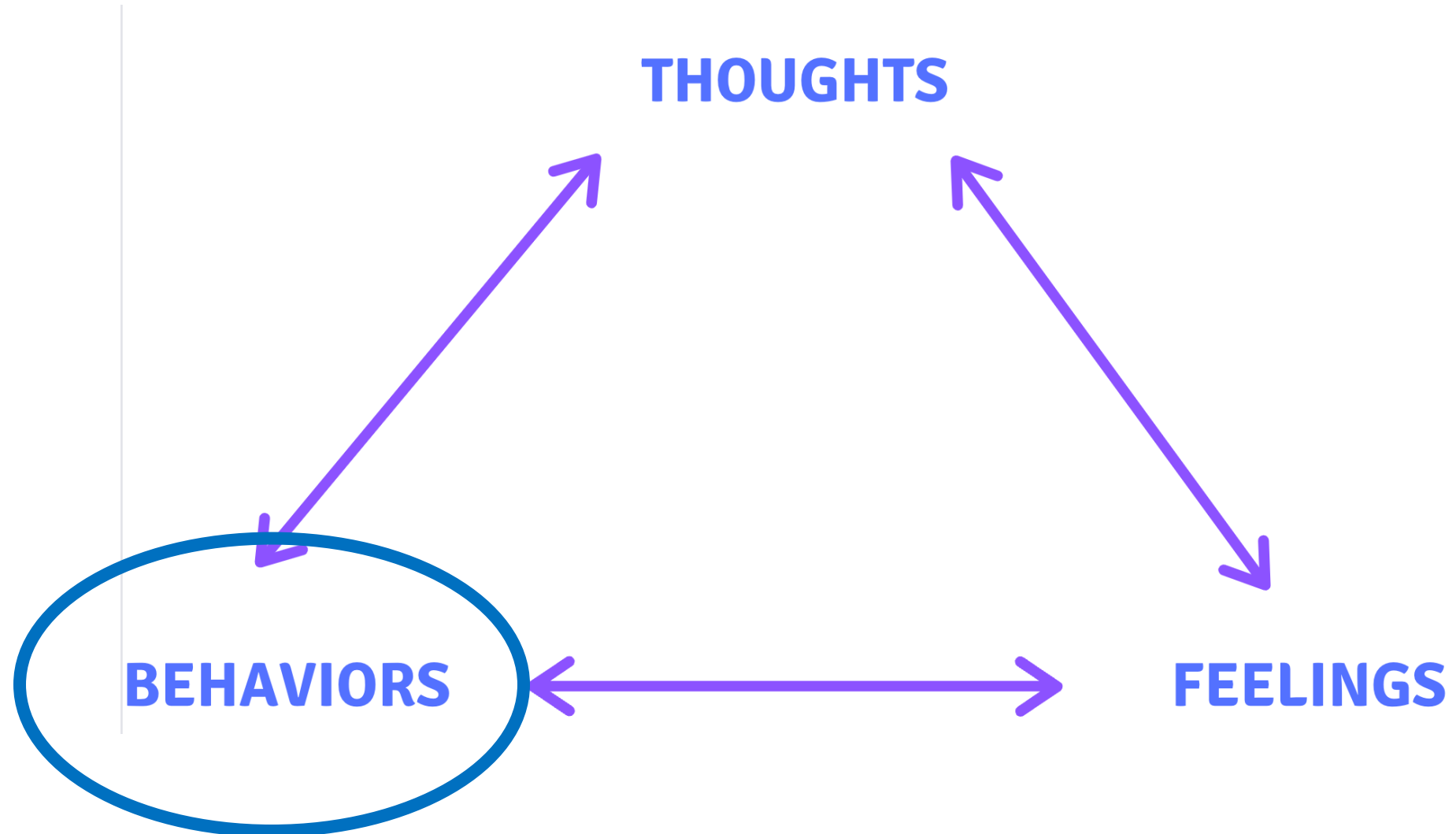
Cognitive Behavioral Therapy



Cognitive Behavioral Therapy



Cognitive Behavioral Therapy



Mindfulness



Mind Full, or Mindful?

Acceptance and Commitment Therapy

- Focus on defining what's most important to you
- Take steps towards valued goals
- Accepting situations that are out of your control



Physical
Health



Mental
Health &
Behaviors

Physical
Health



Mental
Health &
Behaviors

Health-focused interventions

- Medical cares
- Behavior pain management
- Pill swallowing
- Tolerating visits
- Talk with your medical team about your plan



Things change



“It takes a village”



friends



Resources

- **Muscular Dystrophy Association's Resources:** <https://www.mda.org/care/resource-list>
- **Anxiety Management:** Breaking free of child anxiety and OCD by Eli Lebowitz, PhD
- **Parenting books:** Parenting the strong-willed child by Rex Forehand, PhD; SOS! Help for parents by Lynn Clark, PhD
- **Neuromuscular disease books:** Dan and DMD, Running in FireFighter Boots

