

Making a Plan & Lining Up Your Care Team

Parent JOIN THE FIGHT.
END DUCHENNE.
Project
Muscular
Dystrophy

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What is the plan?



- Complex diagnosis and a complex system!
- Determine your goal
 - what's best for him/me/us ?
- Learn who's on your team
 - Come together to achieve a common goal

Who's on my team?

- Team Roster/Key Players
- Coaches
- Cheerleaders & Fans
- Officials/Rule Keepers
- Sponsors



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Where's the action?

- At home
- In community
- Away

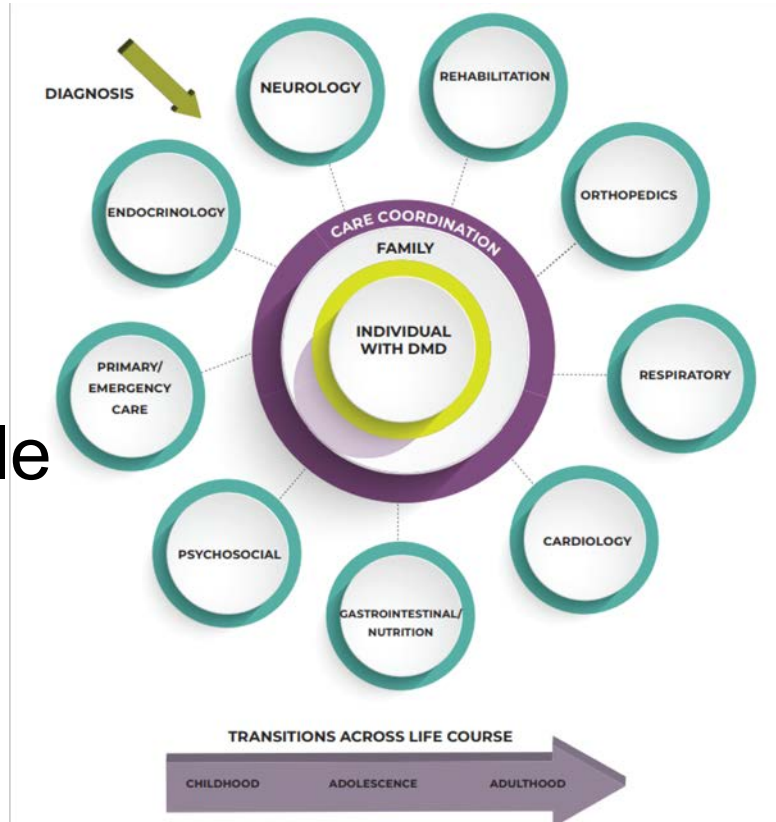


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Your Healthcare Team

Comprehensive & Multidisciplinary

- Changes over time
- Works together
- DMD Knowledgeable
- Communicates with the home team



Your First Team(s)

- Primary Care
- Neuromuscular Team



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Primary Care – Medical Home

- Well child & annual exams - IMPORTANT
 - Continuity of Care over time
- Ongoing psychosocial care
 - Whole family health, coping/adjustment
- Keep immunizations up to date
 - Annual flu shots



Certified Duchenne Care Centers



Neuromuscular Care – To Start....

- Neuromuscular Specialist
- Care Coordinator/Nurse/Social Worker
- Physical Therapist
- Genetic Counseling
- Neuropsychology



Neuromuscular Specialist

- Knowledgeable about DMD!
- Presents options for treatment
 - Steroids, mutation specific therapy
- Presents options for clinical trials
- Oversees big plan of care
- Communicates with team & PCP



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Coordination of Care TEAM

- **Nurse** – Point of contact for questions!
 - Clarifies & simplifies information
 - Identifies healthcare needs
 - Available between visits
 - Helps communicate on your behalf



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Coordination of Care TEAM

- **Social Worker** – Point of contact for questions
 - Assesses coping & adjustment
 - Knows financial resources
 - Facilitates needs being met – referrals
 - Ensure exchange of information



Physical Therapist

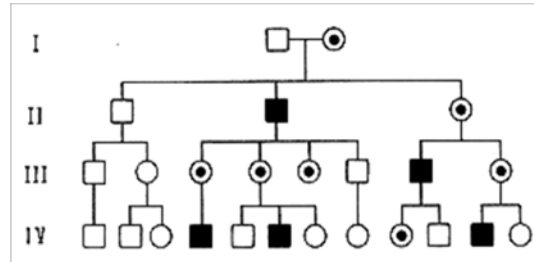
- Assessment of strength & range of motion
 - Timed tests, motor function scales
- Instruction on stretching & orthotics
- Recommendation on activity/exercise
 - Safety, equipment, school/PE, ADLs



Genetic Counseling



- Explain genetic concepts & terminology
 - Meaning of mutations in relation to treatments or trials
 - Example: explaining terms like exons & genotypes
- Identify family who may benefit from genetic counseling
 - X-linked inheritance – “who may be a carrier?”
 - Review reproductive options
 - Facilitate testing



DuchenneRegistry.org

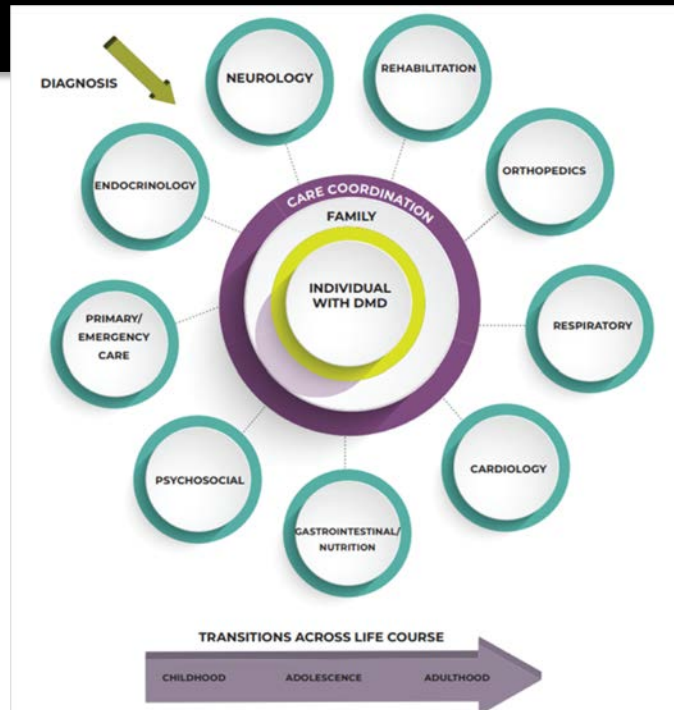
- Free access to genetic counselors
- Advance research & speed progress towards treatments
- The Duchenne Registry Coordinator
Email: coordinator@duchenneregistry.org
Phone: (888) 520-8675
Fax: (404) 935-0636
<https://www.duchenneregistry.org>



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Adding to the team ...

- Neuropsychology
- Cardiology
- Pulmonary
- Endocrinology



Get Plugged In - Community

- Websites – Go for reliable!
- Social Media – Caution!
 - “Connect” Groups
- Explore your clinic team options
 - ESO Tours, conferences, fundraisers
- Connect with others in person



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FOR FAMILIES

ASSEMBLING A CARE TEAM

Links to family
friendly guidelines

For Newly
Diagnosed

Assembling a Care
Team

Transition of Care
Through Adulthood

Classroom
Resources

Webinar & Video
Library

Home > Care > For Families > Assembling a Care
Team

Share



Print



ASSEMBLING A CARE TEAM

It is extremely important that you work with a multidisciplinary **neuromuscular team** that has experience and expertise managing all aspects of Duchenne and is able to meet the standards of **Duchenne Care Guidelines**.

Your neuromuscular team will be led by a **neuromuscular specialist** and will include many **sub-specialists**, each giving input into the best and most appropriate plan for your care. A **care coordinator** will help to organize your care, as well as communication between members of your team, your **primary care providers**, and you.



Thank you!