CARE CONSIDERATIONS CHECKLIST
EARLY NON-AMBULATORY STAGE

Parent Project Muscular Dystrophy
JOIN THE FIGHT. END DUCHENNE.

This checklist is intended for use by individuals with Duchenne muscular dystrophy or their caregivers, to help manage care. Not all people with Duchenne will need to see a specialist in each medical area below. Talk with your neuromuscular specialist about any concerns and for referrals.

At this stage, you will most likely need a wheelchair for mobility.

Neuromuscular Care

Your neuromuscular specialist (NMS) is the lead doctor for your care, who specializes in muscles. You should see the NMS about every 6 months.

- ☐ The NMS, along with the rehabilitation team, measures your function, strength, range of motion, posture, and positioning of arms and legs using the same measures and tests each time. This occurs every 6 months or as needed.
- ☐ Continue your recommended corticosteroid (steroid) treatment and other prescribed therapies; these are recommended lifelong.
- ☐ Never stop taking steroids abruptly.
- ☐ The NMS will send a summary of each visit to you, your primary care provider (PCP), and communicate with other providers as needed.

Cardiac Care

A cardiologist is a doctor who specializes in the heart who you will see every year.

- ☐ Your heart health should be evaluated every year using an electrocardiogram and echocardiogram or cardiac MRI (magnetic resonance image). These show your heart rate, rhythm, structure, and function.
- ☐ The cardiologist may require you to wear a Holter monitor for 24 hours. This is a device that shows your heart rate and rhythm over 24 hours.
- ☐ Start taking heart medications when cardiac tests show a decline in heart function or scarring of the heart muscle, or by age 10 even if all tests are normal. Cardiac medications should be continued lifelong.

Respiratory Care

A pulmonologist is a doctor who specializes in the lungs who you will see every 6 months.

- ☐ Your provider measures your how well your breathing muscles are working every 6 months using a group of tests called pulmonary function tests.
- ☐ Get the injectable flu vaccine and pneumococcal vaccine as recommended.
- ☐ Your pulmonologist may suggest manual or mechanical cough assist if your cough is weakening.
- ☐ Your pulmonologist may suggest a sleep study if you are showing signs and symptoms of shallow breathing, called hypoventilation, while sleeping.
- ☐ Depending on your sleep study results, your pulmonologist may suggest non-invasive ventilation to use during sleep.

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Rehabilitation Care

The rehabilitation team may include a physiatrist, physical therapist, occupational therapist, or speech-language pathologist. The NMS will work closely with your child's rehabilitation team on your child's physical assessments.

- ☐ See a physical therapist at least every 4-6 months for evaluation.
- ☐ Continue daily stretching routines and use recommended braces or corrective devices, also known as orthotic devices.
- ☐ Ensure proper and comfortable positioning in mobility devices.
- ☐ Begin or continue using assistive technology as needed.
- ☐ Speak to your rehabilitation team about pain and fracture prevention at each visit.
- ☐ See a speech therapist for speech and language concerns.

Orthopedic and Surgical Care

An orthopedic surgeon is a doctor who specializes in the bones, muscles, joints, tendons, and ligaments.

- ☐ Provider monitors for curvature of the spine, known as scoliosis, every year by X-ray or visual inspection. If the curve in your spine is greater than 20 degrees, you may need surgery.
- ☐ Discuss possible interventions to improve your foot position while in your wheelchair with your providers.
- ☐ Talk to your cardiologist and pulmonologist when considering any surgery.
- ☐ Talk with the anesthesiologist about safe and unsafe anesthesia before surgery. A list may be found at **ParentProjectMD.org/Surgery.**

Endocrinology and Bone Health Care

An endocrinologist is a doctor who specializes in hormones, the chemicals in the body that influence puberty, growth, and bone health.

- ☐ Tests to monitor the health of your spine and bones are recommended. The provider may use an X-ray of the spine from the side (a lateral X-ray) every 1-2 years and a DEXA scan (dual-energy X-ray absorptiometry), which measures bone density every 2-3 years.
- ☐ Discuss the use of bisphosphonates to treat osteoporosis.
- ☐ See a bone health expert at the earliest sign of fracture.
- ☐ Provider measures non-standing growth by measuring leg or arm length every 6 months.
- ☐ Provider monitors pubertal development every 6 months. You may need testosterone therapy if you have not started puberty by age 14.

Gastrointestinal and Nutritional Care

A gastroenterologist is a doctor who specializes in the digestive system. A registered dietitian nutritionist (RDN) is an expert in food and nutrition. You may be referred to these types of providers to address issues with weight gain or loss, nutrition, and digestion.

- ☐ See a Registered Dietitian Nutritionist (RDN) at every clinic visit if appropriate.
- ☐ Review your diet and fluid history and develop a nutrition plan with the RDN if needed.
- ☐ Monitor weight and BMI at each visit.
- ☐ Have an annual blood test to measure vitamin D and calcium levels. Take vitamin D and calcium supplements as needed.
- ☐ Have an assessment for problems with swallowing, acid reflux, digestion, and constipation at every visit. You may be referred to a gastroenterologist if needed.
- ☐ Discuss the possibility of placing a gastrostomy tube, or G-tube, that can deliver nutrition directly to your stomach with your provider. This may be necessary if you have trouble swallowing or maintaining weight.
- ☐ See your dentist every 6 months.

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Psychosocial Care

Psychosocial health (mental health and social well-being) is as important as physical health. Your multidisciplinary team should include a psychologist, social worker, and/or psychiatric nurse/advanced practice nurse.

- ☐ Discuss your mental health, and the mental health of your family, at each visit. Your provider can do formal or informal mental health screenings as needed.
- ☐ See a psychologist to complete a comprehensive assessment of your development, learning, and behavior if needed. This is referred to as a neuropsychological evaluation.
- ☐ Review and update your special school plans or accommodations (such as an individual education plan or a 504 plan) as needed.

Transitions of Care

Planning for the future and learning to manage your own medical care is an important part of becoming an independent adult with Duchenne. This phase is referred to as transitioning.

- ☐ Have time with your providers without your parent or caregivers at every neuromuscular visit.
- ☐ Assess your independence at every visit.
- ☐ Discuss your plans for the future with your teachers, parents, and neuromuscular team. Make sure you have education and training in place to help you reach your future goals.
- ☐ Get involved with school activities and with your friends.
- ☐ By age 13-14, start developing a written transition plan with your neuromuscular team. Review and update this plan annually. Your plan should include a list of assistive services that you'll need to live independently, a plan for who will provide these services, and how to pay for them. Get help from your social worker or care coordinator.
- ☐ You should designate a power of attorney and discuss advanced directives by age 18. Your providers or care coordinator can help you with this process.
- ☐ Discuss what palliative care can offer with your providers.

Emergency Care

Emergency room staff may not have experience caring for people with Duchenne, so it is helpful to bring emergency information with you that is specific to Duchenne. This includes information on anesthesia, fracture management, oxygen, steroid stress dosing, and more. PPMD has this information available on their website (**ParentProjectmd.org/Emergency**) to print or it is available within their free Apple or Android App (**ParentProjectMD.org/App**).

- ☐ Have emergency information, either on a card or a mobile app, with you at all times.
- ☐ Have a summary of your last NMS visit, provided by your NMS, with you at all times. These will include the diagnosis, all medications, recent test results (including heart and lung function), and any reoccurring medical problems that you may have.
- ☐ Take any equipment that you use and your medication with you to the emergency room or hospital.
- ☐ Contact your NMS if you need to go to the emergency room or hospital for any reason.
- ☐ If you are taking steroids, have a copy of the PJ Nicholoff Steroid Protocol (available at **ParentProjectMD.org/PJ**) which provides information on preventing adrenal insufficiency and indications for stress dosing of steroids.
- ☐ Take your power of attorney form to the hospital with you if you are over age 18.

Notes

Primary Care

Primary care providers (PCPs) are doctors, nurse practitioners, or physician assistants who specialize in pediatrics, family, or internal medicine. This provider should work closely with your NMS.

- [ ] Continue seeing your primary care provider for routine visits, including well checks, minor illnesses, and immunizations.

Information and Support

If you have not already done so, it may be helpful to get in touch with an organization dedicated to helping individuals with Duchenne and their families.

– Parent Project Muscular Dystrophy (PPMD): **ParentProjectMD.org**

Notes

The information in these checklists are based on the 2018 care considerations for Duchenne muscular dystrophy. This set of 3 articles was published in the Lancet Neurology and funded by the Centers for Disease Control and Prevention. Learn more here: **https://www.cdc.gov/ncbddd/musculardystrophy/care-considerations.html**