

CARE CONSIDERATIONS CHECKLIST

EARLY NON-AMBULATORY STAGE

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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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](https://parentprojectmd.org/emergency)) to print or it is available within their free Apple or Android App ([ParentProjectMD.org/App](https://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](https://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.

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