

# CARE CONSIDERATIONS CHECKLIST

## LATE NON-AMBULATORY STAGE

This checklist is intended for use by individuals with Duchenne muscular dystrophy 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 have reduced upper limb function and have difficulty maintaining good posture. Complications of Duchenne, including heart or lung problems, are more likely.

### 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 checked every 6 months using an electrocardiogram and echocardiogram or cardiac MRI (magnetic resonance image). These show your heart rate, rhythm, and 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.
- Continue taking your cardiac medications, which should be continued lifelong.

### RESPIRATORY CARE

A pulmonologist is a doctor who specializes in the lungs that 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 every year and the 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 there are 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.
- Your pulmonologist may suggest non-invasive ventilation to use during the daytime, if you are having difficulties breathing while awake.

### NOTES

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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 every 4-6 months or as often as recommended.
- Continue daily stretching routines if comfortable and use recommended braces or corrective devices, also known as orthotic devices.
- Continue using assistive technology as needed.
- Assess positioning and posture and the need for supports at each visit to prevent scoliosis.
- 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](http://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.
- Have an annual blood test to measure vitamin D and calcium levels. Take vitamin D and calcium supplements as needed.
- Discuss the use of bisphosphonates to treat osteoporosis.
- See a bone health expert at the earliest sign of fracture or back pain.
- Provider measures non-standing growth by measuring leg or arm length every 6 months.
- Provider monitors puberty development every 6 months. You may need testosterone therapy if you have not started puberty by age 14.

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**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 medications 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.

**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**

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