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DPP 01 Adjusting to the Diagnosis

Ambulatory

(bold words should have emphasis)
(223 words)

If you have just received the diagnosis of Duchenne muscular dystrophy. You probably have many questions and are wondering how this will affect your life and your family. In nearly every country, there are organizations that can answer your questions and give you support and resources about Duchenne.

Duchenne is a genetic disease. People with Duchenne are born with a change - or mutation - in the gene that produces dystrophin, a protein that protects muscles. 70% of mothers of Duchenne patients do not have the disease themselves but are **carriers** of the mutation and pass it to their child; 30% of the time, the mutation can happen **spontaneously**. Genetic testing will confirm the diagnosis of Duchenne and show the exact mutation in the gene. As some new therapies may only treat certain Duchenne mutations, this will be important information to have.

Because dystrophin is missing from all of the muscles, many body functions are involved and need attention by different medical subspecialists. It is important that a team that includes all of these subspecialists provides Duchenne care.

A mother of a child with Duchenne should get a genetic test to find out if she is a carrier. If so, other female family members may be at risk of being carriers as well and should discuss this with their doctor. Especially before getting pregnant.

DPP 02 Behavior and adjustment

All

(bold words should have emphasis)
(294 words)

Growing up is a process of dealing with stresses and challenges. Boys have to cope with normal stress situations – for instance: a first bad grade at school – but also with illness related stress situations – like learning to drive your first wheelchair or having a medical procedure that may cause pain. One important stress situation you have to deal with is waiting: wait for others to help you, wait to have things your way.

The good news is that we know from research that most boys grow into a better adjustment as they grow older. In other words: you learn to adjust to these difficult situations as you grow older. One important protective factor is help from friends and others. So you should be stimulated to spend time socializing.

In some cases boys and young men with Duchenne are developed behavioural psychiatric disorders. It is believed that these behaviour disorders may be related to dystrophin in the brain. Three behaviour problems are important to remember. First, attention problems may bother you as in attention deficit hyperactivity disorder or ADHD. Which has to do with difficulty staying focused and paying attention. Or stopping your behavior once you started it. Secondly unwanted and recurrent thoughts may bother you and result in repetitive behaviours such as hand washing or counting. Which is called obsessive compulsive disorder or OCD. Finally, social interaction may be impaired due to autism. This may lead to difficulty with change, focus on details and an inability to empathize with others.

These behaviour problems make raising boys with Duchenne more difficult. If you have any doubts or questions you should ask your specialist for advice. A psychologist or psychiatrist may help in making a diagnosis and a treatment plan. Early detection is key.

DPP 03 Bone Health

All

(bold words should have emphasis)
(207 words)

Bone health is important to reduce the risk for fractures.

Breaking bones is more often seen in Duchenne, not only because of more frequent falls but also because of the quality of the bones.

For your bones to stay healthy Calcium and vitamin D are important. Be sure to eat foods high in calcium and vitamin D, and to get outside - sunshine gives you even more vitamin D.

The doctors will check your diet and levels of vitamin D each year. If levels are low, you may need to take a supplement.

If you are not walking, but able to stand, it is important to spend some time standing each day using a standing frame, long leg braces or wheelchair stander. This will help the bones in your back and legs stay stronger.

The doctors will check your bones every few years using a DEXA scan and x-rays. The DEXA scan will measure the thickness of your bones; the x-ray will look for small breaks, or fractures, in your backbone or spine.

If your bones are a little thin, it is advised that you see an endocrinologist. This doctor may prescribe medicines, called bisphosphonates.

This medicine will help your bones to be thicker and stronger.

DPP 04 Cardiology

All

(bold words should have emphasis)
(269 words)

Your heart is a muscle too and must be checked at **least** yearly from the time you get the diagnosis of Duchenne. The doctor who looks after your heart is called the cardiologist. This doctor will listen to your heart to be sure that it sounds like it should. He will do a test, called an EKG, to check how fast your heart beats and the rhythm of those beats.

If your heartbeat needs to be checked longer, the doctor may ask you to wear a Holter monitor. This is a small portable device - no larger than a cell phone - that will measure your heartbeats for one or more days. They will get either an echocardiogram or a MRI of the heart – these tests allow the cardiologist to look at your heart and to make sure it is the right size and is pumping blood correctly.

The cardiologist will **also** measure your blood pressure. If heart problems are found, medications, called either ACE inhibitors or angiotensin receptor blockers, will be prescribed. These treatments should be started at least by age 10, even if your heart tests are completely normal. They will help to keep your heart strong. If the heart does become weaker, other medicines, such as beta blockers or carvedilol for instance, and antimineralcorticoids, spironolactone or Eplerenone, will be added as needed.

If you have severe chest pain that does not go away, you should call your cardiologist and go to the emergency room. Tell the medical staff that you have Duchenne and that this might be a sign that your heart is in trouble.

DPP 05 Cardiac devices

Late LoA

(bold words should have emphasis)
(239 words)

Some people living with Duchenne muscular dystrophy may have heart rate and rhythm issues: 'Heart rate' is how fast or slow your heart beats; 'heart rhythm' is the coordination of those heart beats. An EKG will monitor both your heart rate and rhythm; this should be checked every 6 months. If issues with heart rate and rhythm are detected, there are small devices that can record the heart rate and rhythm, and some that may help the heart to beat normally.

A loop recorder is a device that will record your heart's rate and rhythm. This will let your cardiologist know if you might need additional cardiac monitoring or new, or different, medication.

A pacemaker is a device that will also record, and can help to control, your heart's rate. A pacemaker uses small electrical pulses delivered to your heart, that will either speed up, or slow down, your heart rate, if your heart rate becomes abnormal.

An intra cardiac device, or ICD, will also monitor the rate and rhythm of your heart. If the ICD senses that your heart is in a dangerous rate or rhythm, it can deliver a small shock that will help put your heart back to normal.

All of these devices are very small, and are implanted under the skin, or into the chest wall or abdomen, during a brief minor surgery.

A ventricular assist device or artificial heart may also be an option.

DPP 06 Emergencies

All

(bold words should have emphasis)
(359 words)

Emergencies happen to everyone. If you have an emergency and need to go to the emergency room, there are some special things that people with Duchenne go to do.

Take your emergency card with you. This will let you and the emergency room staff know what to look out for.

If you have a smartphone, there is also an app that you can download that has all of the emergency information on it.

If you use a cough assist machine or breathing machines at home, take them with you to the emergency room.

Take all of your medications with you to the emergency room. You must call your neuromuscular specialist and let them know that you have had an emergency. They can work with emergency room doctors to make sure that you receive the right treatment. Also call your heart or pulmonary doctors if you are having a heart or breathing emergency.

If you take steroids every day, let the doctor know that you must not go more than 24 hours without taking steroids.

If oxygen is needed, your carbon dioxide should be measured in the air that you breathe out or in your blood. Giving oxygen without measuring your carbon dioxide is very risky in Duchenne.

If you have fractured a bone, or had a bump that may have caused a fracture, tell the doctor that you are at risk for FES. FES is a condition where the fat in your chest and the teachers have some fat inside. When a bone breaks, pieces of the fat are released and may get into the bloodstream. If the fat then travels to brain, lungs or heart, it can cause FES, which can be life threatening.

If you have a fracture, or a bump that could maybe cause a fracture, you should watch out for signs of FES. These include difficulty breathing, pain in your chest or head and a change in your behavior, like confusion, dizziness or acting like yourself. If any of these signs are noticed go **IMMEDIATELY** to the emergency room. This is an **EMERGENCY**. Take information from the internet about FES and tell the medical staff that you suspect FES.

DPP 07 Gastro Intestinal and Urinary Tract

All

(bold words should have emphasis)
(266 words)

Eating healthy is important for everyone, but especially if you have Duchenne. Getting the right amount of calories and eating many types of food will give your body the energy and nutrition it needs. A nutritionist can help you to develop a diet that is healthy for you. Ask if a daily multivitamin might be helpful!

Do not eat too much – gaining too much weight is hard on your muscles, bones, lungs and heart. It's also important to drink enough water – this will help with the food going in ... **and coming out** :-)

Many people with Duchenne have problems with constipation. Keep track of your bowel movements and tell your doctor if you are having stomach pain or going more than 1 to 2 days without having a bowel movement. These may be signs of constipation, which is risky for Duchenne and should be treated. There are medicines that will help your bowels move regularly and get rid of the pain.

Also let your doctor know if you are having urine leaking during the day or the night, pain when you urinate, have the feeling that you need to urinate **RIGHT NOW** or urinating more frequently than your friends. Mention these signs to your doctor - there may be a medicine that can help.

You must have healthy teeth to chew! Be sure your teeth are brushed 1 or 2 times a day and see a dentist every 6 to 12 months. Rinsing your mouth and drinking after eating will help to keep food out of your mouth and throat between meals.

DPP 08 Breathing assistance

Early LoA, Late LoA

(bold words should have emphasis)
(385 words)

(please pronounce BiPAP as 'bipap', and CPAP as 'seapp' not as single letters)

Sometimes people living with Duchenne have difficulty breathing. Not breathing well during sleep can make you feel very tired, have headaches in the morning when you wake up or make you feel so groggy during school that you aren't able to do your best. If this happens, you may need a machine to help you breathe. There are several types of machines that can help with breathing. Each machine helps with different breathing problems. To find out what kind of breathing problem you have, you will need a sleep study. For the **sleep study**, you will have to come to the hospital and sleep overnight with a mask on. The mask will help to measure your breathing in and out. The mask doesn't hurt, but it might feel a little funny at first! But you will soon get used to it and fall fast asleep.

The two main breathing problems in Duchenne are "obstructive sleep apnea" and "hypoventilation."

Obstructive sleep apnea means that something is **obstructing**, or getting in the way of your breathing. This obstruction makes you occasionally stop breathing, and maybe snore, getting less total air in and out while you sleep. This is sometimes a problem for younger people with Duchenne. A CPAP machine will use one pressure to help get air into and out of your lungs and is helpful if obstructive sleep apnea is the problem.

Hypoventilation literally means **less breathing**. When people with Duchenne are a little older, the breathing muscles can become weak which causes people to breathe more shallowly. With shallow breathing, less air is going in and out. A BiPAP machine will use 2 pressures - one for breathing in, and one for breathing out - to help avoid shallow breathing. A BiPAP machine can be used while asleep or awake. A CPAP machine will **not** be helpful for hypoventilation in Duchenne.

There are some challenges with breathing machines but don't be discouraged. You may need to try several different masks before finding the perfect one. Also, you will need to get used to the pressure of air on your face. Try wearing the mask without the BiPAP first, slowly turning up the BiPAP, while you are awake.

Don't give up! After you get used to sleeping with the machine, you will feel **SO** much better!

DPP 09 Growth

Ambulatory, Early LoA

(bold words should have emphasis)
(95 words)

Many people living with Duchenne are shorter than their peers. And the use of steroids may cause short stature as well. For some people, being shorter than their peers makes them feel uncomfortable; for others it is not a problem.

It is important that growth is checked at each visit to the doctor, and at least once a year. If growth is under three centimeter per year, it is advised to see an endocrinologist for an evaluation of growth hormone. If there is a low level of growth hormone, this can be treated with medication.

DPP 10 Learning and intelligence

All

(bold words should have emphasis)
(289 words)

In general, the cells in a Duchenne patients brain are in good health and remain so. But in some cases, intelligence may be lower than average. However, and most importantly, learning to read and learning arithmetics - for example multiplication tables - may be an important issue during your school career. It is suggested that specific cognitive functions like automatization, concentration and working memory may be more difficult for Duchenne boys and men. This is probably caused by the lack of dystrophin in the brain. So the brain may be involved, but this is definitely not progressive.

It is important to watch out for signs of possible learning disabilities and to act quickly when you discover them.

Reading is very important for your future as our society is reading based, like reading books, emails, and messages etcetera. So it is essential that you parents and teachers are aware of this higher risk of learning problems. If they have questions about your intelligence, or when speech development or learning to read is progressing too slowly, there may be a reason for further psychological testing.

Ask your medical specialist to start this procedure.

A speech therapist may evaluate language capacities and a psychologist may test intelligence, working memory and concentration. Testing is fun and seldom causes unnecessary stress. The result of these tests may help to make an individual therapy plan and an individual learning plan. Early detection is key.

Technical aids like computer programs or smartphone apps may also help to compensate. Boys with Duchenne should preferably go to a regular school, and the majority of them does so. Regular school has a lot of advantages for both the boys themselves and their peers. But sometimes individual or special education is needed.

DPP 11 Orthopedics

All

(bold words should have emphasis)
(454 words)

(please pronounce FES as letters, not as a word)

It is important to keep **all** parts of your body that can move, moving... **every day**. This will prevent the joints of your body from tightening up and developing so called contractures, which means that your muscle becomes shorter and your joint less flexible. Stretching and wearing ankle-foot braces while sleeping. Wearing shoes - not slippers - while awake. This will help to prevent contractures. When a wheelchair is needed, having the correct seating position is necessary to prevent contractures and scoliosis, which is curvature of the spine. If you are able to stand, spending some time standing each day - with a standing frame, long leg braces or a standing wheelchair - may also help to prevent scoliosis and keep leg bones healthy.

The doctor will check your back in the clinic at least once a year and he will take an X-ray if needed to see if scoliosis is developing. Severe scoliosis can be corrected with surgery. Having good posture while sitting may help to prevent the need for surgery. It is also important to have good ankles and knee position. Sitting with the knees too wide or the feet not flat may cause contractures in the hips, ankles and feet. If you have contractures in your feet, it may not be possible to wear shoes.

If a bone is broken and you go to the **emergency room**, be sure to tell the medical staff if you are taking steroids, and that you have Duchenne and being on your feet is very important. If your broken bone is casted, you may not be able to walk for a few weeks, which may cause you **lose** the ability to walk! Ask if surgical fixation is possible, that will allow walking sooner than casting.

A few things to keep in mind to avoid fractures are:

- Walk carefully on uneven surfaces
- Wear non-slip shoes
- Hold the handrails on a stairway
- Wear your seatbelt in the wheelchair
- And use a non-slip tub or shower mat

In Duchenne, the bones have some fat inside. When a bone breaks, pieces of the fat are released and may get into the bloodstream. If the fat then travels to brain, lungs or heart, it can cause Fat Embolism Syndrome or FES, which can be life threatening. If you have a break, or a bump that could maybe cause a break, you should watch for signs of FES. These include: difficulty breathing, pain in your chest or head and a change in your behavior, like confusion, dizziness, not acting like yourself, etcetera.

If any of these signs are noticed, go **immediately** to the emergency room. This is an **emergency**. Take information from the internet about FES and tell the medical staff that you suspect FES.

DPP 12 Physiotherapy

Ambulatory

(bold words should have emphasis)
(231 words)

Because Duchenne affects all of the muscles, it is important to pay attention to the strength, function and movement of all parts of the body. You will need to find a physical therapist (PT) familiar with Duchenne. The PT will help you with exercises that will help you keep your body moving. These stretches should be done at least once per day. The PT will work with Rehabilitation medicine to prescribe foot and ankle braces to wear during sleep. That will help stretch your heel cords so you can maintain walking ability as long as possible. Also, they will monitor the muscles and track muscle strength and function. The PT will talk to you about what activities are safe and what activities to avoid.

In general, activities that **move** your muscles but do not put **stress** on your muscles - like swimming - are good for you. Activities that put stress on your muscles - like walking up or down hills - should be avoided. Every four to six months, muscle strength and function should be evaluated by your physical therapist.

Falling can be very dangerous. To avoid falling, be especially careful outdoors and on uneven surfaces, and wear non-slip shoes when you are on slippery surfaces. Make sure to use non-slip bath or shower mats and use handrails on both sides of stairways for support. **And always wear your shoes!**

DPP 13 Physiotherapy

Early LoA, Late LoA

(bold words should have emphasis)
(267 words)

If your muscles start to get tired, using walking aikes, scooters or manual wheelchairs may help to give your muscles a rest. Using knee-ankle-foot braces or KAFO's may help you walk a little longer. When walking is no longer possible, and if you have a standing device, it is very important to spend some part of each day standing.

Besides moving regularly you will also need to exercise your lungs. Your personal trainer will teach you how to stack air in your lungs to help your breathing muscles.

If you are using a wheelchair, your physical therapist will check the way you sit in your scooter or wheelchair to make sure that your body is supported and in the proper position.

Falling is very dangerous, so wear your seatbelt at all times and use anti-tippers on your wheelchair to prevent tipping over.

Using a lift system may help support you and lower risks of injury during transfers.

Stretching the muscles at least once a day, and wearing ankle and foot braces during sleep, will help prevent muscle tightening and will allow the muscles of the legs and feet to function longer. Breathing in and being very tired during the day. **And be sure to change your body position regularly.**

It is also important to stretch the muscles in the neck, shoulders, elbows, wrists, hands and fingers to keep them moving and functioning. Keeping the body active and moving is important and there are many activities, like swimming, wheelchair soccer or hockey that are fun and help your body stay strong. **Move everything that you can, every day!**

DPP 14 Puberty

Early LoA

(bold words should have emphasis)
(110 words)

Puberty is a natural part of growth and development. There are several stages of puberty. A doctor should check the stage of puberty at least once yearly from the age of 9. Puberty usually starts before the age of 14. If it has not started by age 14, it is advised that you see an endocrinologist – that is a doctor who is specialized in the treatment of hormones. The endocrinologist will check your levels of testosterone, and if none there is, start puberty to start. If testosterone is low, supplemental testosterone will allow puberty to begin and progress normally. Adequate testosterone levels are necessary for puberty and help with bone health.

DPP 15a Pulmonary

Ambulatory

(bold words should have emphasis)
(301 words)

(please pronounce BiPAP as 'bipap', and CPAP as 'seapp' not as single letters)

The doctor who looks after breathing is called a pulmonologist. You will need to take a test each year, called a pulmonary function test - or PFT - to measure your breathing. During the PFT a machine measures how deep you can breathe, how strong your breathing muscles are and how well you can cough. The therapist may teach you exercises to do at home that will help to keep your breathing muscles strong and flexible. These exercises are called air stacking. If your cough becomes weak, you may need assistance to move the mucus out of your lungs. Your therapist and pulmonologist will show you ways to help assist your cough. It is possible to manually assist coughing or to use a cough assist machine.

Getting your vaccines, such as pneumovax and yearly influenza vaccines, will help you keep fit. If you have a cold or other illness that affects your breathing, it is important to see your doctor early. You may need medicine to prevent this illness from becoming worse. When you're sick it is extra important to cough regularly and use cough assistance or ambubag when needed.

When you see the pulmonologist, be sure to tell them any breathing problems that you are having. Signs that you may be having problems breathing include snoring, headaches in the morning when you wake up and being very tired during the day. The pulmonologist may ask you to get a so called sleep study to see how you are breathing at night. This test will let you know if you might need assistance with breathing during sleep. If the sleep study shows that you do need assistance with breathing during sleep, the doctor may order a machine, called a CPAP or BiPAP machine, that will help you to sleep and breath well.

DPP 15b Pulmonary

Early LoA, Late LoA

(bold words should have emphasis)
(359 words)

(please pronounce BiPAP as 'bipap', and CPAP as 'seapp' not as single letters)

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If you breathing becomes weak while you are awake, you may need breathing assistance while awake and asleep. Breathing assistance can be given either by removable facemask or by a tube that is placed into your windpipe, also called trachea. Your doctor will discuss both of these options and help you to choose the best option for you.

DPP 16 Steroids

Ambulatory

(bold words should have emphasis)
(217 words)

Steroids like prednisone, prednisolone, calcort or deflazacort are known to slow the loss of muscle strength and motor function in Duchenne. The goal of steroid use is to help continue walking longer, preserve upper limb strength and breathing, and to help keep the spine straight. Steroid use should be started early, but not before the age of 2. Steroids can be taken many different ways for instance: daily, weekly, 10 days off/10 days on, etcetera. Daily dosing has been found to be the most effective, but may cause more side effects. Prior to starting steroids, childhood vaccines should be complete and immunity to chicken pox should be checked.

Steroids may have side effects that should be watched, such as behavior changes, decreased growth, weight gain, delayed puberty, shoulder monitoring, cataracts, and blood pressure changes. Your neuromuscular specialist should monitor these at every visit. It will be important for you to eat a healthy diet that includes adequate calcium and vitamin D. Stopping daily doses of steroid suddenly can be very dangerous – even life threatening. If you have to vomit and have missed your steroid doses for more than 24 hours, call your neuromuscular specialists or go to the hospital. In any medical situation, be sure to let the medical staff know that you are taking steroids.

DPP 17 Steroids

Early LoA, Late LoA

(bold words should have emphasis)
(146 words)

It is important to continue to take steroids after loss of ambulation. Steroids will help to maintain upper body strength, arm and hand strength and breathing. Attention to the side effects of steroids is needed to continue as long as they are taken. Weight, height, puberty, bone health, pain, behavior and blood pressure should be monitored at least yearly. Continued healthy eating, with adequate amounts of calcium and vitamin D are important. Vitamin D levels should be checked every year and supplemented as necessary.

It is **extremely** dangerous to stop taking steroids immediately – even life threatening. If you want to discontinue taking steroids first discuss it with your neuromuscular specialist.

If you are unable to take your steroids for over 24 hours, call your neuromuscular specialist or go to the hospital. In any medical situation, always let the medical staff know that you are taking steroids.

DPP 18 Surgery

All

(bold words should have emphasis)
(221 words)

If you need to have a surgery, it is important to have it done at a hospital that is familiar with Duchenne. Even if your surgery has nothing to do with Duchenne - for example, many people need to have their appendix removed - it is important that everyone involved in the surgery is aware of the special surgical needs of Duchenne patients. Alert your physical therapist that your surgery is coming up. They will help with you to get you up and moving safely after the surgery. To make sure that it is safe for you to receive anesthesia, have your heart and lungs checked before surgery.

Anesthesia is the drug that puts you to sleep during surgery. Some types of anesthesia are not safe in Duchenne. Make an appointment with the anesthesiologist before the surgery to be sure that they know this:

NEVER use succinylcholine! This is a very dangerous drug in Duchenne and should never be used.

Always avoid inhaled anesthesia. IV anesthesia is safe in Duchenne, inhaled anesthesia, or other gas can be risky.

Local anesthesia and nitrous oxide also known as laughing gas, are safe in Duchenne.

A list of unsafe and safe anesthesia can be found on the PPMDD website. Make sure the anesthesia doctors have this list.

DPP 19 Transition

Early LoA, Late LoA

(bold words should have emphasis)
(310 words)

As you grow older, you will need to think about where you will receive adult Duchenne care. You should start to develop a plan to transition from your pediatric doctors to adult doctors around age 14 – most people move to adult doctors around age 18. Your pediatric doctors will help you to find adult doctors that can provide neuromuscular care, as well as care for your heart, lungs, bones, and the rest of your body.

You will also need to have a family doctor to make sure that your adult health needs are addressed. Your pediatric doctor can help you to find an adult family doctor near your home.

If you are receiving financial assistance or medical insurance from your state or country, you may need different arrangements as an adult. Ask your doctors what you or your parents need to do to make changes to your financial assistance and medical insurance.

All adults should develop an emergency care plan – this plan states what you want done to your body in an emergency situation. Some hospitals call this an Advanced Directive. Ask your doctors and parents to help you to develop your own emergency care plan.

You will need to have a plan for what you will do after high school – will you work? Or go to university? Or learn a trade? Start to think about what you will do so that you can plan ahead and live your dreams!

You may choose to live at home with your parents or live independently. There are many options. Start to talk with your doctors and parents about which option might be best for you.

Romantic relationships are a part of growing up. If you have questions or concerns about romantic relationships, talk with your doctors about them. They will be able to answer all of your questions.