

Duchenne Patient Information For Children

(Target Group 6–12 years)

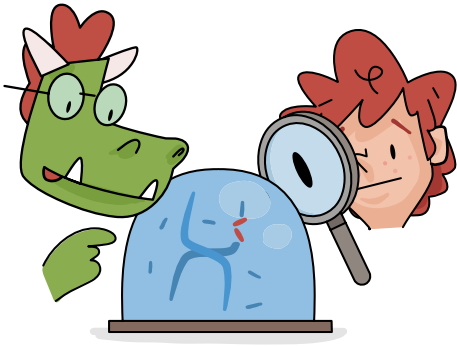


6–8 years: this booklet is best read together with the parent(s)/carer.

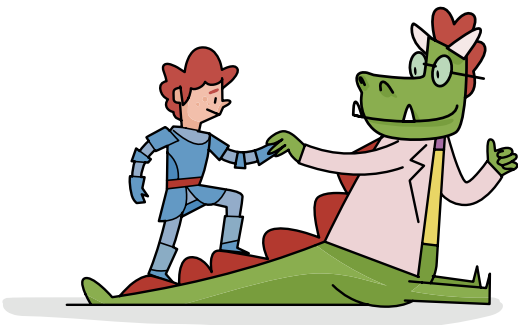
9–12 years: children can read it on their own but parents should be available to answer questions.

The Purpose of This Booklet

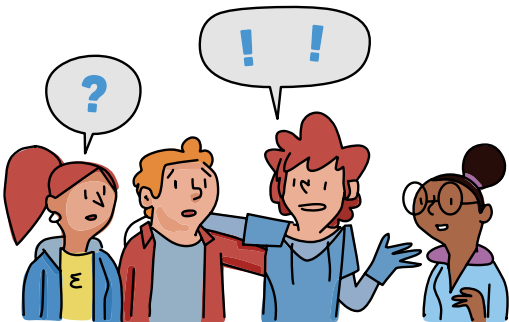
This booklet is about Duchenne disease.



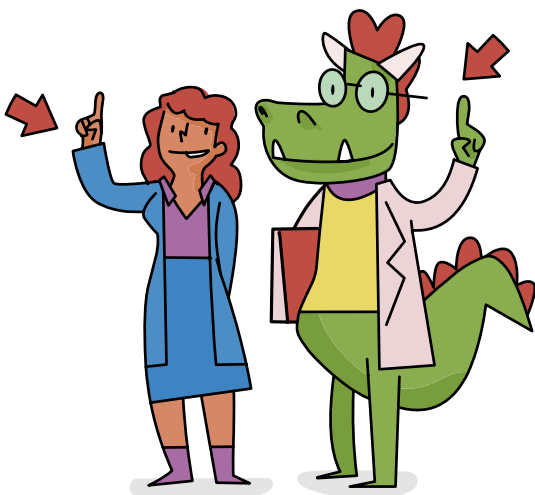
It explains the disease, how it develops, what the symptoms are and what medication you can take.



You can also use this booklet to find out what you need to do to stay as healthy as possible and who can help you.



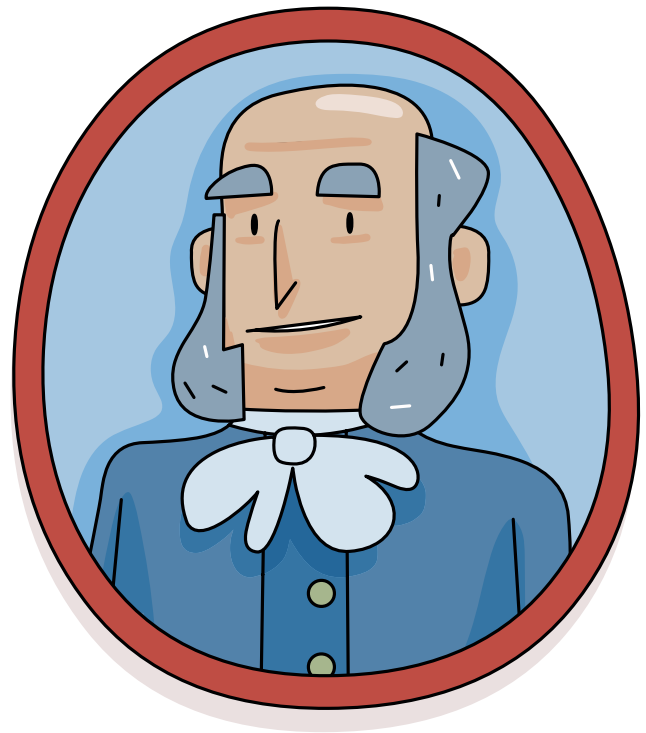
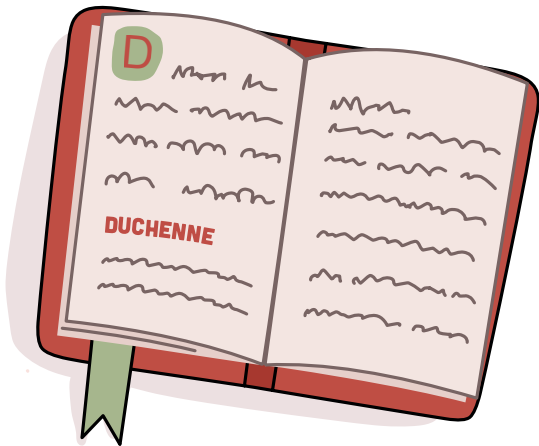
We will give you tips on how to talk about this at school, with your friends and with your family.



We will also tell you who to contact if you have any questions or want to talk about your disease.

Duchenne Disease

Dr Duchenne was the first doctor to describe the disease.



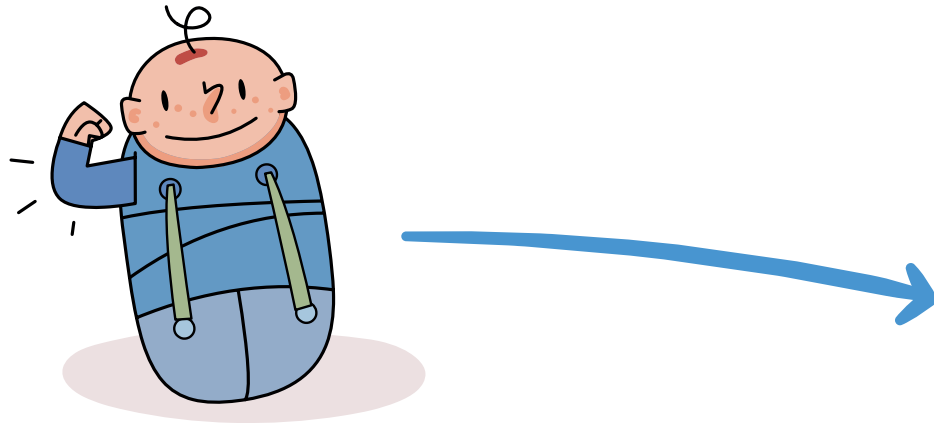
Other names for this disease are:
Duchenne muscular dystrophy

English term:
Duchenne muscular dystrophy

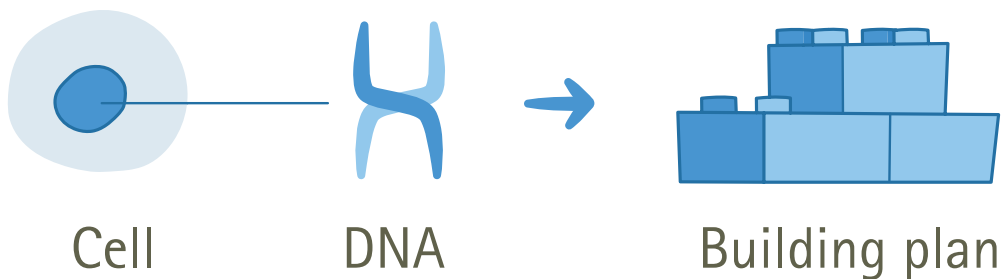


What these difficult words mean is that the muscle fibres slowly break down so that the muscles can no longer work properly.

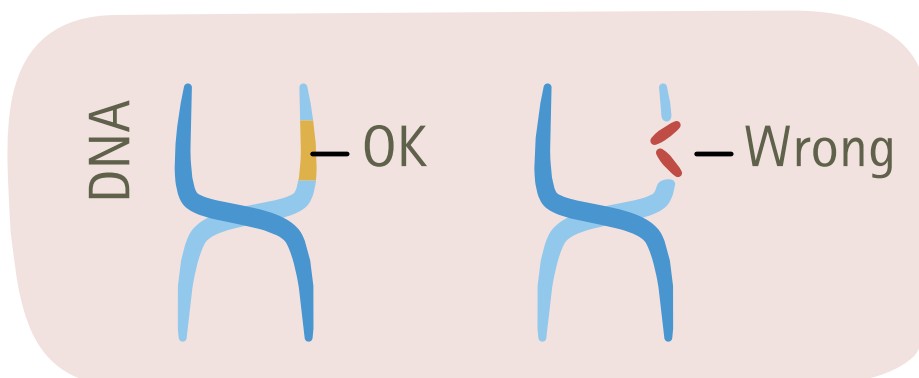
What is wrong with me?



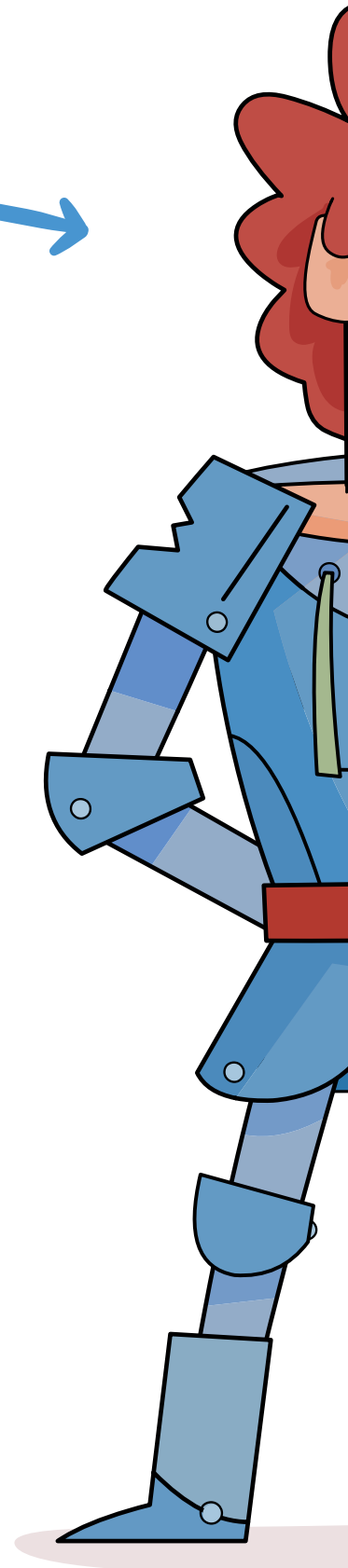
This disease is genetic, meaning that you are born with it.

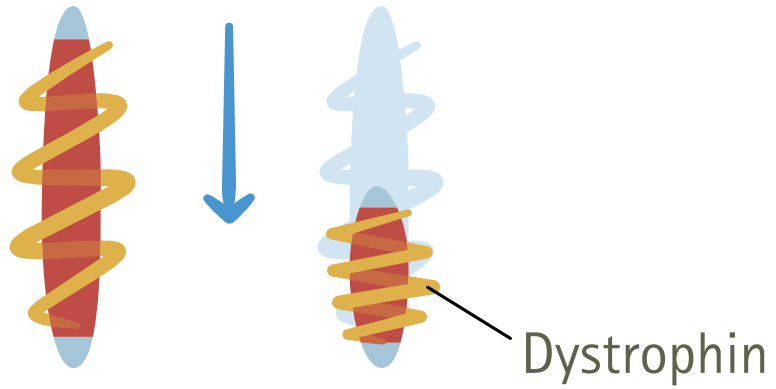
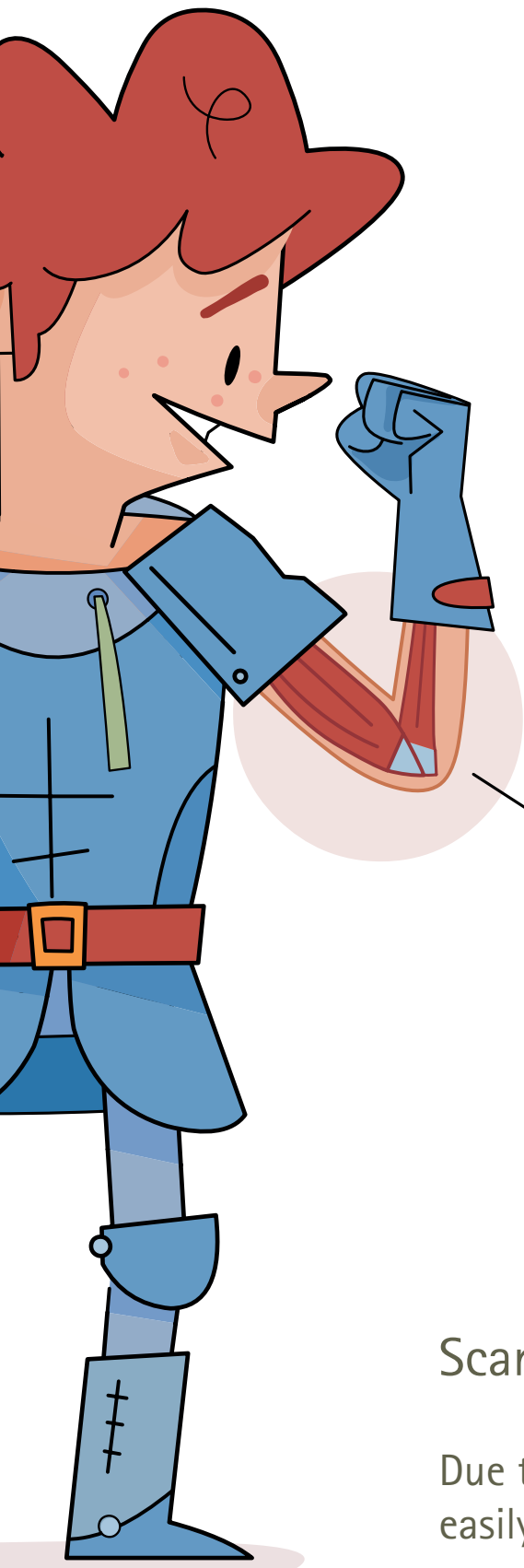


The nucleus of cells in your body has a genetic code (DNA) that determines all your characteristics. This genetic code is your unique building plan.

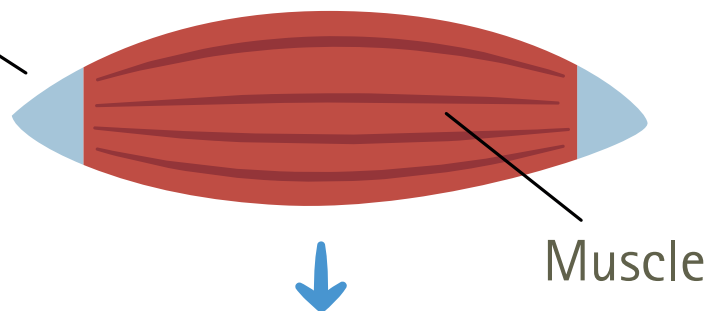


There is an error somewhere in your genetic code which means that your body does not produce the dystrophin protein properly.





This dystrophin protein is a kind of shock absorber that allows your muscles to contract and relax normally without being damaged.

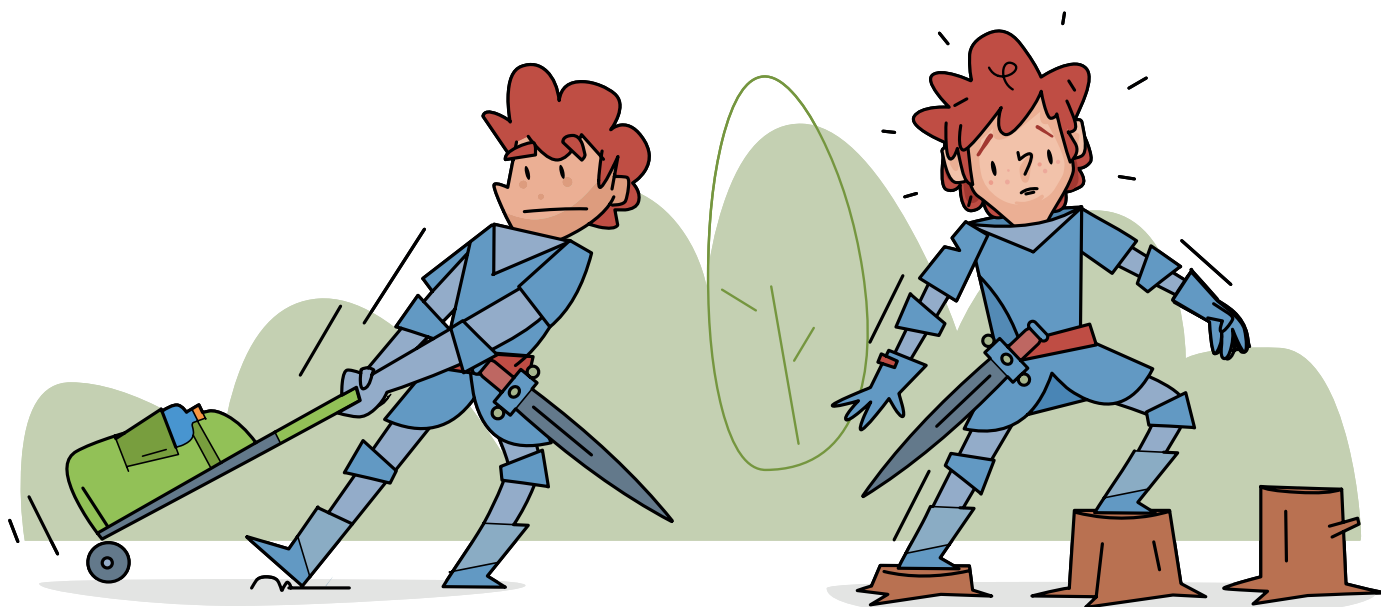


Scar tissue

Damaged muscle

Due to the lack of dystrophin, muscle fibres are very easily damaged, even during normal movement. This causes your muscle cells to break down slowly and be replaced by scar tissue.

What does this mean exactly?

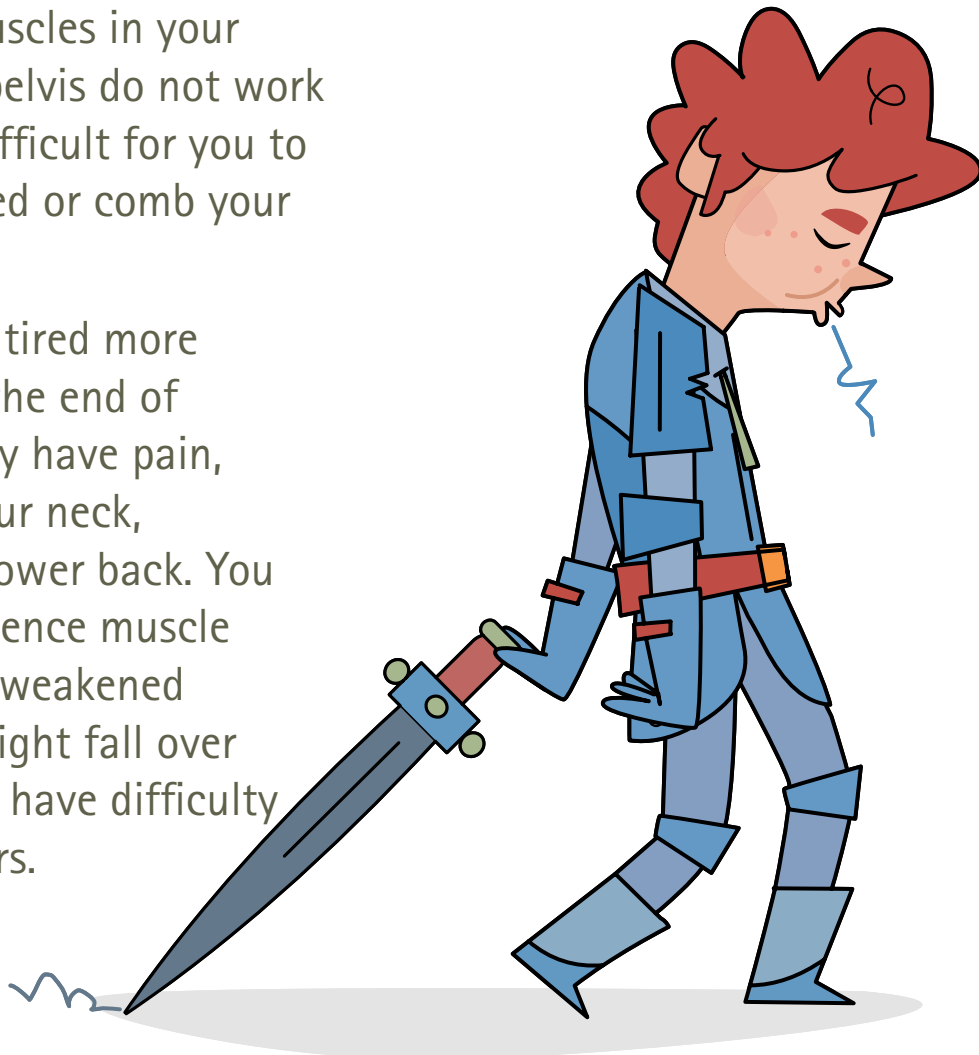


As a result, your muscles can no longer work properly and you lose strength.

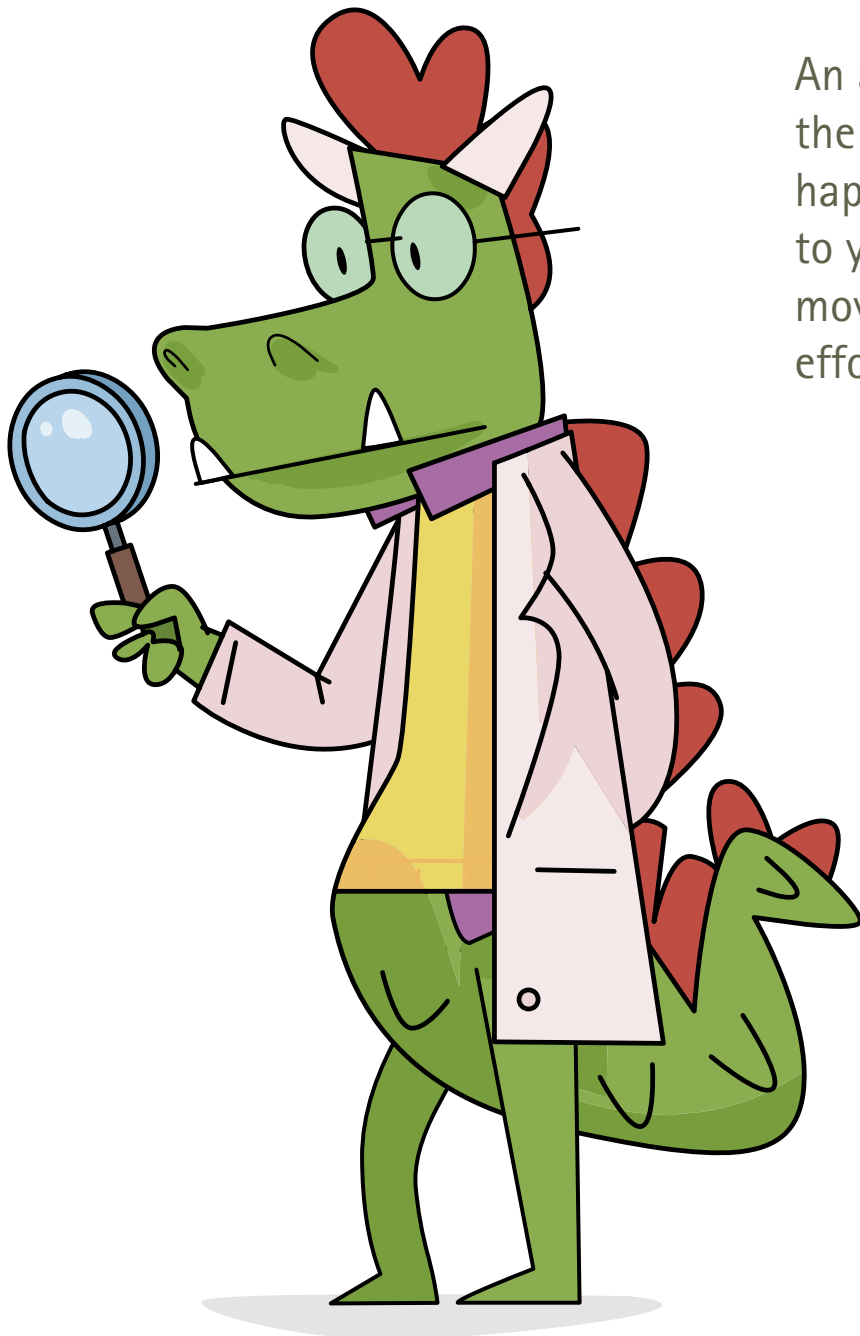
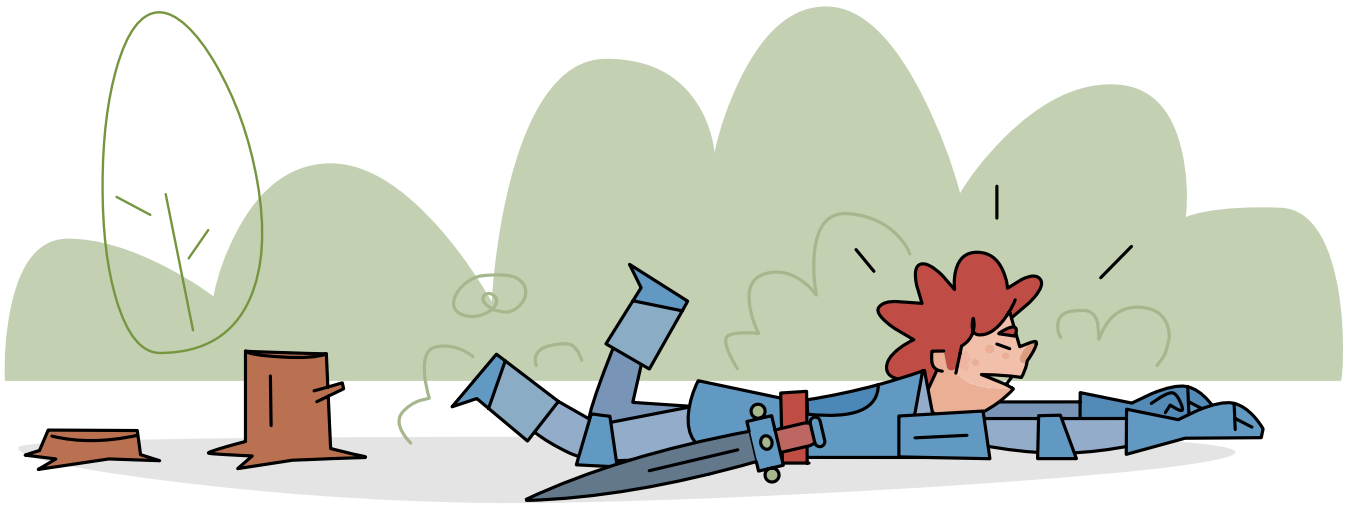
It takes more effort to live your daily life.

Because the muscles in your shoulders and pelvis do not work properly, it is difficult for you to walk, get dressed or comb your hair.

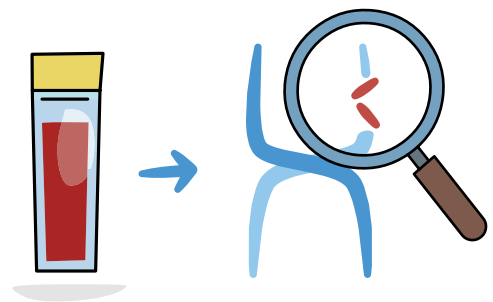
This makes you tired more quickly and at the end of the day you may have pain, especially in your neck, shoulders and lower back. You may also experience muscle cramps in your weakened muscles. You might fall over more often and have difficulty walking up stairs.



How did they find out?

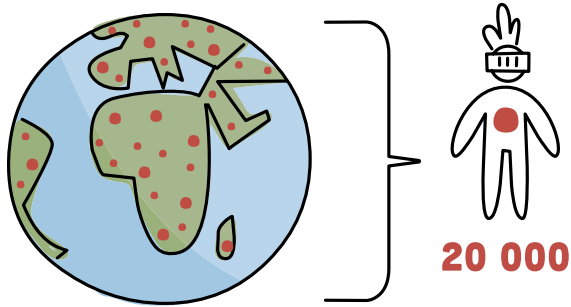


An appointment will be made with the doctor to find out why this happens. The doctor will listen to your parents and see how you move (e.g. if you have to make an effort to stand up or walk a bit).

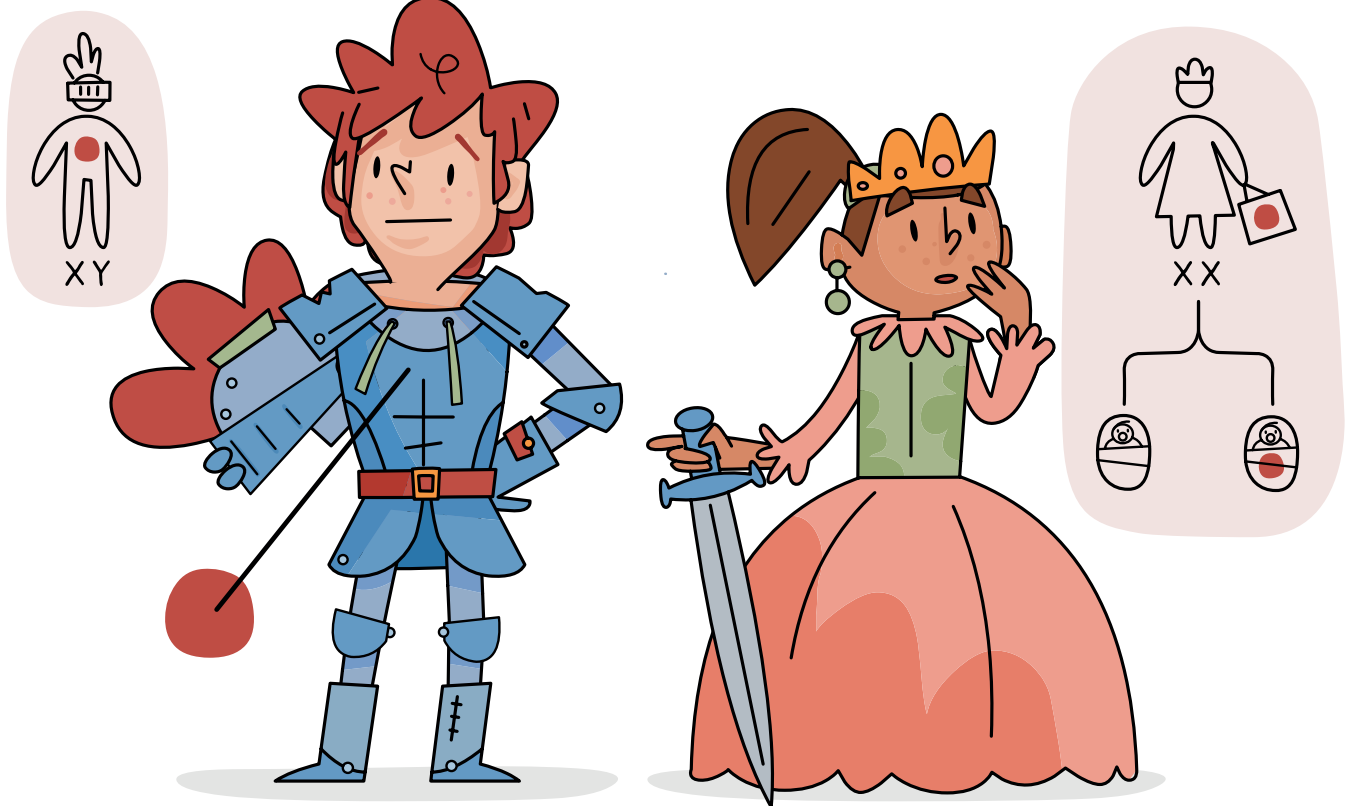


Doctors can detect the error in your genetic code by testing your blood or by checking a piece of your muscle to see if there is enough dystrophin protein.

Am I the only one who has this?



Every year about 20,000 boys are born with the disease worldwide (1/3500 births).



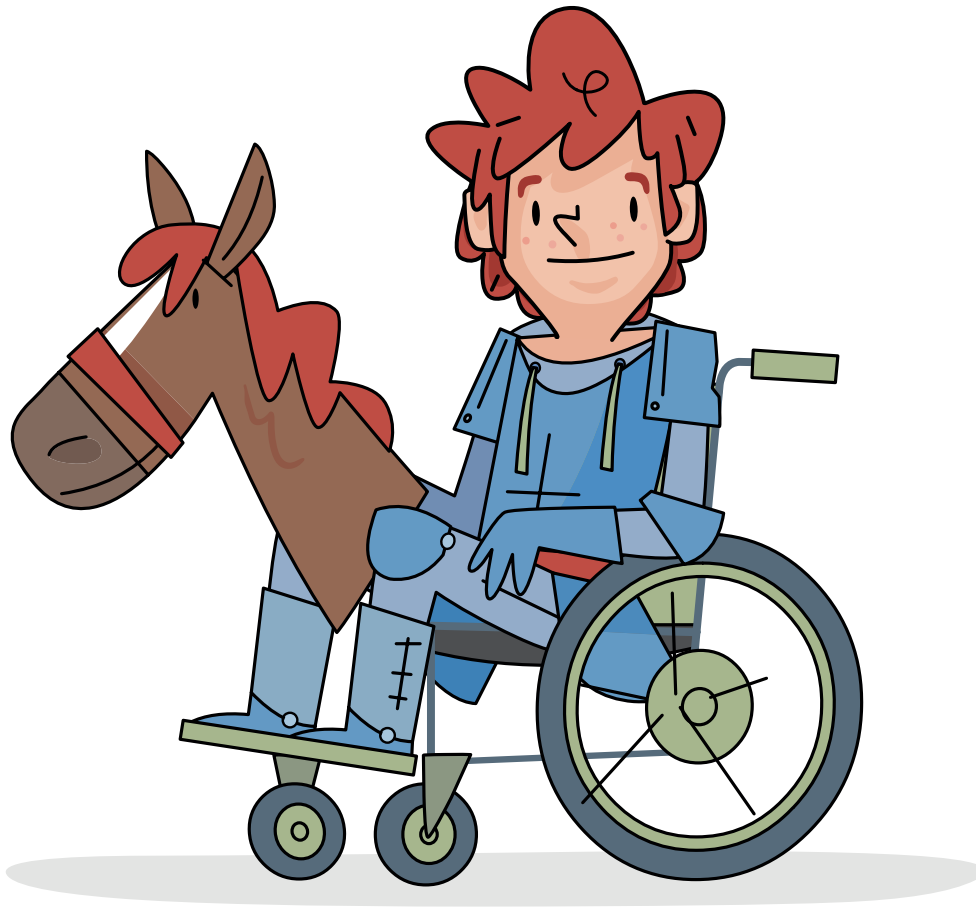
● = DUCHENNE

The disease only occurs in boys because the error in your genetic code occurs on the X chromosome and because boys only have one X chromosome.

Girls have 2 X chromosomes. They can carry the DNA error and potentially pass it on to their children, but they do not become ill.

Women who are carriers have a small risk of developing a weaker heart.

What are the long-term consequences?



After a while it becomes too difficult for you to walk easily and then it is time to look for support aids (e.g. adapted bicycle or electric wheelchair).

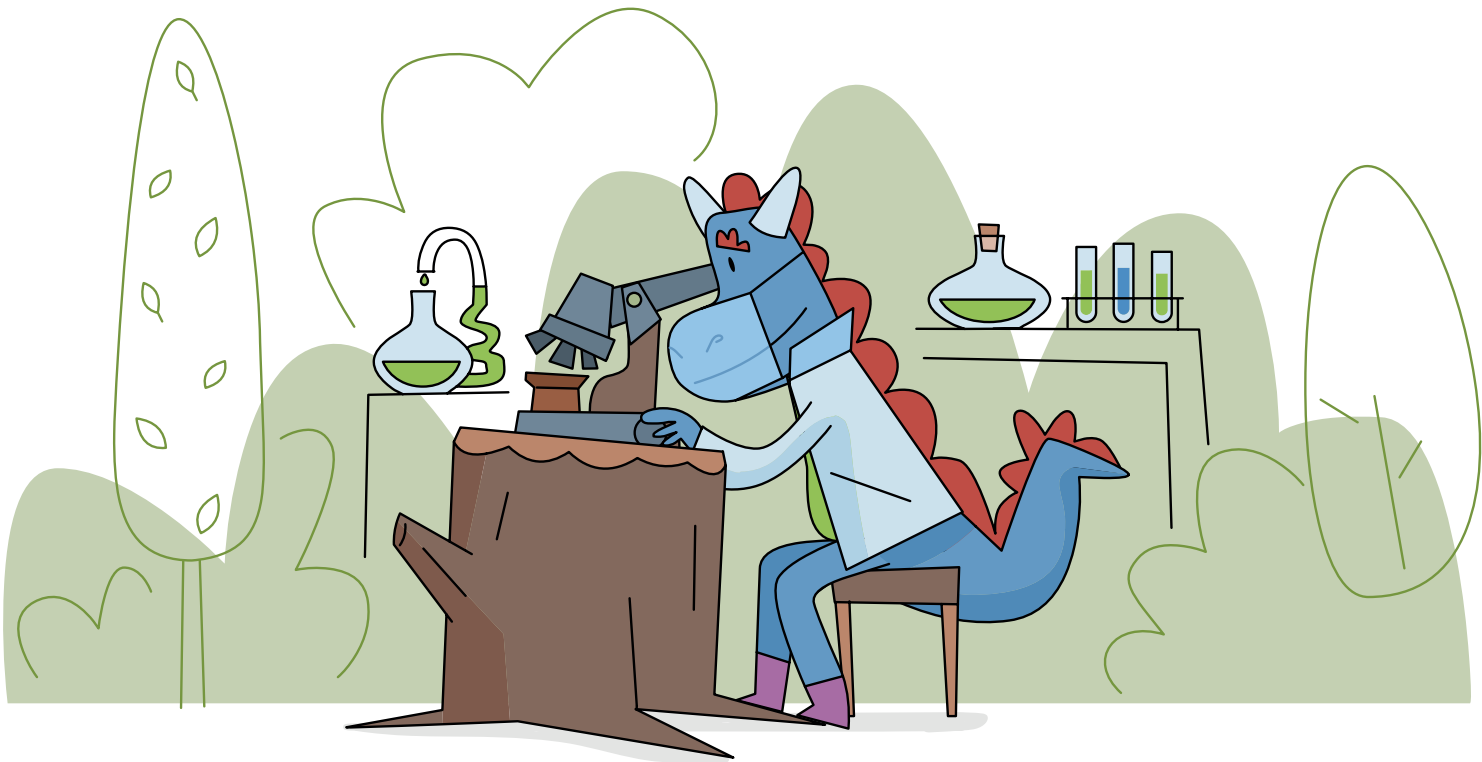
As your arm and shoulder muscles weaken, you may have difficulty getting dressed and undressed, or using the wheelchair. There are tips and aids to help you as much as possible.

Your spine may become overloaded and begin to bend a little.

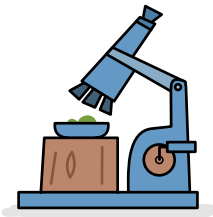
Our body has a lot of muscles (more than 750!), they are involved in many processes in our body without us having to do anything (such as digestion, breathing, pumping blood).

If your muscles are weakened, you will find it difficult to digest your food properly, you will find it difficult to breathe and your heart will get tired.

Can this disease be treated?



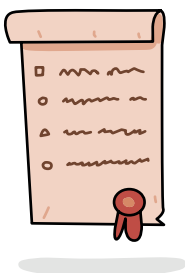
At the moment, there is medication that slows down the disease and make you feel less tired.



There is no cure for the disease yet, but scientists are working hard to find one.

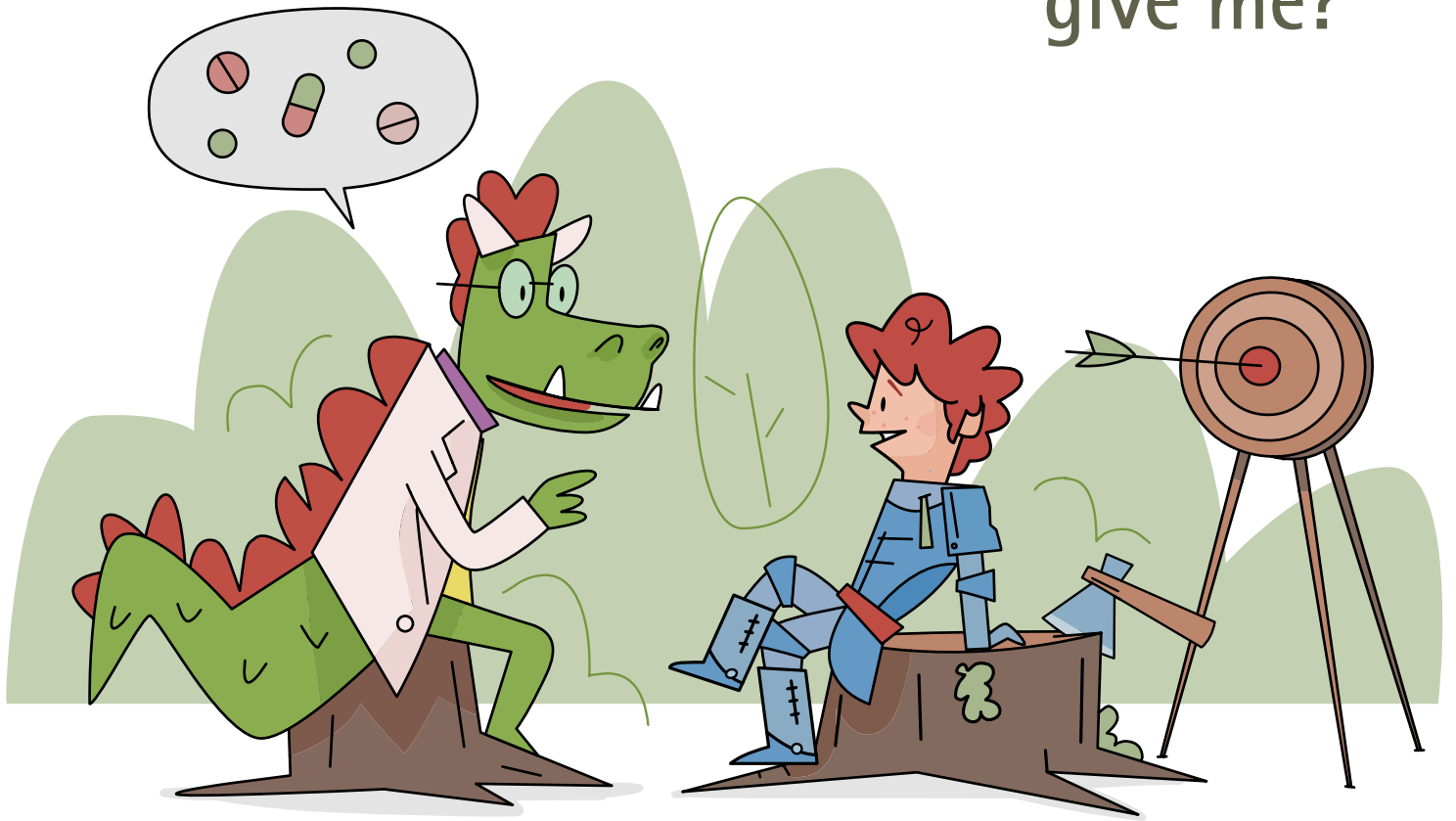


Your doctor can give you more information about ongoing clinical trials or possible new treatments.



Your name may be recorded on a list (patient register). Doctors can use this list to let you know about any clinical trials you may be able to take part in.

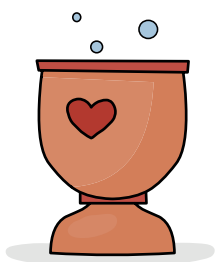
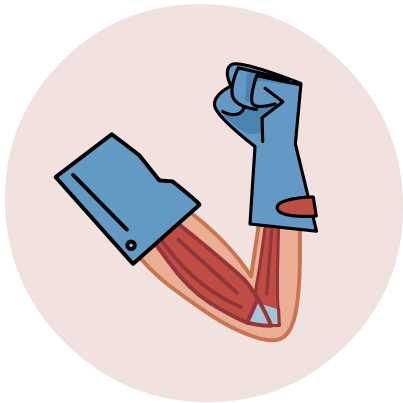
What medications can the doctor give me?



Corticosteroids

This will help maintain muscle strength for longer.

It may cause you to gain some weight and grow a little slower. Your blood pressure may also rise. The doctor will discuss the possible side effects and monitor them regularly. If there are too many side effects, the doctor may adjust the dose or prescribe another type of corticoid.

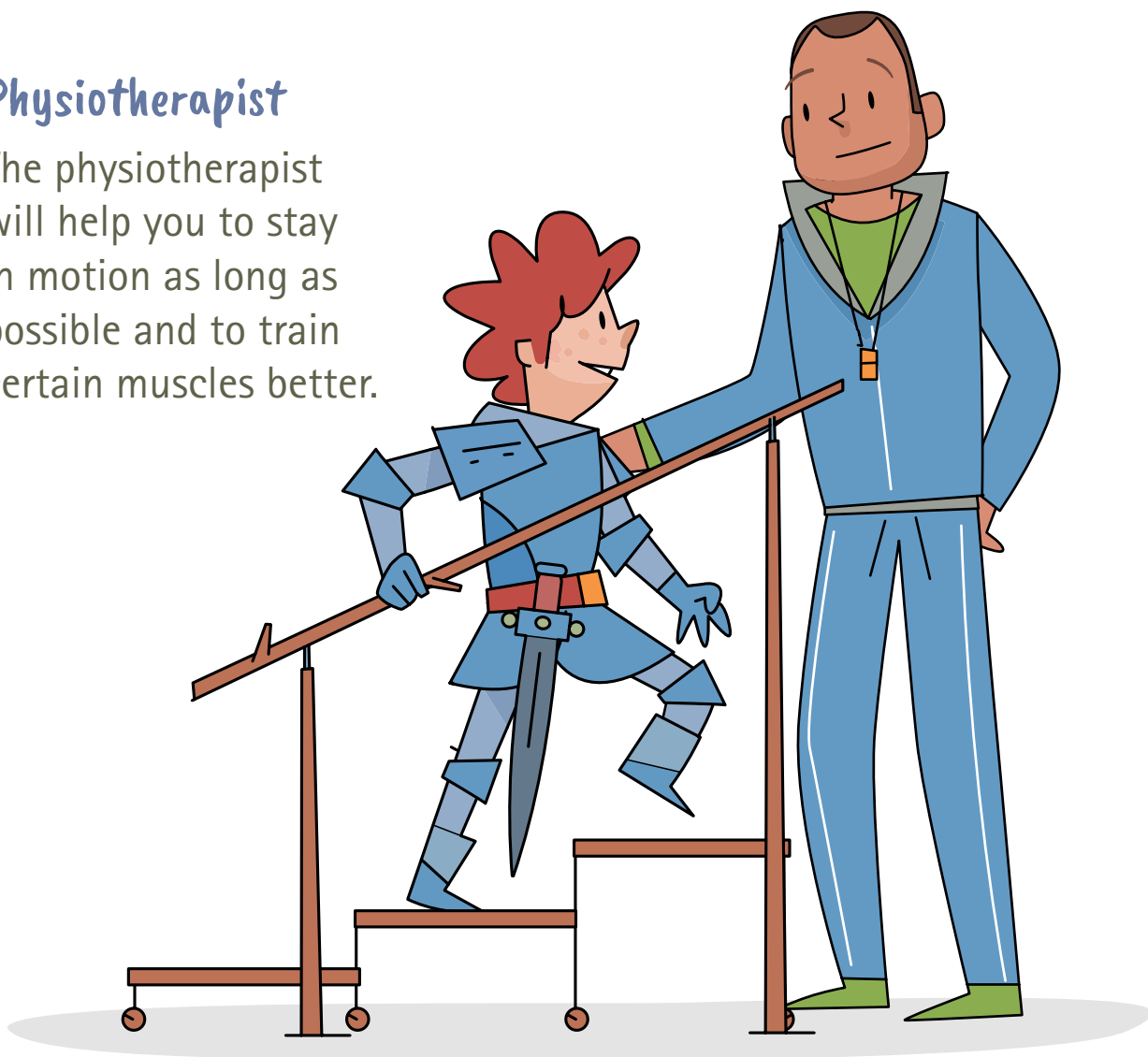


Depending on your symptoms, the doctor may give you something to improve the functioning of your heart, to avoid intestinal congestion etc.

What can I do to stay as healthy as possible?

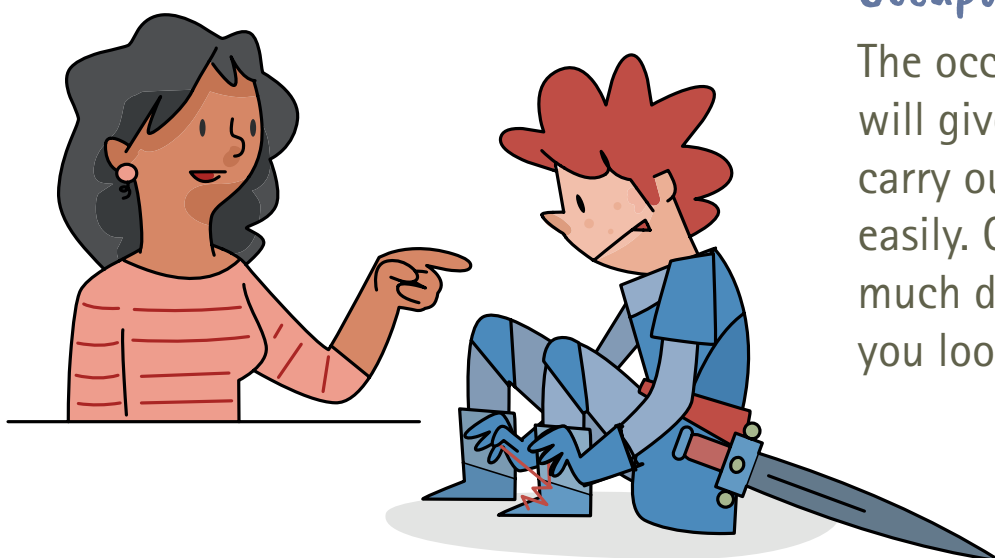
Physiotherapist

The physiotherapist will help you to stay in motion as long as possible and to train certain muscles better.



Occupational therapist

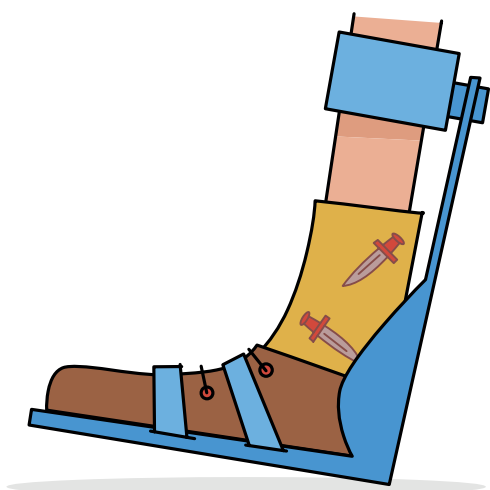
The occupational therapist will give you tips on how to carry out daily activities more easily. Once you have too much difficulty, they can help you look for suitable aids.





Speech therapist

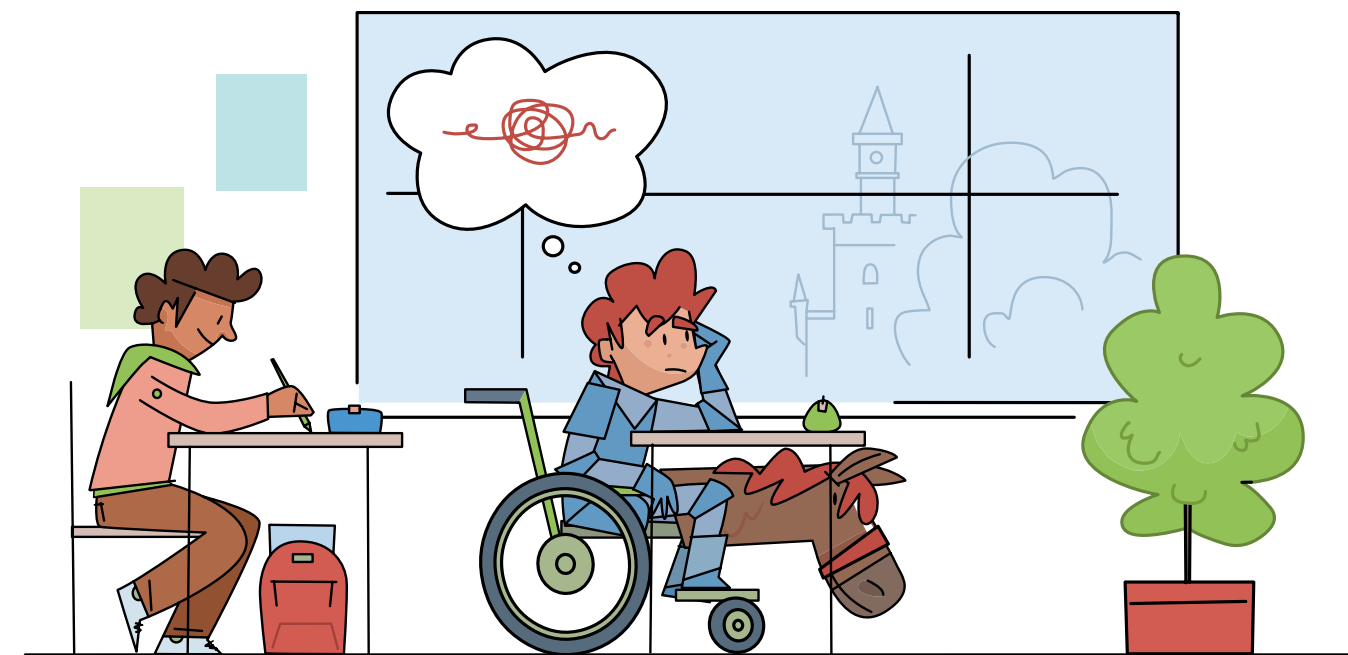
The speech therapist is there to support you in speaking and can give you advice if you have trouble swallowing.



Sometimes the doctor prescribes splints, which help to keep the shape of your feet (worn at night) and give you more support when walking (worn during the day).

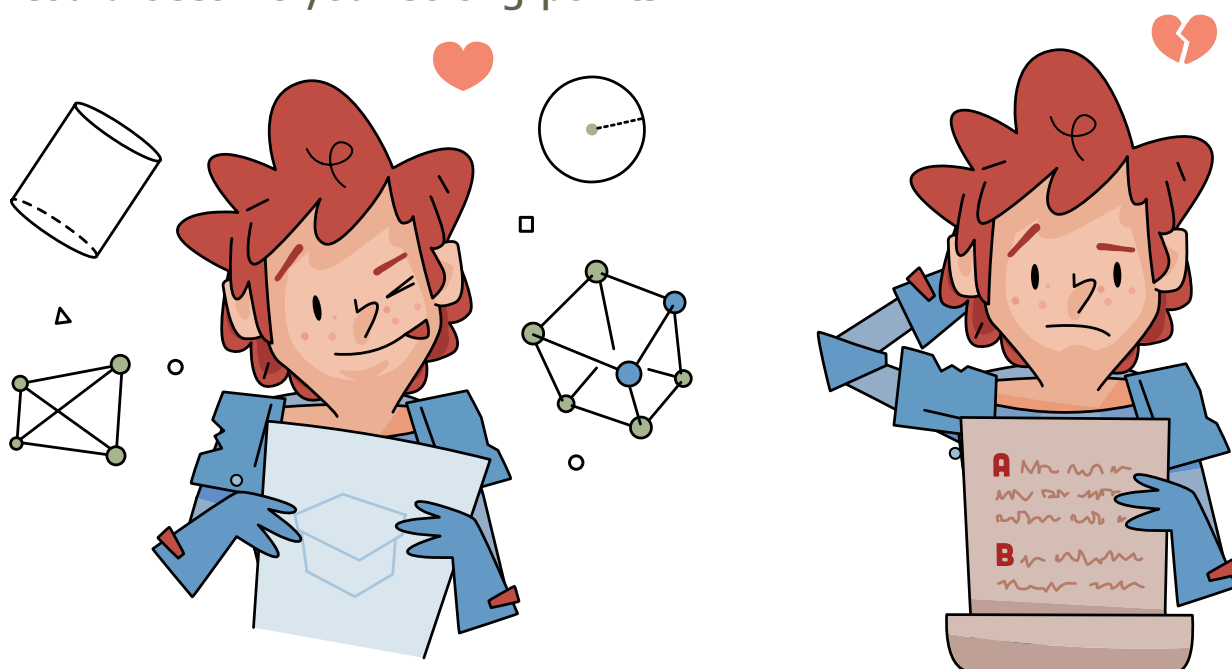
If, after a while, you find that your breathing becomes more difficult, there are aids to improve it.

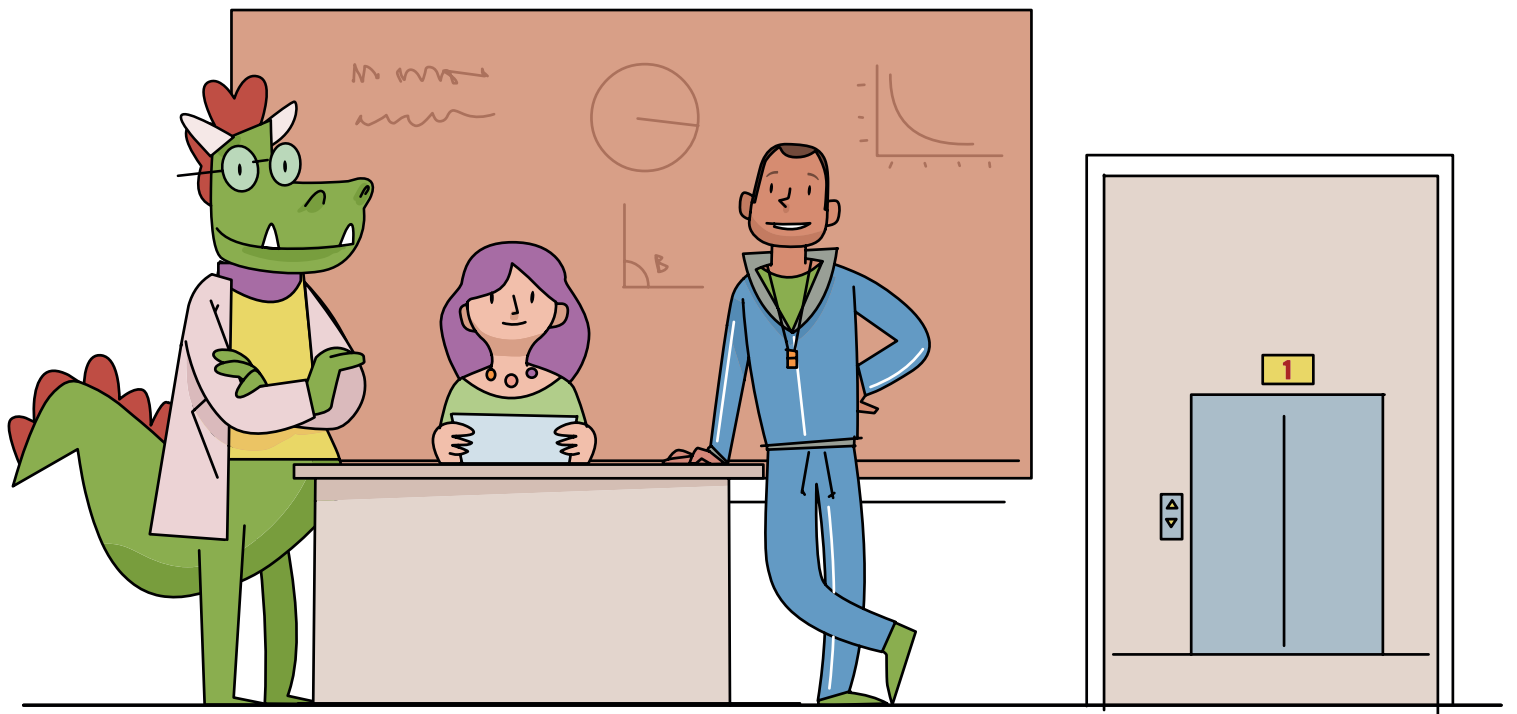
What about school?



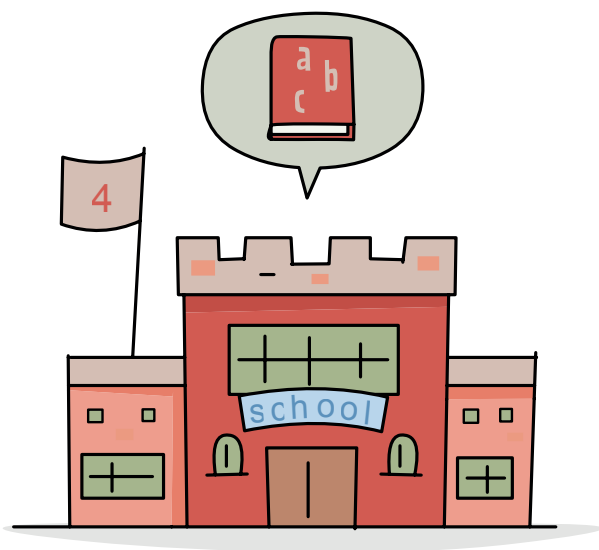
For some boys, the disease also causes learning difficulties or difficulty concentrating. Dystrophin also has a function in the brain. A lack of this substance will make it harder for you to concentrate. You may also notice that language lessons are a little less easy for you.

The good news is that children with Duchenne often have very good spatial awareness, so drawing and certain forms of maths could become your strong points.





Your school can request extra support especially for you. A counsellor can provide the necessary adjustments so that you feel comfortable at school, both for the subject matter and for your chair or the material you work with.



If it is nevertheless advisable to change schools: you can go to a specialised school, such as a type 4 school. These schools are specially equipped for children who need more support.

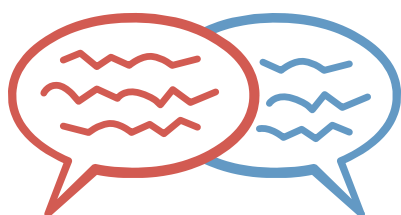
What about my hobbies and friends?

Taking up a hobby can make you happy and is a way to make friends so it is important. Therefore, it is important to find a hobby that suits you.

You may notice that it is not easy for you to practise a sport. But did you know that there are sports clubs that organise lessons for people who need a little help?

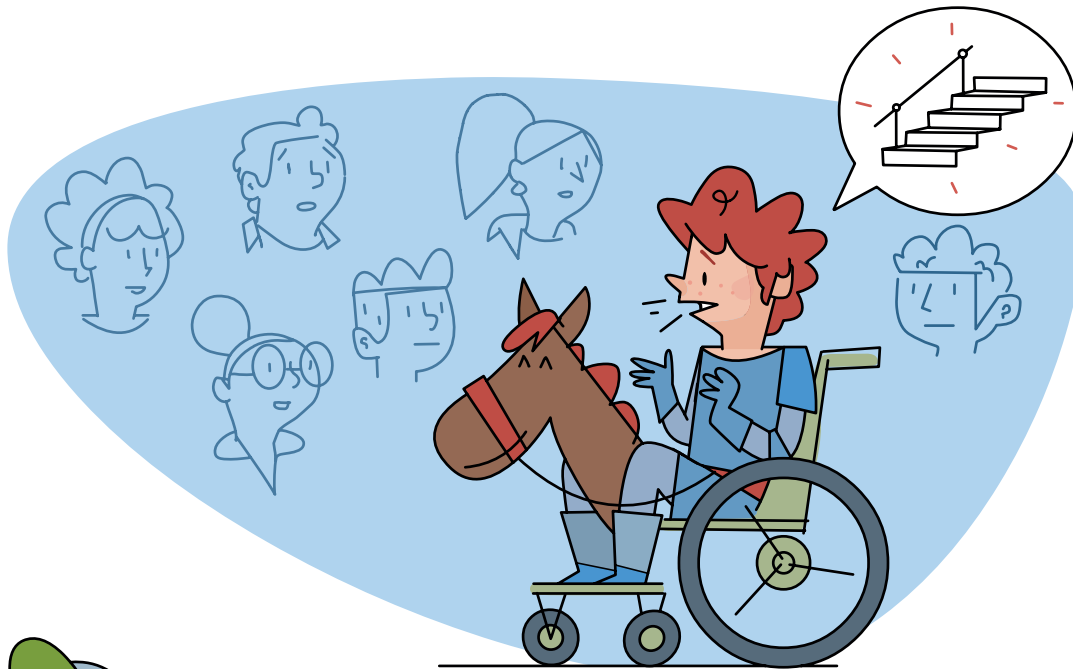


Maybe drawing lessons are for you?



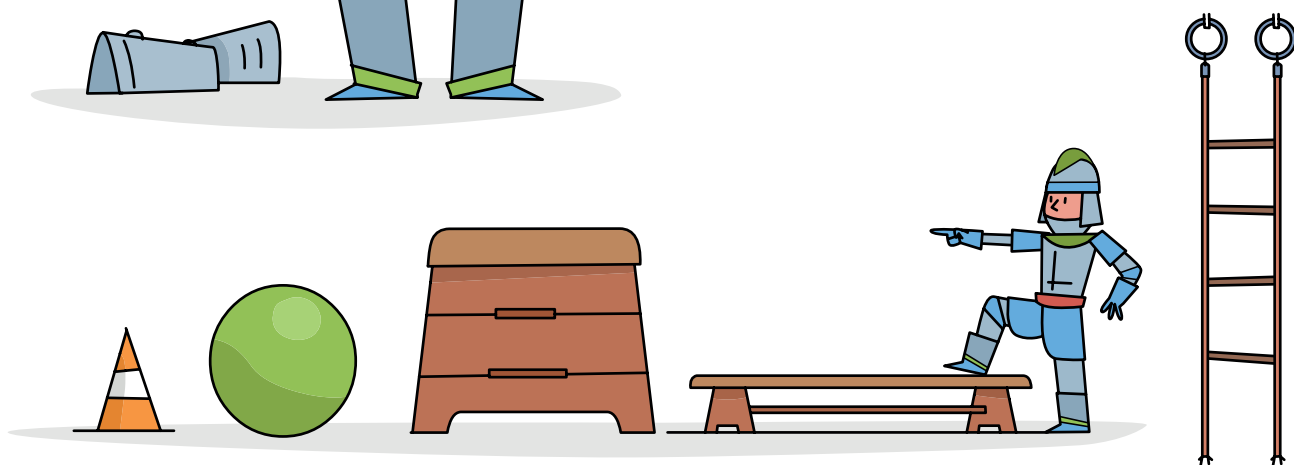
Talking to your friends about your illness also helps, so they have a better understanding of how you feel and can help you to fully fit in.

How do I talk to my friends?



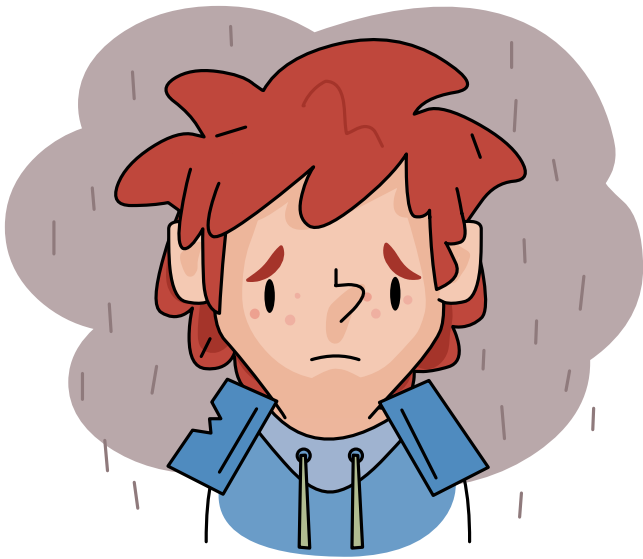
Try telling your friends or classmates how much effort you have to put into walking or taking the stairs?

To them, it is a bit like having to move around wearing a heavy suit of armour. Their muscles would have to work very hard and they would get tired very quickly.

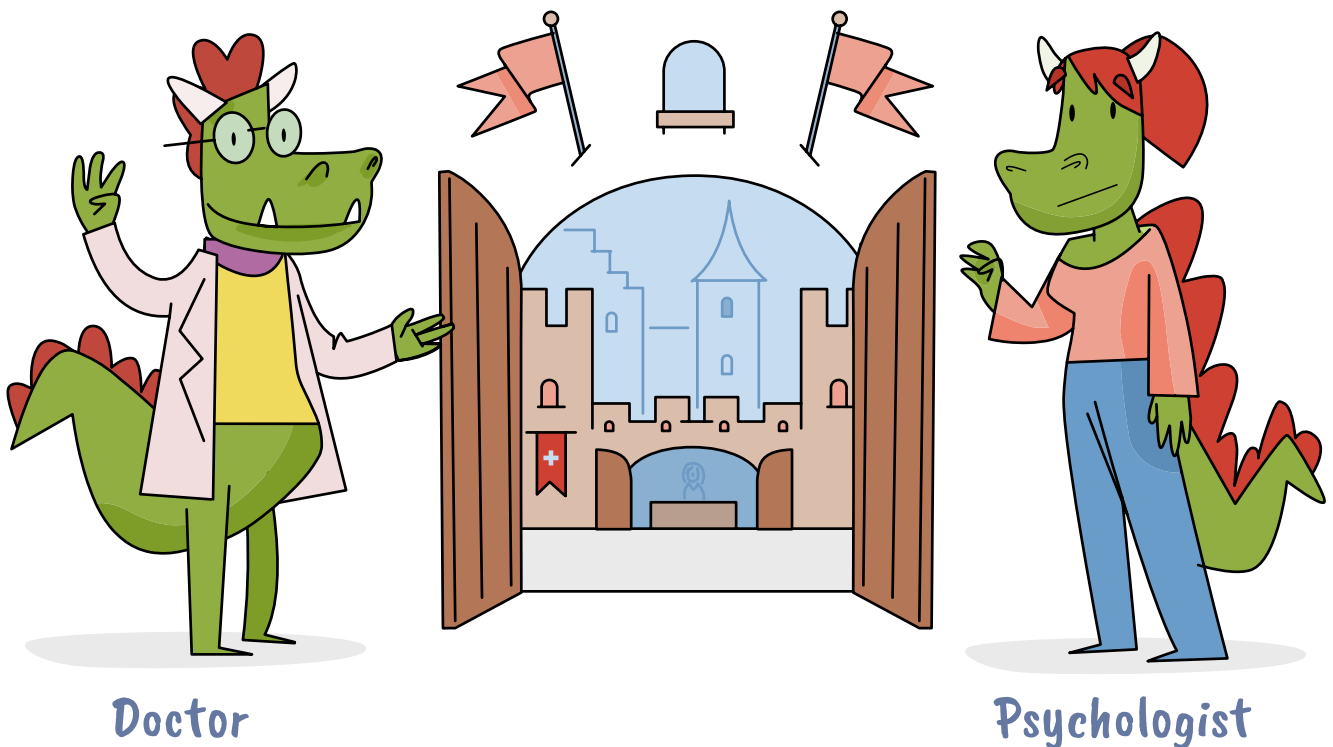


Perhaps your teacher could organise a gymnastics lesson where the children have to do an obstacle course wearing a harness.

Are you still confused and do you have any questions?



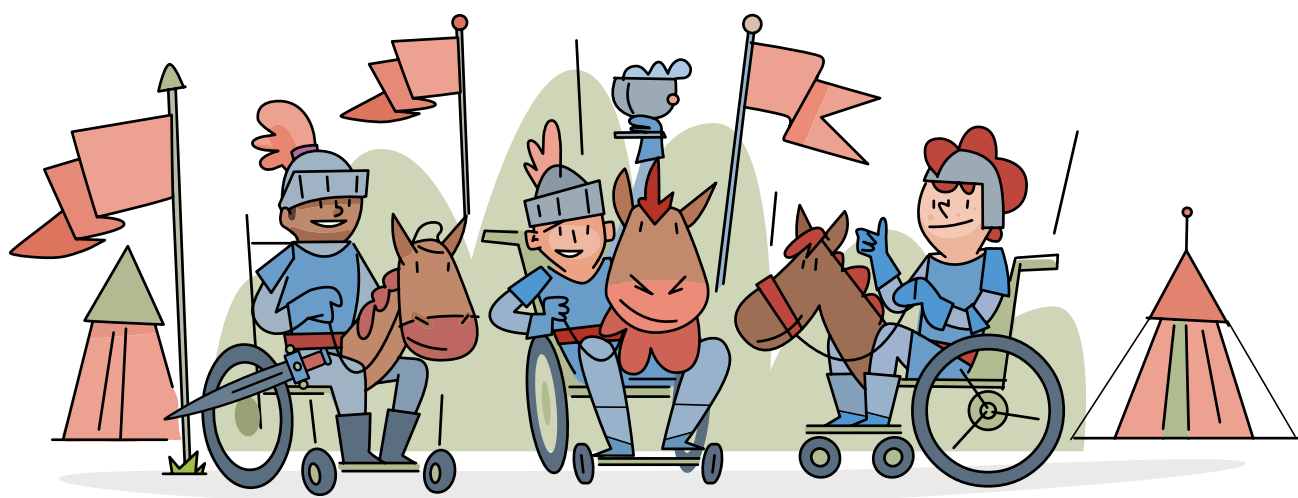
If you find that you feel a bit down or anxious when you think about your illness, you can always contact the doctor and the psychologist at the hospital.



They will answer all your questions as well as they can and help you to think about the positive things.

There are also organisations that are fully committed to organising fun activities where you are the centre of attention. Be sure to take a look at their website or join their Facebook groups.

Links to organisations



Spierziekten Vlaanderen: <https://spierziektenvlaanderen.be/>

RaDiOrg: www.radiorg.be

TREAT-NMD: <https://treat-nmd.org/>

Duchenne Parent Project Belgium: <https://www.duchenneparentproject.be/>

Association Belge contre les Maladies neuro-Musculaires: www.telethon.be

This booklet has been made possible by the Ridderfonds and the UZ Brussel Foundation. With the support of donors, companies and legatees, we conduct innovative scientific research and do charitable work within our KidZ Health Castle.

Would you like to support us with a donation? You can do that to account number BE75 3630 9458 5851 making sure to state Ridderfonds! Do you know a company that would like to help us? Get in touch via foundation@uzbrussel.be or on 02 477 57 11. There is more info at www.uzbrusselfoundation.be.

Note: For donations from 40 euros a year, you get a tax certificate. This entitles you to 45% tax reduction!





Universitair
Ziekenhuis
Brussel



Universitair Ziekenhuis Brussel
Foundation



KidZ
Health
Castle