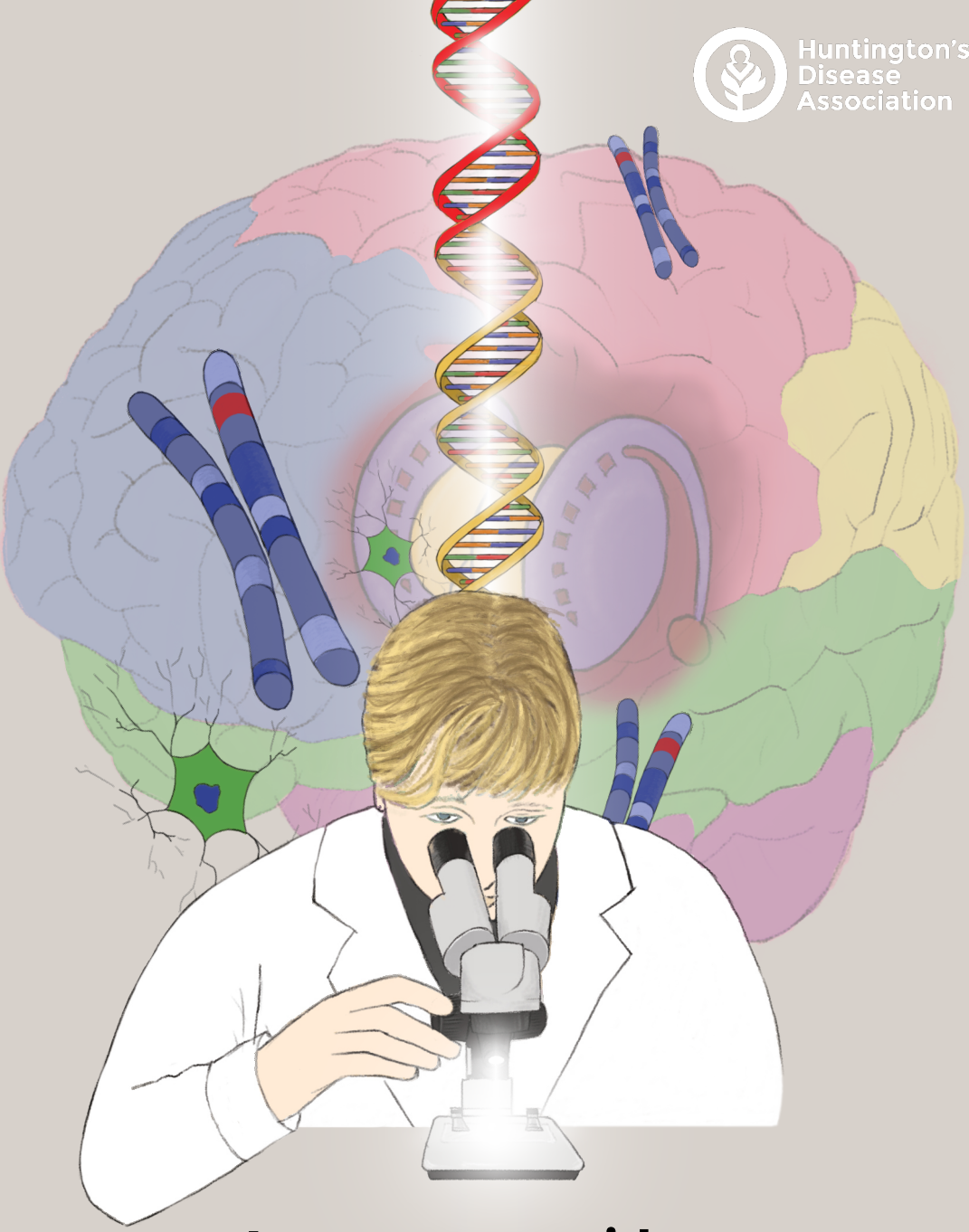
Huntington's Disease Association



A teenagers guide to Huntington's disease

Introduction

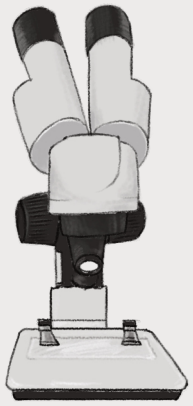
Thank you for taking the time to read this book, we've written it for young people who have Huntington's disease in the family. We understand that you might be just starting on your journey with Huntington's or that you may have been on your path for a while.

We also recognise that Huntington's disease is an illness that can be difficult for people to get their heads around. This is your little book and it will hopefully help you get to grips with the basics of the disease as well as finding things that help you to manage and cope through the tougher times.

Though you might not know anyone else who has Huntington's in their family, we can assure you that you are not alone. There are other people your age across the UK, and the world, who will face similar challenges and enjoy many of the same successes. Here, at the Huntington's Disease Youth Engagement Service, (HDYES for short) we will support you throughout your journey offering advice, listening to you and working with you to help create a brighter promising future.

Alongside family and friends, the people at the Huntington's Disease Youth Engagement Service are here to listen and support you.

Contents



Useful words and phrases used throughout the book:

Processing - the speed at which our brains understands something.

Cognitive - the processes which we use when understanding things, creating or accessing memories, using our judgment, and employing reasoning. These processes are the ways in which we decode and interact with the world around us.

Involuntary movements - movements we don't mean or intend to make.

Voluntary movements - movements we intend to make and do on purpose.

Empathise - putting yourself in someone else's shoes to understand how they are feeling.

Degenerative - something that gets worse over time.

Huntingtin - a protein that is made by our bodies. It is found in a few parts of the body but mainly in the brain.

Mutant - the medical term for something that has changed and is different to what it is expected to be.

Mood swing - a sudden change in how someone is feeling which may change the way they act.

Gene - genes carry our genetic code and tell our bodies what proteins to make.

Apathy - a lack of interest, concern or enthusiasm.

Conceived naturally - when a couple become pregnant after having sexual intercourse.

Hereditary condition - a disease that is passed down through generations of a family through faulty genes.

mRNA - messenger RNA carries information to make proteins. It gives the body instructions to make specific proteins such as Huntingtin.

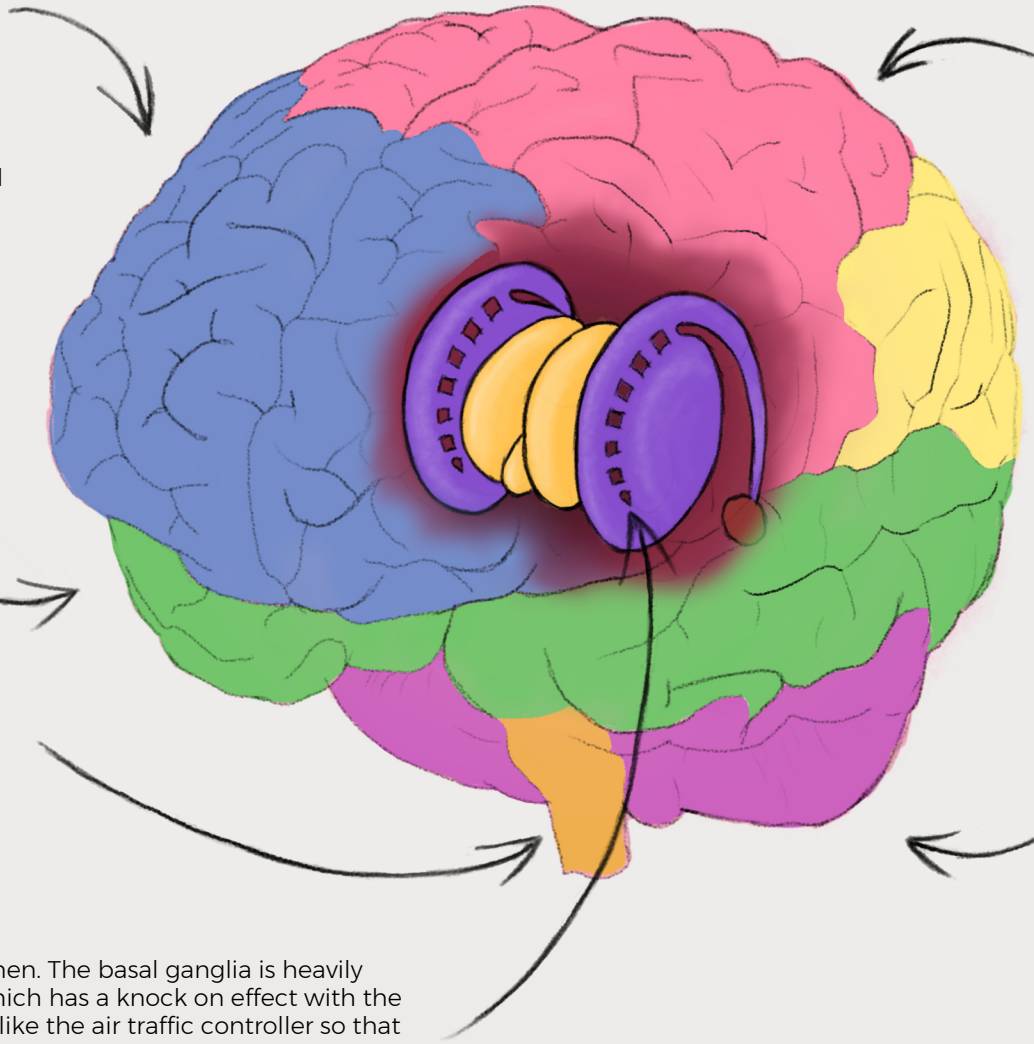
Our brains: The basics

The frontal lobe is where our personality is housed as well as our emotional 'control' centre. It helps us recognise right from wrong, predict consequences of our actions, solve problems, control our impulses, understand what is socially appropriate behaviour as well as having a role in memory and movement. This part of the brain is heavily affected by Huntington's disease.

The temporal lobe's main function is helping us to interpret sound. It also helps to recognise objects. This part of the brain is not affected by Huntington's disease.

The brainstem sends and receives information from the brain to and from the body. It has a role in automatic functions like a heartbeat. This is not affected by Huntington's disease.

The basal ganglia contains a few smaller components of the brain like the caudate nucleus and putamen. The basal ganglia is heavily effected by Huntington's disease which has a knock on effect with the functions of the whole brain. It acts like the air traffic controller so that the different parts of the brain can communicate with each other and send messages from one section to another.



The parietal lobe is where we interpret our senses (touch, sight, smell, taste and temperature). It allows us to pinpoint which part of the body has made contact with an object and helps to understand our body's position in relation to itself (e.g. being able to touch your nose with your finger). This part of the brain is slightly affected by Huntington's disease.

The occipital lobe interprets visual information sent from our eyes, enabling us to see. It allows us to recognise objects and asses distance, size and depth. This area of the brain is only slightly effected by Huntington's disease.

The cerebellum plays a huge part in our movement. It's major role is to coordinate all the muscles to enable our voluntary movements. It also plays a big part in our ability to balance. This part of the brain is affected by Huntington's disease.

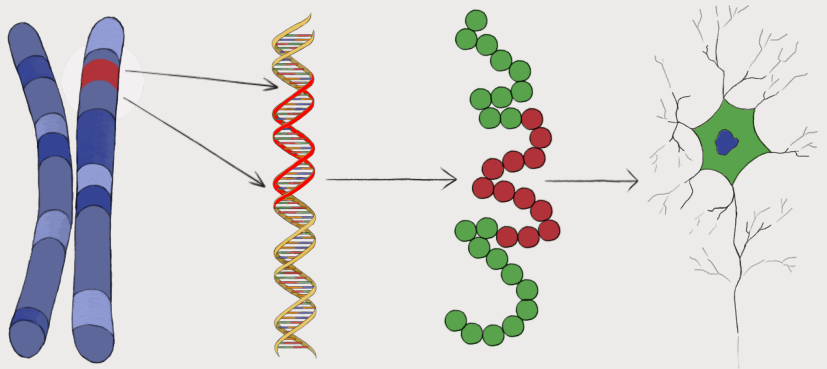
Huntington's disease: The basics

Huntington's is a neurological disease, which means it affects the brain. It is caused by a faulty gene in our DNA.

It not only affects people physically but also affects their mood and thinking. Huntington's disease gets worse over time and, though there is a general pattern of symptoms, it effects each person differently. You might read things in this book that your family member hasn't experienced yet and it's even possible they may never experience. We want this book to help you understand, cope and be aware of future possibilities. We understand that Huntington's is a complicated and confusing illness so please talk to your parents, family and us if you have any questions or aren't sure about something that you read.

Our genes carry the genetic code that tell cells what to do. Genes control cells by telling them what proteins to produce using certain codes.

One of these codes is called the CAG repeat and it produces a protein called Huntingtin. Huntingtin is mainly found in our brains and has a few purposes. For most people the CAG repeat length is fairly short (between 10–26) but for some it can be longer. If the CAG repeat length is 40 or above it means that person will develop Huntington's disease at some point in their life. If a person's CAG repeat is 40+ then they produce what's known as mutant Huntingtin.



It is the build up of mutant Huntingtin that eventually causes Huntington's disease. Confused? Don't worry we'll explain more in chapter 12 which is about research.

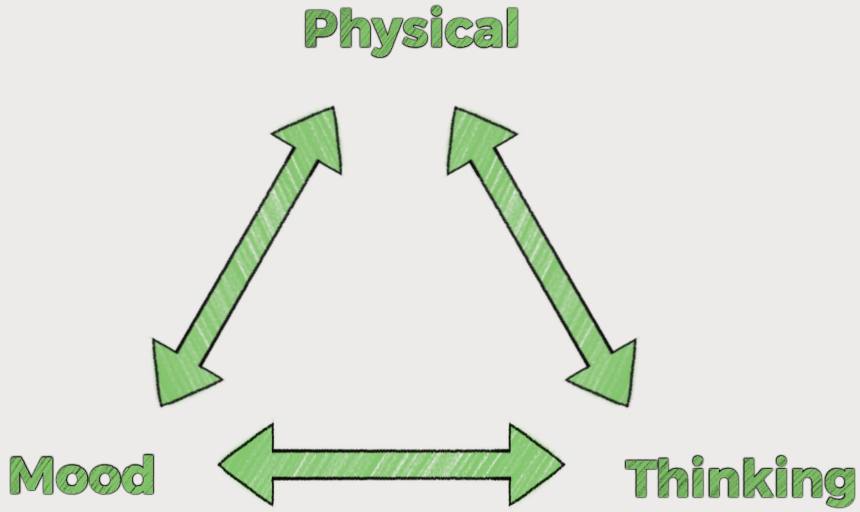
Huntington's disease: The basics

Most people are between 30-50 years old when they start to show signs of Huntington's but in some cases people can show symptoms earlier or later in life. Juvenile Huntington's disease is if people develop symptoms before the age of 21. This is a very rare form of the condition.

We find that it can help to think about the effects of Huntington's as a triangle. This is because there are a lot of symptoms but they all fall under three main areas. Physical, thinking (also known as cognitive) and mood. There is a brief explanation of how Huntington's affects each of these things on the next page.

They can also affect each other. For example, if someone is finding it hard to understand something (thinking) they might get frustrated. But if the person has Huntington's it's possible that they would get more frustrated (mood) than you would expect as it's harder to control their emotions.

Huntington's does significantly reduce how long people will live. Average life expectancy from diagnosis is around 20 years.



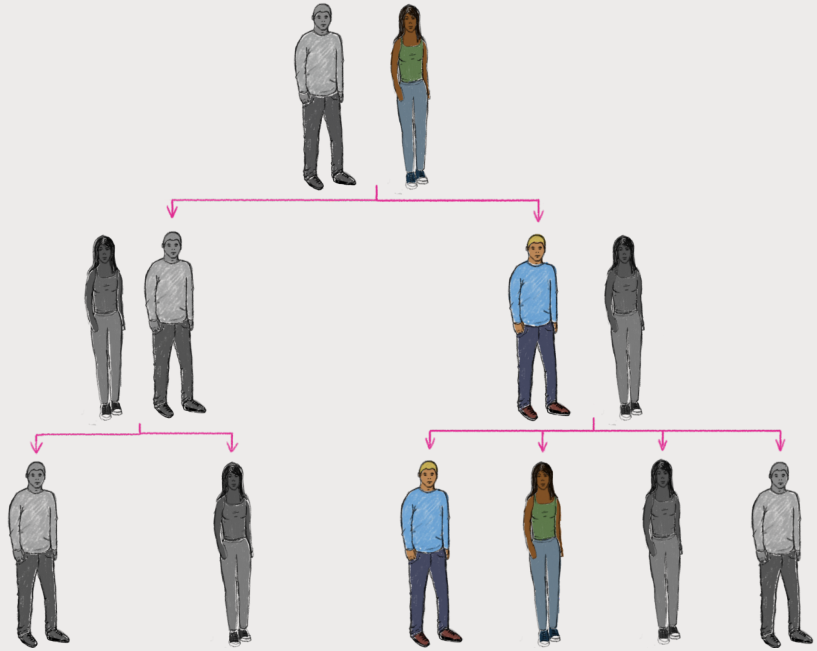
Physical
Huntington's makes it harder for people to control their voluntary movements and they also have involuntary movements.

Thinking
Huntington's causes slower processing and makes it harder for the brain to communicate with itself. These changes also make harder to plan ahead.

Mood
Huntington's can cause people to have mood swings and be less aware of how others are feeling or how their actions impact on people.

What does this mean for me?

Huntington's is a hereditary condition which means that it is passed down in families. Each child conceived naturally to a parent carrying the gene will have a 50% chance of inheriting it. The gene can be passed on from your mum or dad. The gene does not skip generations, so if you do not carry the gene, you cannot pass it on.



Wondering if you might have the faulty Huntington's gene from your parent with Huntington's can be very worrying. Some people feel better if they can check this early on in life rather than waiting to see what happens. You may already be aware that you can have a predictive test to find out if you carry the gene. The test itself is a simple blood-test but it's important to make sure that the decision to have the test is the right one for you. There is a process called genetic counselling before any blood would be taken. The genetic counselling process is really relaxed and flexible allowing you to go at your own pace. Some people want to get tested as soon as possible, some people have several appointments over many years before having the test and many choose not to have a test. You must be 18 to have the test and usually the whole process takes about a year. Usually you will have at least three appointments with a genetic counsellor before having the test.

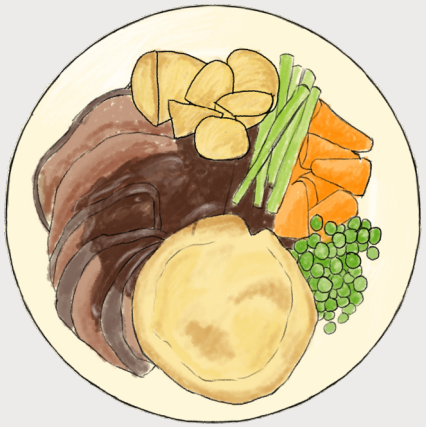
A genetic counsellor isn't a normal counsellor. Their role is to give you all the necessary information about Huntington's and talk through different scenarios that might happen if your test showed you did have the gene for Huntington's (this is known as a positive test result) or that the test showed that you didn't have the gene for Huntington's (this is known as a negative test result). A negative test result, though ultimately good news, can have an impact on how we feel as well. It's important to remember that if you test positive, and carry the gene, it does not mean you have Huntington's at that point in your life but that you will develop the condition later on in your life. The predictive test cannot predict when you will start to show signs and symptoms.

Huntington's will bring about changes to family life and possibly your home. There might be new things around the house to help the person get around and/or a change to some routines so it's important that we try to think about the changes in a positive way and remember that they're happening so that your family is able to look after each other.

A lot of people day dream about their future and imagine what life might bring. For some people, they know from a young age that they want to have a family or that they don't. Living at risk of inheriting the faulty gene will probably impact on your family planning and contraception choices. There are options that ensure you don't pass on the faulty gene to your children. These can even be done without you having to have a predictive test yourself. For more information, you can speak to us or a genetic counsellor and we'll answer any questions you have.

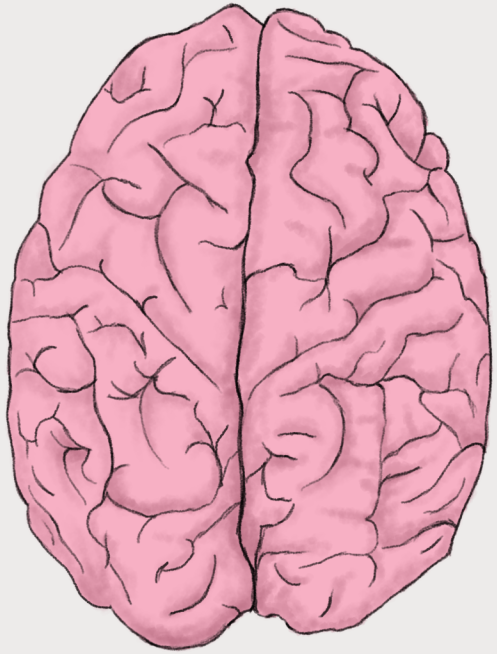
Huntington's disease: Thinking changes

Thinking changes primarily occur because of the damage to the basal ganglia. The basal ganglia is like the air traffic controller for our brains. It directs all the messages that get sent around the different parts of our brain and ensures that we have an understanding of what's going on around us. It helps us to plan and think ahead, to make decisions, as well as having a big part to play in memory and concentration.



Huntington's can make it harder to plan and think ahead. Imagine making a Sunday dinner and all the different foods that need cooking in different ways. You need to decide what's the main part of your meal (chicken, beef, veggie pie etc), what kind of potatoes (mash, roasties etc) and what veggies to have...not forgetting the gravy! That might seem simple enough to us...but then you've got to know how to prepare all the different foods, how to cook them all and how long it takes. You don't want your chicken two hours after your broccoli! All that takes a lot of planning and thinking ahead as well as remembering what to do and when to do it (sequencing tasks). This can be very challenging for people that have Huntingtons.

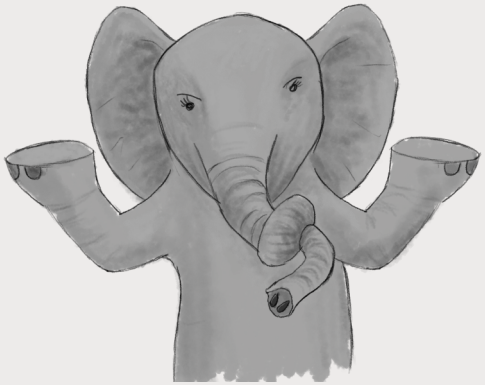
Huntington's causes slower thinking. Have you ever used a really slow computer or phone? Where it takes ages to open up the apps? That's not too dissimilar to how Huntington's effects our brains. The loss of brain cells causes a delay in understanding and then responding.



People with Huntington's can sometimes find it difficult to understand how other people are feeling. People can struggle to see how others are feeling, which can be especially tough if the person they are with is upset. People can also become self-centred, and it can feel like they are only thinking about themselves.

Huntington's makes it harder to control impulses and predict consequences. Because it can be harder to predict consequence, sometimes people can do things that don't seem sensible or fair. If people are impulsive they don't think through what the impact of their choices/actions can have on others.

Huntington's can affect short-term memory and people can be forgetful. It's possible that people might ask the same question more than once. They might forget what you've just told them or asked them to do. We can all be forgetful at times but Huntington's has a big impact on our short term memory because the pathways in the brain don't work as well as they used to.

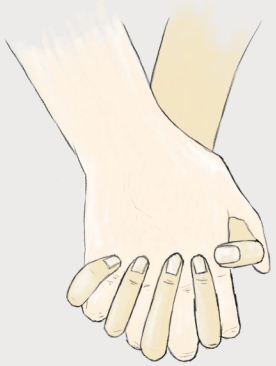


It can be difficult to make decisions. As the condition progresses and thinking is heavily affected, people can find it difficult to weigh up pros and cons and make informed decisions.

Multitasking and switching from one to another can be tricky. Coming back to the idea of cooking a roast dinner...it can be really difficult switching between the different methods of cooking which makes it even harder to make some meals. Or if someone is watching TV and then asked to start a conversation they would need to switch their attention quickly which can be difficult for people with Huntington's.

Shared experiences

We said in our introduction that you are not alone. That is true in more ways than one. You have family and friends around you. You have us (HDYES will always be here for you!), school and young carers to name a few. And, you are part of one of the most amazing communities in the world. You are part of the Huntington's community. We are made up of friendly, caring, knowledgeable (we like to think so at least), experienced, honest and open people from all around the world...and in some way or another, we're all here for you!



"It's important to find new activities to connect. Every time I saw mum I was very aware of the changes. I didn't know how to care for her mobility needs. I was scared to take her out in the wheelchair. I found it hard to ask people how to manage these changes and how to use equipment. Being out in public with mum brought some unexpected feelings and I worried how I would manage if other people said anything or stared. I tended to ignore it but there is no manual to cope in these situations."

"My dad has Huntington's disease, but that's not the thing I think about when I think about him.

It is frustrating, but my perception of him does not revolve around his forgetfulness, nor his cocktail of medication. He is far more than the anger I feel towards the fact that I can't watch a film without also listening to a torrent of mumbling and feeling incessant shifting beside me. I simply can't hide the fact that I could, one day, deteriorate like him, because I still feel lucky; not many people have a dad as good as mine.

When I think about my dad, I think about long conversations, wherein we symbiotically discuss, laugh at and rail against everyone and everything outside of our living room. I think about the future he wants me to experience, and how I know he'd do everything in his power to guide me to personal satisfaction. I think about his bravery, the courage he calls upon when volunteering for a medical trial. I think about fortitude, empathy, stupid jokes, and kindness.

Huntington's has taken a multitude of his faculties, but it's yet to take my dad away from me."

"I felt a sense of rejection from my mum because she was fixated on other things. I had made the effort to go and see her and she didn't seem bothered about me."

"To me, Huntington's disease is what broke my family, it's what damaged my mum, it's what my grandma lost her long battle to. But most of all, it's what I fear the most, it's what I think about on a night, worrying and scared that the people I care about, besides my mum and grandma, could develop it too. People like my aunties, uncles, siblings, future children or even me. But, it is also what made me realise that we have to make the most of our lives, going out and having fun, making memories with the people we love and living life with no regrets."

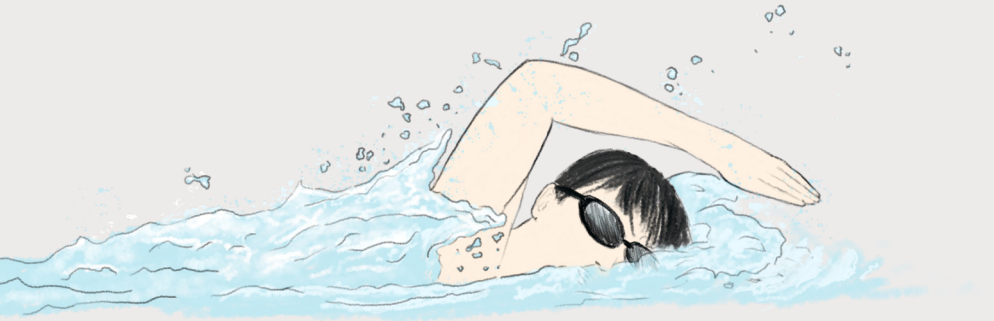
"Dad only seems to show one emotion. He can't be angry and sad at the same time and I find it hard to predict how he'll react to things I say and do. Dad is less emotionally aware of others and can't read how I'm feeling."

"When people say Huntington's, it makes me think about my future, my past and my mum and grandma. It makes me anxious and stressed of what's to come. The way I deal with it is with a hobby I like (dance and listening to music). This helps me put my thoughts and attention on dancing".

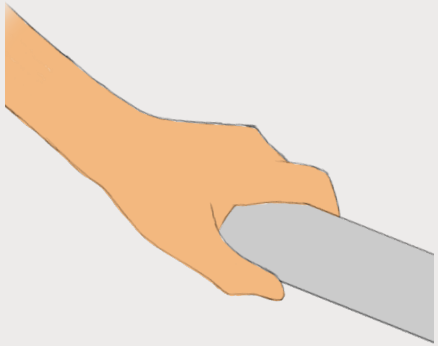
Huntington's disease: The physical changes

The brain is like the conductor of an orchestra and tells each muscle when and how to move. Problems with movement happen because the messages from the brain are no longer being transmitted properly and the brain is also sending messages without us choosing to. It's like the conductor can't read the music properly and so the orchestra are told to play the wrong note.

People with Huntington's can struggle with making voluntary movements (actions). That means it's harder to control the movements they want to make (like doing up buttons, writing or walking).



It's really important that people keep fit and active. There are so many activities that people can do even if they need a bit more support than before. A structured activity can be good (like yoga, or swimming) but just walking the dog, dancing round the kitchen, playing active computer games are all great. The important thing is doing something that is enjoyable. Thinking of an activity to do together could really help with your relationship.



Walking aids and wheelchairs can help people to get around if walking has become too challenging. But sometimes a person may not want to use them so their home might need changes to keep you and them safe. Just like you, they'll be finding these changes scary as well as all the new people that help them/you with the changes

People with Huntington's might start to sound different because their speech is slurred. Speech is a movement I hear you say? Yep, there's all sorts of muscles that are involved and have to be conducted (like an orchestra) in just the right way to make a sound come out!

People with Huntington's often have involuntary movements. It might be tricky for the person with Huntington's to sit still because of involuntary movements. Sometimes we might call these twitches, jerks or shakes. The medical term for these movements is chorea. Involuntary movements are only really a problem if they prevent the person from doing something they want to do (like walking). Many people with Huntington's are not bothered about the movements unless they are very severe or stop them from sleeping. Other people who don't know the person with Huntington's can find them distressing but this is not necessarily a reason to treat them.

Just like speech, swallowing is also a movement. If we don't chew our food properly or we swallow too much too quickly we are likely to choke. As time goes on, the person with Huntington's will have to change the types of food they eat to reduce the risk of choking on it. If it becomes really hard to swallow safely, the person might decide to be fed by a tube that goes directly into the stomach. This tube is commonly known as a PEG.

Things that I can do to help myself

We often hear that talking to someone is the best way to manage our mental health and emotional wellbeing and that's with good reason. Have you ever heard "a problem shared is a problem halved?" Clichés can be a bit played out but many of them hold some truth. Talking about how we feel, what's worrying us, what's upsetting us, what we find difficult and very importantly, our successes, gives us chance to process, understand and, not forgetting, celebrate which in turn helps us to cope. You are never alone with your feelings. Someone always feels or has felt the same even if the reasons are different.

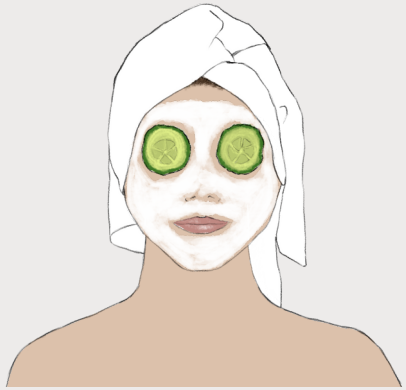
Get active! Physical exercise is a great way to feel better about life as a whole!

Try to accept help from those around you.

Spend time outside and in nature! It seems simple enough but being in nature helps us to relax, clear our heads and get some gentle exercise.

Trust your support network and if there's an offer for it to grow then take it. Ask HDYES about opportunities to meet other young people with Huntington's in the family.

Try to remember that there are no wrong or bad emotions to have. You will no doubt feel lots of conflicting and challenging emotions which could cause you feel guilty or confused.



Get involved with HDYES and talk to our youth workers...they're not so bad once you get to know them!

Give yourself a break! It can be very challenging to balance school life, home life, a social life and all the challenges brought on by Huntington's. Taking some time to yourself helps you to relax, recharge and give yourself some self-care!

Show yourself some love! Self-care is essential in looking after our emotional, mental and physical health! Everyone's idea of self-care is different so what does self care mean to you? What is important to you? Often, they can be the same things. Self-care is to be enjoyed and you should look forward to it. It shouldn't be something you 'have to do' but something you 'want to do.' It's so important to take time for yourself to do things that bring you happiness. We've got some examples of what self care can be.

Examples of self-care::

Having a facial

Watching a live sports event

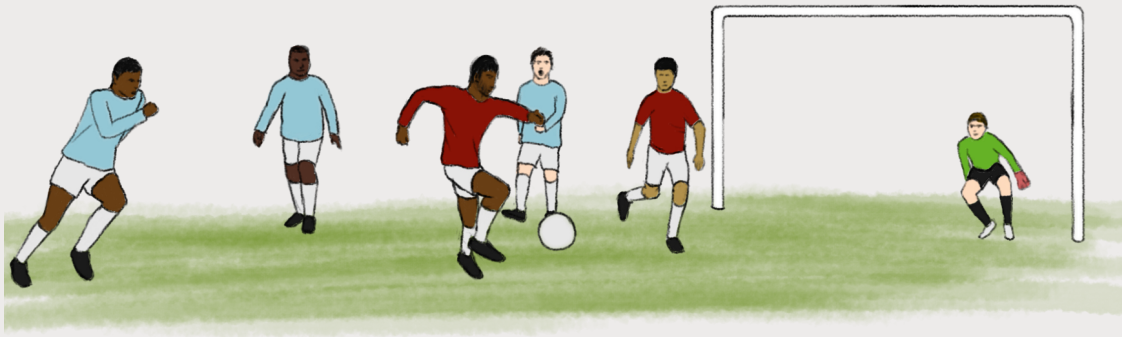
Playing a game

Spending time with friends

Going to the cinema

Going for a walk

Meditation, yoga and tai chi have been around for hundreds of years. They help us to be mindful allowing us to focus on the present and not worry about the past or the future. These are excellent ways of reducing stress and anxiety. There's loads of physical ways too!



Huntington's disease: The mood changes

Huntington's disease makes it much harder for people to control their emotions and to recognise how others might be feeling. It can make people seem demanding, self-centred and stubborn so it's important to remember that this is the condition and not the person.

Mood swings can be a troublesome effect of Huntington's to manage. It's possible for people to become angry, aggressive or depressed very suddenly. Mood swings can affect us all, for people with Huntington's they are more common and harder to control.

Huntington's can cause apathy which is easy to mistake for laziness. People can seem like they can't be bothered or that they don't care but the reality can be that they might feel exhausted or the connection in their brain isn't made to follow up on what they're supposed to do or what you might expect them to do. People might not be thinking of what they need or want to do at all and can often be content like that as long as their immediate needs are met.

We can all be a little stubborn at times and dig our heels in about something. However, Huntington's presents something a little different. Sometimes your family member that has Huntington's might be completely unwilling to listen to your point of view on an issue or take part in what you have planned.

Huntington's can cause people to lose their ability to empathise with others. This can be tricky if your family member doesn't always recognise when you're in a particularly good mood or if you've had a really difficult day. It doesn't change how your family member feels about you, nor does it lessen their desire to celebrate or support you but it does make it harder for them to pick up on body language, facial expression and understand how you might be feeling.

Perseveration is the term used to describe when people with Huntington's become obsessive with or stuck on things. These things can be far ranging from talking about the same idea/ thought to being obsessive with a certain person.

One of the hardest things to manage, is if your family member with Huntington's is particularly horrible, aggressive, nasty or abusive to you or someone else, emotionally or physically. This can happen because of a combination of everything talked about already (impulse control, mood swings and being more irritable) and it's important to remember that this is the condition and not person saying or doing these things. However, that doesn't mean it's ok. You should always tell an adult who can support you to get help.

How can I help make things easier?

Huntington's can be extremely frustrating for the whole family. This section of your book hopes to give you strategies and tips on how to manage some of the changes that Huntington's can bring. Not everything works for everybody, nor do things work every time. However, like with many things, the key approaches are consistency (making sure everyone is doing it the same way), sticking with it and patience.

You're already doing one of the most important things you can...learn. Having a good understanding of Huntington's disease will empower you in managing difficult situations and knowing how to overcome barriers.

If your family member is struggling to make decisions, then make it simpler. Give them options to choose from or ask yes/no questions.

Pausing — taking a minute to breathe and think about what's happened. This will hopefully help you to make a better response and not get frustrated.

Having a structured routine that the family is able to stick by will help keep things calm and running smoothly.

A whole family approach will help to maintain a good routine and consistent approach. Talk to each other and share if something helps to manage certain situations. Though there can be difficult times with Huntington's, families can grow stronger and become even closer.

Walk away if things get too heated. Huntington's can cause people to say hurtful things that they don't mean. Take some time to yourself and try to remember that it's Huntington's, not the person, saying these things.

Sometimes it can be difficult to engage people that have Huntington's. Despite making plans in advance you can find that on the day, people don't want to do it anymore. Using a calendar, along with gentle verbal and visual reminders can be a great way of encouraging people to stick to plans as it gives people time to prepare themselves mentally for what is going to happen. By not changing the routine suddenly it gives people the extra time they need to process the change. Having a calendar also helps with appointments!

Try your best to stick to what you're supposed to do around the house. It might be chores, it might something that you said you would help with (like setting up something on the computer...not some adults strong points!). As one of the symptoms is impatience this will hopefully stop arguments based around things that haven't been done.

Allow time when having a conversation. You are only able to take in so much information and Huntington's makes this much harder for people. Giving one piece of information at a time and waiting for a response before moving on in the conversation will help to make sure what you've said is understood.

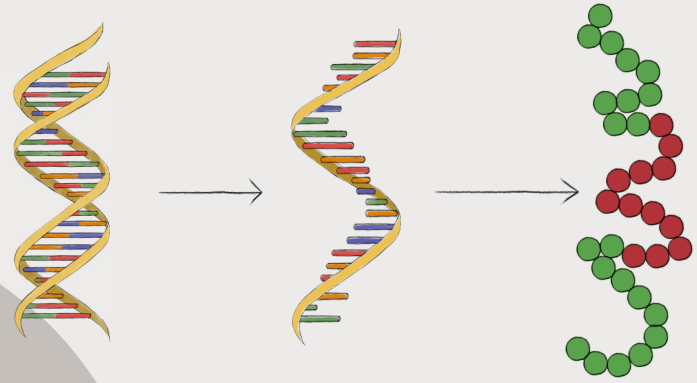
Research: A change is coming

As things stand (in 2021) there isn't a drug available that can help with the progression or stop the onset of Huntington's disease. We say this because there are several pharmaceutical companies who have or will be starting trials for drugs and treatments that could do these things and completely change how people live with Huntington's. There has never been as much hope and promise for a successful drug to fight against this condition.

There are two leading treatments for Huntington's at the moment, gene therapy treatments and Antisense oligonucleotides (or ASO for short). ASO's require an injection into the spine, whereas gene therapies use genes to prevent the disease.

If you've made sense of that, you're doing really well indeed! Basically, ASO's lower the amount of Huntingtin being made by the gene whereas gene therapy alters our DNA and genetic code. AMAZING! We have drawn two very basic diagrams on the next page to help explain how an ASO drug works.

The image below shows the process of how the mutant Huntingtin protein is produced.



Gene *mRNA* *Mutant Protein*

ASO

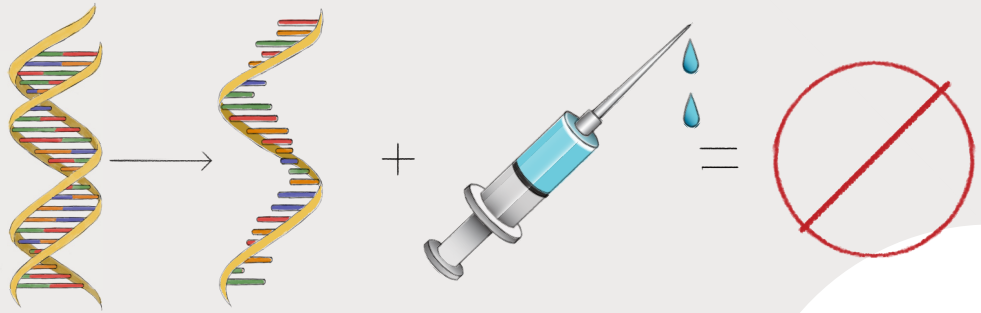
These drugs are injected into the spine so they can get directly to the brain in safest way. People need to have regular injections every few months. The drugs combine with mRNA to stop them from producing the protein which causes Huntington's disease. There are differences in how these drugs work so be sure to check in with us or someone who knows if you want to know exactly how they work.

Gene therapy

These drugs can last for years, decades and potentially a whole life time. However, they use a harmless virus to enable it to change our genetic code that can only be administered through a direct injection into the brain. Once implemented, the drug stops the gene from producing the 'bad guy' mutant Huntingtin protein and so would prevent or halt the progression of Huntington's disease.

Research can get pretty confusing and it can help to look online to get a better understanding of it. Please be sure to get all your information from reliable and trustworthy websites. We have listed a few websites on the next page we would recommend.

The image below shows where an ASO drug intervenes and stops the production of the protein.



Gene *mRNA* *ASO Drug* *No Mutant Protein*

What else is out there?

Remember in the introduction when we said that you're not alone? It's not just family and friends who are here to help and support you...there's lot's of people and lot's of services that want to help you and your family! Whilst no one would choose to have Huntington's in their family it gives you access to a very exclusive and very wonderful community that we tend to call the 'Huntington's community! We are filled with other family members of all ages and from all over the world. We're also filled with people who work for charities (like us!), doctors, nurses, physio therapists, dieticians, speech and language therapist, occupational therapists and I think we'll stop there because you're getting the picture. The Huntington's community is all over the world and we want to help you and celebrate all the amazing things that you do through your journey!

You have your book that will help you with the basics but we know that there's a whole world out there on the internet and it's packed full of awesome information and ways of communicating with other people in our community. Usually, Google is our friend when we want to find something out but it isn't always the best when it comes to Huntington's disease. Some websites out there give false information about the condition or focus on the worst case scenarios. Huntington's can be really tough so we would recommend checking out these sites as we know they give accurate and appropriate information:

hda.org.uk - this is our website and has loads of information about Huntington's as well as keeping you up to date with what's going on.

hdyo.org - this website was created by an awesome dude called Matt. He has Huntington's in his family and made this website especially for family members of all ages.

hdbuzz.net - the best way of keeping up to date with all the research and medical news about Huntington's. They do an amazing job of making science simple so that we can understand but it still gets a little muddy at times so remember to ask if you don't understand something!

What is HDYES? What can they to do help? Good questions! We work with 8-25 year olds across England and Wales who have Huntington's in their family. We offer emotional and practical support so that you feel empowered in your decision-making and ability to cope with the challenges thrown up by Huntington's disease. We can offer home visits, school visits, telephone calls, video calls and group activities (such as climbing or bowling). We can meet people in a local café if home isn't suitable and you're not in school anymore. We can talk over text, Facebook, WhatsApp, email...in a nutshell we are open to supporting you in the best way for you. We're all about making sure you're getting what you need from our service in a way that you feel comfortable with. We work with other services like school to ensure that the people around you understand your needs and how to support the best way they can as well.

You can also find us on Facebook, HDYES Facebook, Instagram and Twitter.

Call HDYES on 0151 331 5444

Text us on 07718 424905

Email us at hdyes@hda.org.uk

We are always here for you but there are others here for you as well. School is always a good place to start if you're finding things tricky. You can speak to a trusted teacher, head of year or anyone that you feel confident talking with. There's also a fantastic organisation called Young Carers who offer support and group activities to anyone who has a long term illness in their family. We would be happy to give you more information about your local young carers group if you wish. These are just some of the services that are out there and we can help you access plenty more no matter what you're concerned about.

Huntington's Disease Association

Further information can be found at:

www.hda.org.uk

info@hda.org.uk

0151 331 5444

HDYES Facebook - @HDAYouthService

Twitter - @hda_tweeting

Instagram - @hdauk

Facebook - @hdauk

Huntington's Disease Association

Suite 24,
Liverpool Science Park IC1,
131 Mount Pleasant,
Liverpool, L3 5TF

Registered Charity no. 296453
A company limited by guarantee. Registered in England No.2021975

Date of publication April 2021 first edition

Design and Illustration by Gawk