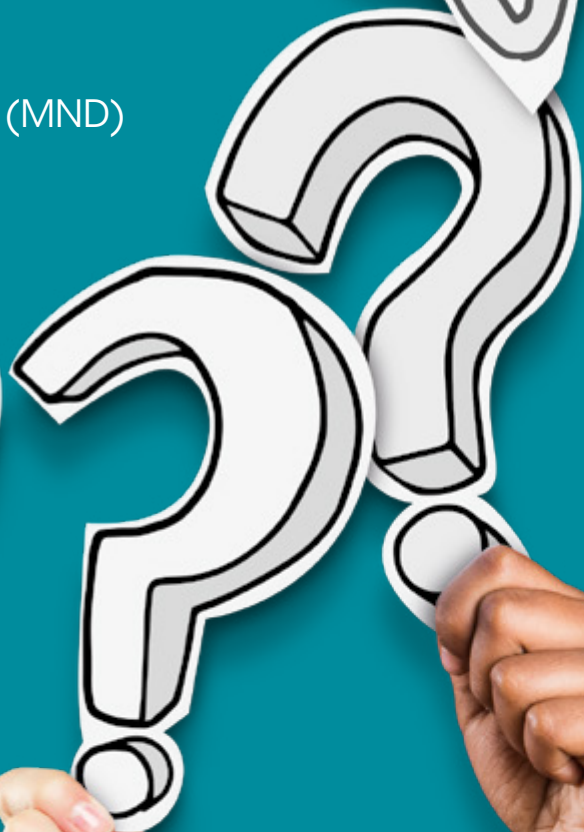


mnda

motor neurone disease  
association

# So what is MND, anyway?

A guide for young people  
affected by motor neurone disease (MND)



*Together, you're not alone*

## What do other young people affected by MND think about this guide?

***“This guide is awesome! It's extremely thorough and really easy to read. It carefully takes you through the MND journey, one step at a time.”***

Olly, former young carer

***“Vital information in the detail you need, because MND is complex. Yet the content is so simple and clear. The quotes are brilliant and I love the interactive pages to make notes. This is a fantastic tool for young people and I would have found it so useful.”***

Lily, former young carer

***“I'm pleased with the guide. Everyone has worked really hard on getting this all together. It looks really good!”***

Paige, former young carer

***“Having shared the journey and lost someone to this disease, I know how much support lies in these pages. This guide gives the true story and meaning of those three letters, MND. It has been carefully crafted, not only by experts, but by the people it is intended for - young people affected by MND.”***

Matthew, former young carer

***“We thought So what is MND anyway? was easy to navigate and answers all the right questions. The information was very useful and informative. We learnt a lot about MND and would use this guide if we knew someone with MND.”***

Year 8 students and members of the School Council, The King's School, Wolverhampton



The production of this guide has been generously supported by Futures for Kids and the Edith Murphy Foundation



Patient Information Forum

This information has been evidenced, user tested and reviewed by experts.

[piffick.org.uk](http://piffick.org.uk)

## What do professionals think about this guide?

*“I was really impressed by the range of information covered and I’m sure that many young people close to someone with MND will find this information invaluable.”*

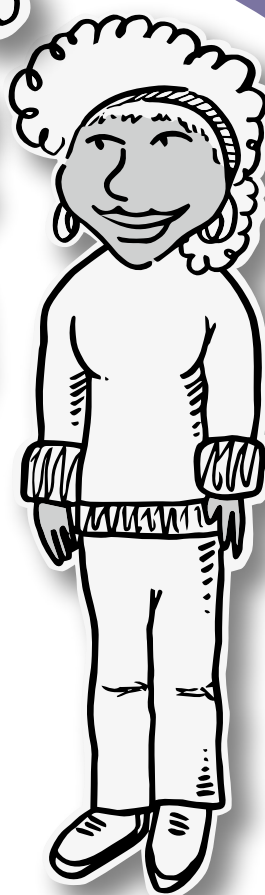
Penny from the Online team,  
Carers Trust, London

*“The content, layout, literacy levels, and the types of questions asked and discussed, provide all the necessary options needed by young people of this age.”*

Teresa Badger, Teacher and Student Welfare  
Manager, The King’s School, Wolverhampton

*“This guide is excellent, with a really nice, open, approachable ‘voice’. It’s very clear and well-written and will be of great use to young people affected by MND.”*

Winston’s Wish, the charity for  
bereaved children



## A MESSAGE FROM LILY SWEENEY

Hello,

**My name is Lily, I'm 19 years old and from Somerset. I love running, writing and theatre. Although you may not share the same passions as me, we do have something very big in common...**

**We have known someone with motor neurone disease.**

I was 10 years old when my father was diagnosed with MND. He died as I approached 13.

**So what is MND, anyway?** Now that's a big question. If you are anything like I was, you may not know a great deal about MND. But I found through experience that it was better to be prepared and this guide may help you.

It has been created by professionals to support you. Hopefully, it will not only help you understand the illness, but find ways to continue living as normally as you possibly can.

MND is a rare disease and many people may not be aware of it. This can make it a very isolating illness, but know that you are not alone. This guide includes comments from young people, like us, who have first-hand experience with the illness. We are part of a bigger community than you might realise.

**So what is MND, anyway?** is easy to read and answers the main questions you are likely to have. Turning the next page is the first step towards understanding this illness. Read as much as you want to, you can always read more when you feel ready.

Simple headings will direct you to the information you need. Don't worry about being overwhelmed with medical terms – you won't be! The simple facts and quotes in this guide can help you cope with what's to come. When you are close to someone with MND, it can really help to know what you are about to face, so you can try to prepare.

Everyone's experience with MND will vary. You may feel differently to those around you, even those closest to you, and that is okay. It's good to know where to seek help if needed, and that the Motor Neurone Disease Association can support and guide you too, as well as the person you know with MND. I have made some wonderful relationships through my connection with the charity, and found their information invaluable.

At first, this disease feels impossible to face, but eventually it will get easier. Information such as **So what is MND, anyway?** can make the process a bit more bearable too.

MND taught me that every moment is precious and I make the most of every opportunity now. Losing someone close to you is tragic, but does not mean the rest of your life has to be a tragedy.

Best wishes,

Lily Sweeney x



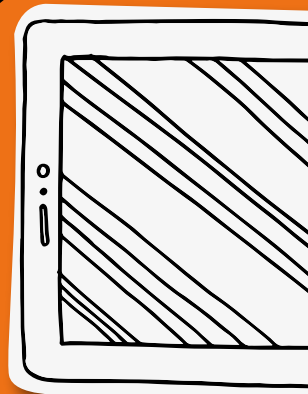


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1 How can this guide help me?



If you are aged 13 to 18 and close to someone with motor neurone disease (MND), this guide is for you. It will help you understand MND and how it can affect the person who has been diagnosed.

It will explore how these changes could affect your life too.

You may be:

- **visiting someone with MND**
- **living with someone with MND**
- **helping to support the person at home**
- **providing their main care.**

If you're worried about things changing, you may be feeling anxious or confused. These are natural reactions. Whatever your situation, we hope this guide will help answer your questions.

“ **Simple explanations about what could happen let you know what to expect.** ”

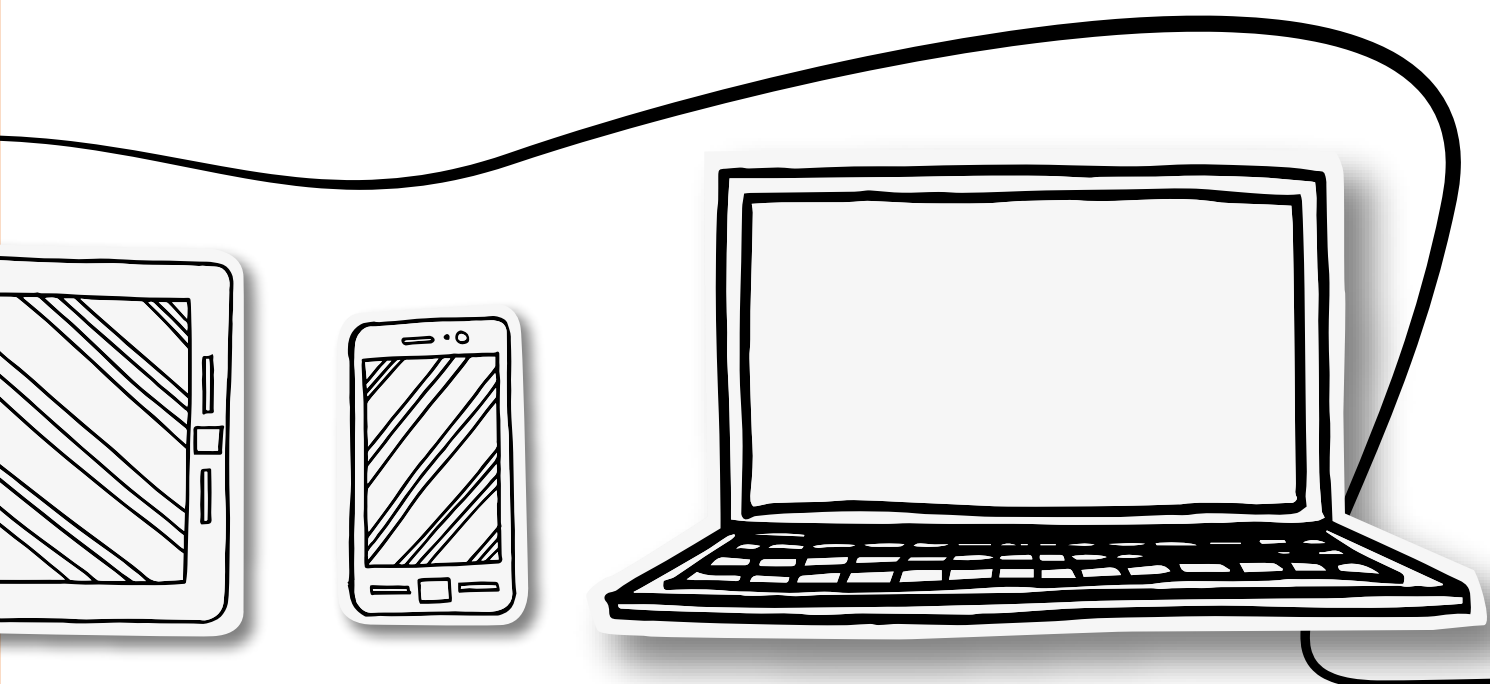
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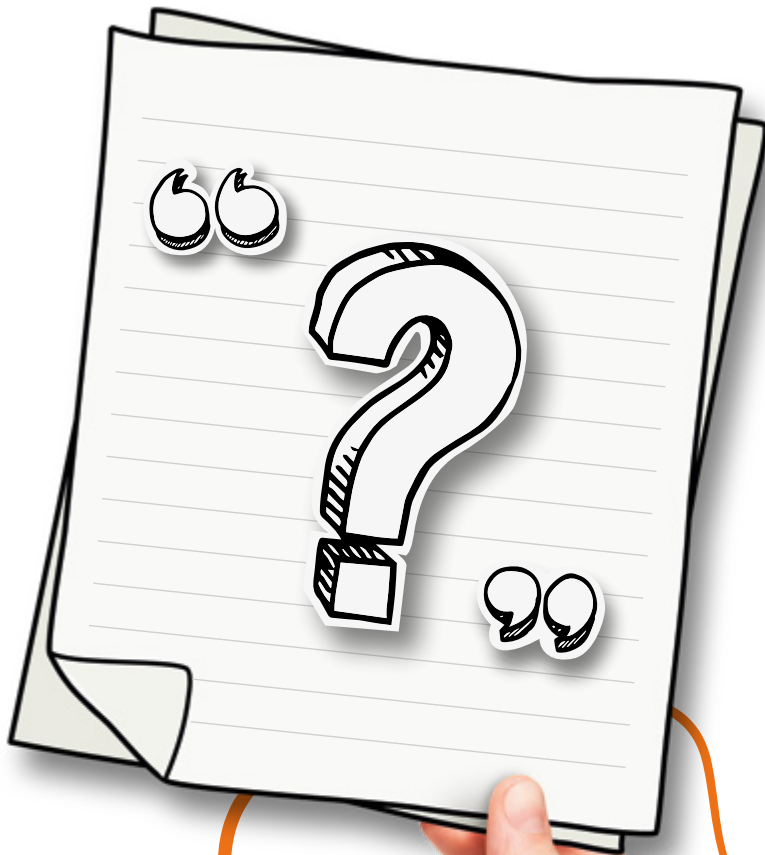
**If I had to go through it again, I'd want to know the background about the disease and the how and why. Also what happens next?** ”

## Is this guide available in other formats?

Yes. This guide is provided in print, as a download or for use on a mobile device, such as a smart phone or computer tablet. You can find the online versions at:

[www.mndassociation.org/ypinfo](http://www.mndassociation.org/ypinfo)





## What are the notes pages for?

You can use some pages to scribble down questions, notes or other bits of information as you go through the guide.

We hope you find these useful, but they haven't been supplied as homework! The choice is yours.

The online version lets you download these notes pages too, so you can fill them out onscreen if you wish, or print them as separate items.

## Can I trust this information?

It's easy to find information on the internet, but it may only be someone's opinion. Sometimes this can cause worry and could even be wrong.

*“When I was 10 I looked online, but you just find lots of bad stuff, the worst. It's not what you want to see.”*

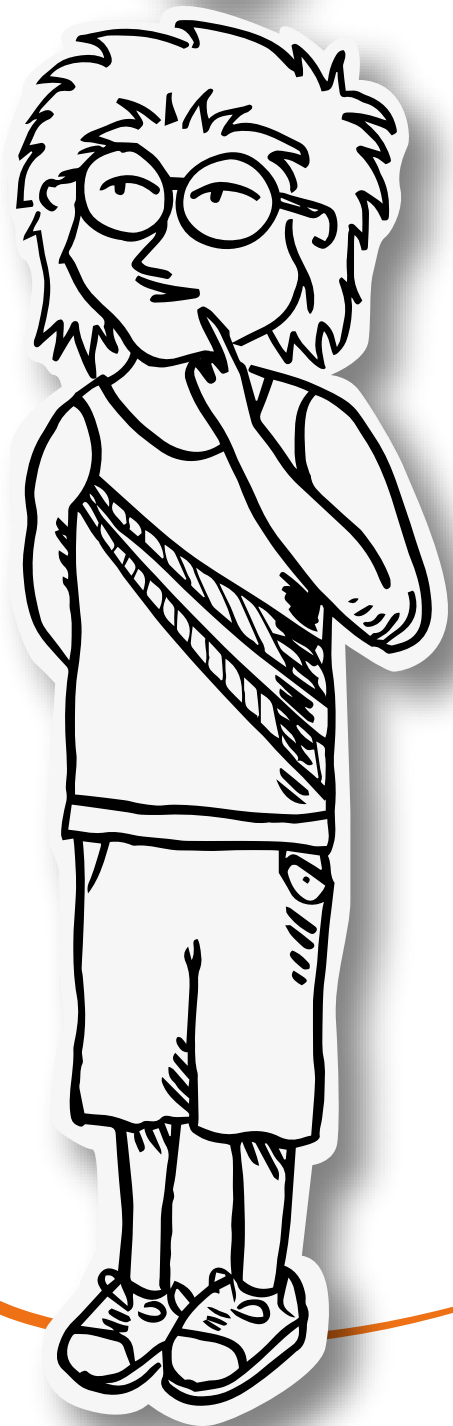
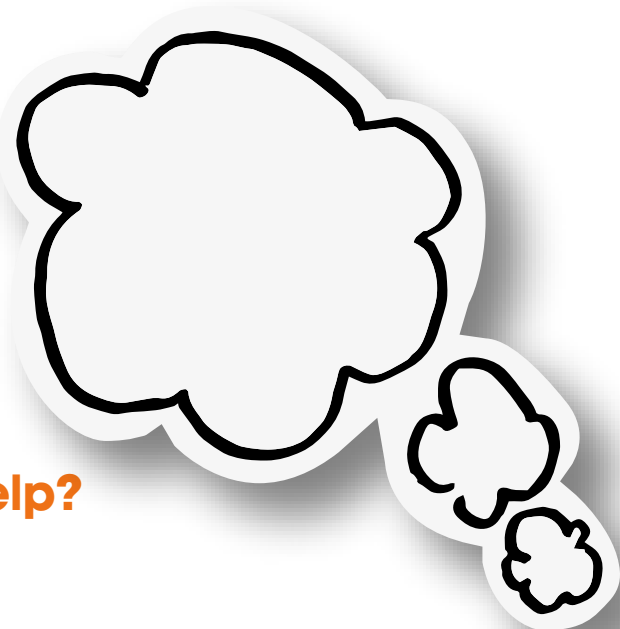
This guide is based on qualified research and written under the PIF Tick quality mark. This means our information is seen as trustworthy.



## Why does the guide use quotes?

The quotes in this guide are all from other young people affected by MND, who wanted to share their thoughts and feelings with you. Your own experience is unique, but knowing you are not alone in this can help.





## What if I need more help?

If you have any more questions or need support, contact our email for children and young people's services:

**cyp@mndassociation.org** or our Young Connect helpline. The team can help you with information or simply listen:

Telephone: **0808 802 6262**

Email: **youngconnect@mndassociation.org**

“*The fact that your helpline can be contacted by young people as well as adults is the best part. You're here for us too.*”

For more suggestions about support, see **Section 6: Who can help?**

We also provide information for children and young people on our website, at: **www.mndassociation.org/cyp**

“*I think we all feel a bit lonely and isolated when MND hits our family. It's easy to feel angry and guilty too, but it's not so strange really is it? Let yourself off the hook a bit.*”

# 2 What is motor neurone disease (MND)?



## What does the disease do?

The human body has lots of muscles and we use many of these to move. Messages from our brain tell our muscles what to do.

For example, if you want to kick a ball, a message from your brain tells the muscles in your leg to kick. You don't feel this happening, as the messages travel too quickly.

These messages travel to the muscles along nerves.

There are two types of nerve in the body:

- **Sensory neurones, which control the way you feel and sense things, like sight, hearing, smell, taste and touch.**

These **are not** usually affected by MND.

- **Motor neurones, which control movement.**

These **are** affected by MND.

With motor neurone disease (or MND for short), something goes wrong with the motor neurones. The messages stop getting through. When this happens, muscles can't move properly.

If muscles aren't used, they become weak and get smaller. This is known as wasting.

This means the person with MND finds it harder to do the things they used to do. It can affect how they walk, talk, move, eat, drink and breathe. As these symptoms get worse, other people have to provide support.

**MND just felt like letters being thrown around the house, like NHS or any others. It didn't really seem to have any meaning.**







## What causes MND?

Nobody knows exactly what causes MND, but lots of research is going on to find out. Scientists think several things may need to happen for someone to get MND.

Genes can play a part in this. Genes are little codes in our cells that make up who we are. Sometimes genes are different to the way they should be and cause unexpected things to happen, but we don't always know why genes have changed.

However, it is thought that other triggers are also needed for MND to begin. These may be things in the environment around us and can be different for each individual. This makes it difficult for scientists to work out why MND happens.

## Will I get MND one day too?

You may worry about your own future and whether you might get MND.

“There are odd moments when I worry, like if I talk too quickly and slur a word or something. I had a speech problem when I was younger, so I know it's nothing really. You're just more aware of yourself when you've seen MND up close.”

MND is not an infectious disease. You can't get it by touching someone who has been diagnosed.



“My dad looked on the internet and had all these ideas about what caused his MND, but nobody really knows. It wasn't his fault.”

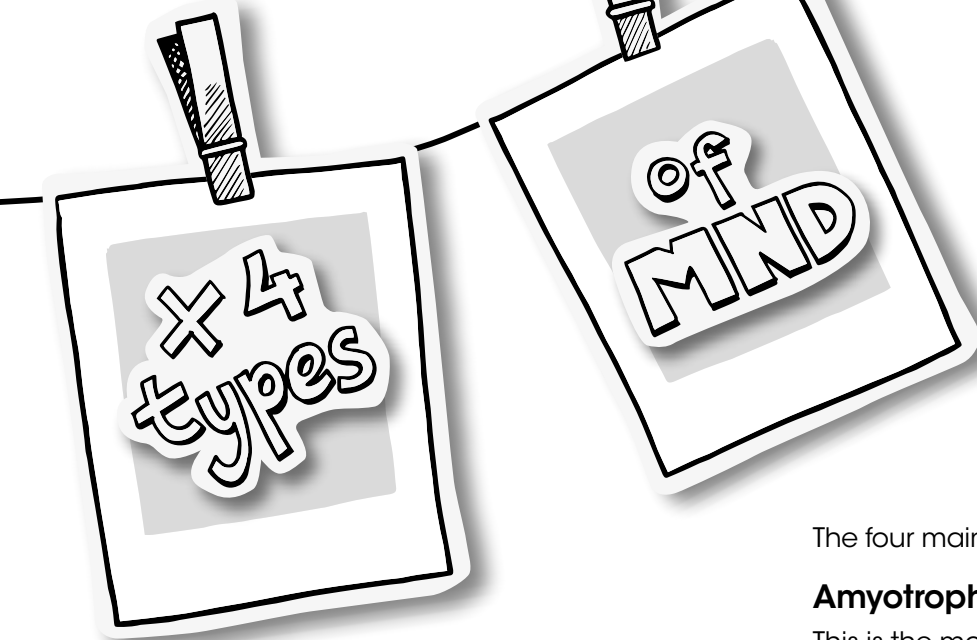
***It is not anyone's fault if someone gets MND. It is not caused by something someone does and no-one is to blame.***

## Who gets MND?

MND affects adults, not children. Although young adults can get the disease, this is very rare. It is more common over the age of 50.

Up to 5,000 people in the UK have the disease at any one time. Compared to other diseases like cancer, this is a small number, which means that MND is quite rare.

“At some point I think I was told MND wasn't like a cold - if he sneezed on me, I wasn't going to catch it.”



Most people with MND can't think of anyone else in their family who has had the disease. However, in rare cases, more than one person in the same family has had it because of the way their genes work. Scientists and doctors are trying to find out why this happens.

“ I prefer to think it probably won't happen and just get on with life. ”

**MND is quite rare, so the risk of you getting it when you're older is very small.**

## Are there different types of MND?

MND is the word used in the United Kingdom to describe all types of the disease.

You may see the term ALS used in information from The United States (they sometimes call it Lou Gehrig's disease too, after a famous baseball player who had ALS).

Although MND and ALS are the common names, there are four main types of MND. These are difficult to diagnose and one type can be confused with another. This means the person with MND may not know which kind they have.

Each type affects people in different ways, but they cause similar symptoms. Over time, the way people move, speak, eat, drink or breathe may change. Not everyone has the same symptoms or in the same order, so it's difficult to say what will happen next.

The four main types of MND are:

### **Amyotrophic lateral sclerosis (ALS)**

This is the most common form of MND. People with ALS often start with weakness in their arms and legs. The first signs might be dropping things or tripping up when walking.

### **Progressive bulbar palsy (PBP)**

PBP affects about a quarter of people diagnosed with MND. In the early stages, people may notice their speech starts to slur or they have difficulty swallowing.

### **Progressive muscular atrophy (PMA)**

PMA affects a smaller number of people with MND. At first, people tend to notice weakness or clumsiness in their hands.

### **Primary lateral sclerosis (PLS)**

This is a rare form of MND causing mainly weakness in the legs, although some people notice clumsiness with their hands. They may also have speech problems. PLS is the slowest form of MND, which means the symptoms take longer to get worse.

For details about symptoms, see **Section 3: What is living with MND like?**

### **Kennedy's disease**

We also support people with Kennedy's disease at the MND Association. This is a different condition, but it can be confused with MND at diagnosis. The two diseases have similar symptoms, such as muscle weakness, but these take longer to develop with Kennedy's. Men are usually affected by Kennedy's, but women experience symptoms in rare cases. The disease is caused by a gene that works in a different way than expected, which means Kennedy's can be diagnosed by gene testing.

## How do you find out if you have MND?

When someone first notices something is wrong, it can take time before they do anything about it.

**“He kept dropping things. He’d go to the fridge and drop a bottle of lemonade. It would just fall out of his hand, but we didn’t think anything of it.”**

In the early stages of MND, people often think they have a slight injury that will heal on its own. When the problem doesn’t go away, they usually visit their GP (family doctor) for advice.

As MND is rare, the GP may also think something else is wrong at first. They may see the person several times before realising the body’s nerves could be involved.

At this point, the GP usually refers the person to a neurologist for tests. A neurologist is a doctor who specialises in conditions that affect the brain and nerves.

The neurologist will examine the person and ask lots of questions about their symptoms and how these affect daily life. They will then do some tests.

### Getting tested

There is no single test to prove someone has MND, so specialists do lots of different tests to make sure it isn’t something else. Tests could include scans of the brain or body, physical examinations, and tests to check how well a nerve is working.

If no other conditions are found that might be causing the problems, a diagnosis of MND is usually given.

**“Mum says she told me about the diagnosis, but I don’t remember it at all. I think I blocked it out.”**

It can take a long time to diagnose MND, sometimes over a year.

The person you know may have felt frustrated and worried while waiting for their results. If you thought they were angry or withdrawn during this time, it may simply have been their own anxiety.

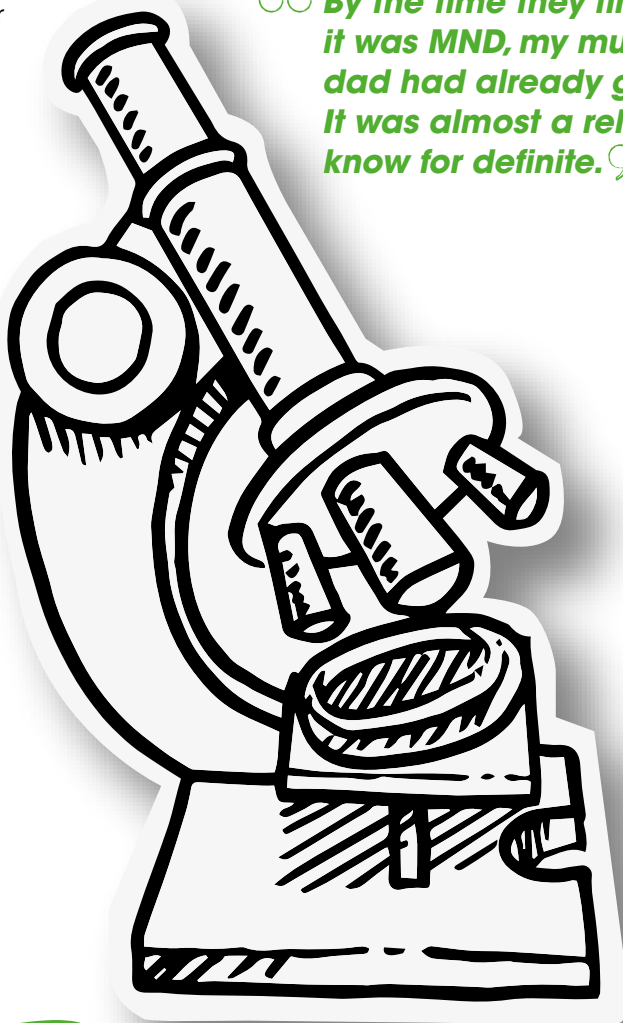
Once the diagnosis has been made, the neurologist will refer the person to other health professionals who can help with the symptoms of MND.

**“My dad kept going for tests, but it took ages for them to finally decide it was MND.”**

Although a diagnosis of MND can be a great shock, there is sometimes relief after the long wait. Once people know what is happening, they can start to put things in place to get the right support.

You can find out more about support in [Section 6: Who can help?](#)

**“By the time they finally said it was MND, my mum and dad had already guessed. It was almost a relief to know for definite.”**



## Is there a cure?

Unfortunately, there is no cure for MND at the moment. People with the disease do not get better and, in time, will die from MND.

***“ I used to get really angry at all the health professionals who came to the house because I thought they weren't doing enough to help, but really I was angry at the fact that they couldn't cure my mum. ”***

However, scientists are constantly discovering new things about MND and the way it works.

Some people with MND are prescribed a drug called riluzole, which is taken every day. It is not suitable for everyone, but doctors can advise. Riluzole is not a cure, but can slow down the progression of MND by a few months.

***“ It probably happens a lot, that families look for anything that might lead to a cure. Dad explored all sorts of things and he even went on a new drug trial. ”***

While there is no cure, there is support available. This can help the person with MND feel more comfortable and do things for themselves for as long as possible.

Support can vary, but might include:

- **treatment and therapy**
- **medicines to help manage symptoms**
- **equipment and aids**
- **money to help with extra costs**
- **help around the house**
- **personal care, such as getting washed or dressed**
- **nursing care, where medical needs become more complex**
- **help for family and carers.**

You can find out more about support in [Section 6: Who can help?](#)

## How long can someone live with MND?

This is a very difficult question to answer. The disease works differently from one person to another and it depends on the type of MND they have.

***“ I was more scared about what might happen next, than about losing him. You never know what's going to happen with MND. ”***

MND is a progressive disease, which means symptoms get worse over time. For some people, these changes take a long time and they may live for a number of years. For others, the changes happen quickly, over a period of months or a few years, meaning they have a shorter life.

***“ Instead of getting down, I am determined to live the life I feel was robbed from dad. Living the life you have is so important. ”***



66

***I was always on to the carers if they didn't do things right. I'd show them how to do tasks, like putting his head into a brace for support. If it wasn't done correctly he would be uncomfortable. 99***

## Does MND hurt?

MND is not thought to cause pain as a disease, although research is going on to look at this more carefully. However, someone with MND can feel pain and discomfort from the way muscles and joints stiffen. They can also get cramps.

As muscles become weaker, it can be difficult to get into a comfortable position when sitting in a chair or lying in bed. Being helped into a new position can ease this.

Exercise can also help to stretch muscles and loosen joints. If this becomes difficult for the person to do, they can be assisted by someone else moving their limbs. This should always be done following guidance from a physiotherapist who understands MND. This way, any exercise will suit the person's needs and can be reviewed if things change.

People with MND can get very tired, so it is not a good idea to over-exercise.

Some people with MND try complementary therapies, such as aromatherapy or acupuncture. These therapies will not stop or slow down the disease, but they can help people feel more relaxed. Some people say they ease symptoms and pain too.

If more help is needed, the person can ask their GP for advice about medication to ease pain.







## How does MND affect the body?

MND mainly affects muscles in the legs, arms, mouth and throat, but not everyone has all of these problems. Symptoms can start in the muscles of one part of the body, such as the legs, then affect other areas, such as the arms or throat.

The way this happens can vary. MND can progress at different speeds and no one has exactly the same symptoms in the same order as someone else with MND.

**“Dad could still swallow and didn't develop any breathing difficulties.”**

There are ways to help people feel more comfortable with MND. For example, through physiotherapy, medical equipment or medicine to ease symptoms.

### What is not affected by MND?

MND doesn't usually affect the senses, so people with MND can still see, hear, smell, feel, touch and taste things.

## Does it get difficult to walk?

Many people with MND find their legs are affected. If this happens, the person will gradually find it harder to walk, stand, climb stairs or keep their balance.

They may need to use a stick, a walking frame or a wheelchair to help them get around.

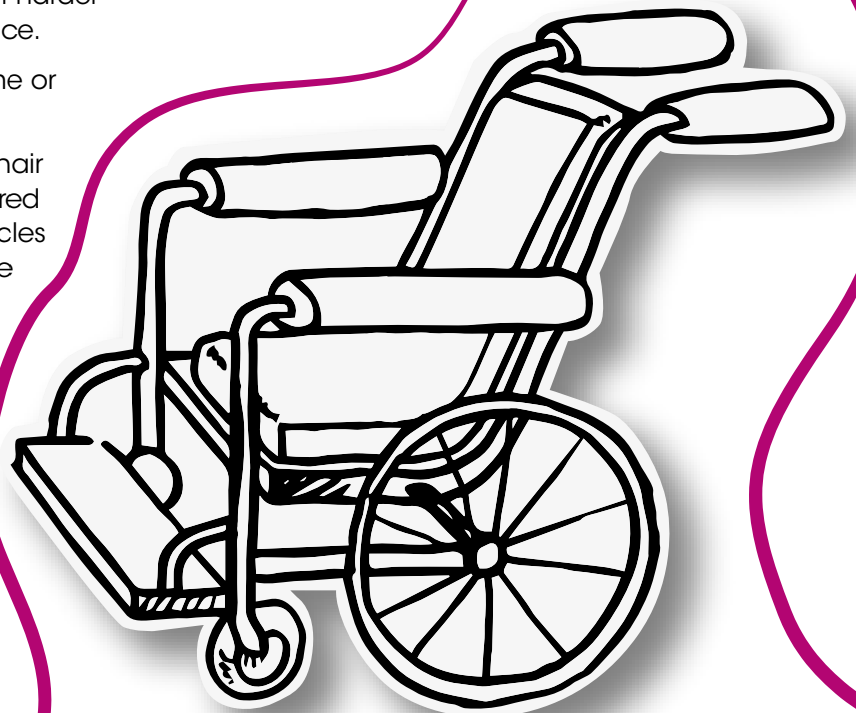
At first, people with MND often use a wheelchair to manage activities where they might get tired quickly, such as going shopping. As leg muscles become weaker, they may no longer be able to stand or walk and need the wheelchair at all times.

“

**It started with dad tripping up and finding it hard to go upstairs. After that the physiotherapist gave him a walking frame so he didn't fall, and then later he got a wheelchair.”**

At this point, a hoist may also be needed at home. This is used to help the person get from one place to another - from a bed to a chair, or on to the toilet. There are different types of hoist. Some are attached to the ceiling and others can be folded away if not in use.

A stairlift or through-floor lift can also be fitted in the house.





**“ MND has gradual drip-drip effect, but it's life changing. Things like a stairlift going in, rails and handles, and a seat in the shower. I did like the electric chair that tipped you out though - we had fun with that! ”**

## **Are arms or hands affected?**

MND can affect someone's arm and hand movement. They may need equipment to help them with tasks, such as opening doors, getting dressed or feeding themselves.

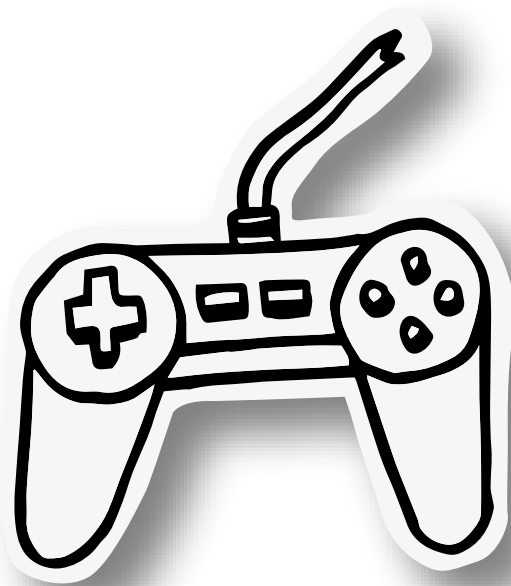
There are lots of aids, gadgets and equipment to help people stay independent for as long as possible.

People with MND can also use special switches and remote controls for various tasks, such as opening curtains or switching on a television. These are known as environmental controls.

An occupational therapist, known as an OT, may visit the person with MND. Their job is to help people with disabilities stay independent for as long as possible. They work out what equipment will suit someone's needs and may provide some items free of charge. Their advice helps families avoid buying expensive equipment that doesn't suit the person or won't help for very long.

**“ We'd play computer games with dad. In his last few months he couldn't use the controls anymore, but he still enjoyed watching us play and would get involved that way. ”**

Sometimes changes are made to the house to make it easier for the person with MND to continue living there. This could include installing a wetroom or moving their bedroom downstairs. This can feel difficult, as the house and everyone living there has to adapt to the needs of the person with MND.



**“ We had to convert a room downstairs into a bedroom and get a toilet fitted. ”**

You will probably find this feels easier after a time, as new ways of doing things become more familiar.

## **Will speech and communication change?**

We use lots of muscles in our mouth and throat, which can be affected by MND, although not in all cases. If this does happen, it can make it difficult for the person with MND to talk clearly or loudly. Over time, you may find it hard to understand what they are saying.

**“ If someone's speech and communication go with MND, you start to recognise what they need in other ways. It's a good skill to learn. ”**

MND can also affect:

- **muscles in the face, so it's harder to smile or show emotion**
- **muscles in the arms and hands, so it's harder to gesture or write.**

The person may need equipment to help them communicate. Depending on someone's needs, there is a wide range to help. Communication equipment can include simple things like notepads, alphabet boards and word or picture cards.

Support can also be provided using a computer, tablet or smart phone.

Some apps and computer programmes use electronic voices to help the person 'speak', from text they enter onscreen or from stock phrases.

Lots of progress has been made on a technique called 'voice banking', where someone can record their own voice. These recordings can then be used to produce an electronic voice when needed, instead of using an unknown voice. Voice banking has to be done before the voice changes too much.

A speech and language therapist can assess the needs of the person with MND. They can then advise on communication aids and whether something like voice banking would be suitable.

Unless they have a hearing problem, it's important to realise the person with MND can still listen and understand, even if they find it difficult to speak.

If their speech gets worse you may find it hard to understand what they are saying. You can ask them to repeat things, but this takes patience as it can be frustrating for you both. Remember, the person is frustrated with MND, not with you.

**“He'd get angry that he couldn't get his message across and I'd get angry with myself for not understanding. It just took so long. It was usually something simple like, 'My bum's numb' but it was important in that moment.”**

Always try to work out what the person is trying to say, rather than pretending to understand or ignoring them.

Some families work out special signals to help communication.

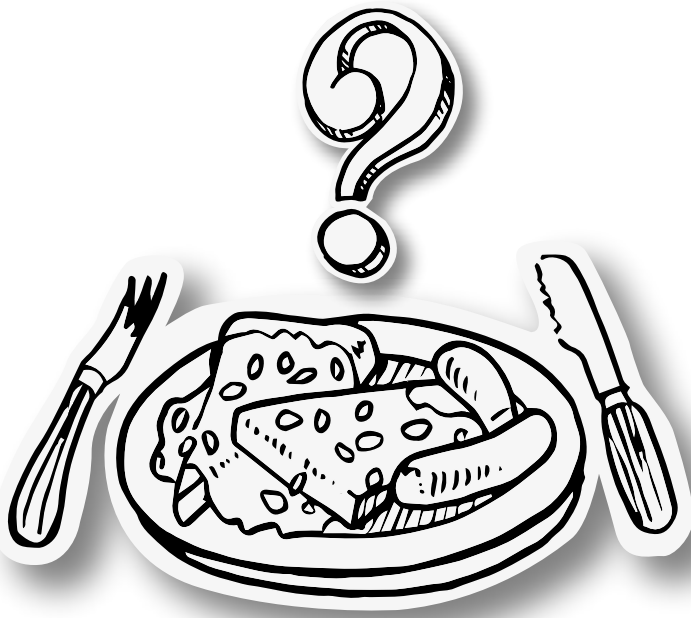
**“When he couldn't speak or write anymore, he'd move a hand or his eyes for things and we'd know.”**

If someone cannot speak, they can still listen and may enjoy hearing your news.

Even if the conversation is one-sided, you can tell them the latest gossip from school, college or work.

**“Dad couldn't go out much, so I'd bring the outside world home with me.”**





## Can the person still eat and drink?

Some people with MND find it gets difficult to eat and drink. Mealtimes can be slower and they may get frustrated. You may find this upsetting, but there is help available.

These problems happen for two reasons:

**Movement:** if someone's hands or arms are affected they may find it difficult to hold cutlery or lift their hand to their mouth. Many aids can help, such as knives and forks with a wider handle that can be gripped more easily. Some people find a support for their arm is helpful.

**Swallowing:** if muscles in the mouth and throat are affected, it can be harder to chew, swallow or drink. Softer or liquidised foods may help when eating. A speech and language therapist (SLT) can prescribe a thickening powder to make watery liquids thicker and easier to control when swallowing.

*“My dad had trouble drinking tea and coffee so mum used this thickening powder - he said coffee was ok, but tea tasted horrible!”*

People with MND usually lose weight when their muscles get smaller (or waste). This can get worse if they don't eat enough food to meet their needs. Foods with lots of calories, such as cream and butter, can help. A dietitian can also prescribe drinks with extra nutrients to help them maintain weight.

*“When he'd let me help, I'd make food or prepare his drinks. He drank liquid meals for a while.”*

If it becomes difficult to eat or drink by mouth, the person with MND may decide to have a feeding tube. They can then choose to have liquid meals, fluids and medication through the tube.

The feeding tube is inserted through the skin under the waistline directly into the stomach. It cannot be seen when wearing clothes and, once healed, it is not painful.

This operation is called a gastrostomy, but people often refer to this operation and the tube as a PEG, RIG or PIG. These are shortened medical terms for the way that the tube is inserted.

For more explanations of medical terms, see [Section 7: What do all the medical words mean?](#)

The feeding tube can be inserted early, so the person can get used to it gradually before it's really needed. They can use it to top-up their diet with liquid food, but still eat or drink small amounts of things they really enjoy. Later, they may need to use the tube for all their food and drink.

*“I used to help with mum's feed. I'd use the syringe to pump the feed into the tube. We'd joke that it was roast beef and Yorkshire pudding, or steak and chips going in.”*

## Problems with saliva

Some people with swallowing difficulties also have problems with their saliva, or spit. If they can't swallow easily, saliva can gather or pool in the mouth, and dribble out. When saliva pools, it can make the person cough a lot.

Other people with MND get a dry mouth, where their saliva becomes very thick and sticky. This can also make them cough.

Sometimes, the person with MND finds their cough gets weaker. A professional, such as a physiotherapist, can teach them exercises to help make their cough stronger. Also, if they feel happy using one, there are portable machines that can help someone cough and clear their throat.

*“At first I was embarrassed when she started dribbling and all this spit was coming out of her mouth, but after a while I got used to it and would wipe her face and make sure she had tissues ready.”*

These symptoms can be very distressing for the person. They are likely to feel embarrassed too, especially if they have to keep clearing their throat or mopping up the saliva. It can help to keep tissues or soft cloths in easy reach.

There are medicines and products that can help control saliva, depending on the problem. The person's GP can give advice.

## Does it get difficult to go to the toilet?

Most types of MND do not affect the muscles that help us to go to the toilet, but some people may experience problems. For example, if they have trouble moving about, it can be difficult to get to the toilet in time.

People who have primary lateral sclerosis (PLS), one type of MND, may get the feeling that they need to go urgently.

Other people become constipated (they find it difficult to poo) because they are not moving around as much and become 'bunged up'. Some people with MND also drink less to avoid going to the toilet and this can make constipation worse. Getting enough fluid and exercise or assisted exercise can help. There are also medicines to relieve the symptoms if the problem carries on.

There are adapted washer-dryer toilets that can help a person with limited movement to manage the controls. These toilets have extra functions to help people keep clean. Some people with MND find these very helpful.



## What about breathing?

MND can affect muscles in the chest that help with breathing. This means it takes more effort to get air into the lungs, so people get out of breath more easily. Others find it difficult to sleep and can't get their breath when lying flat.

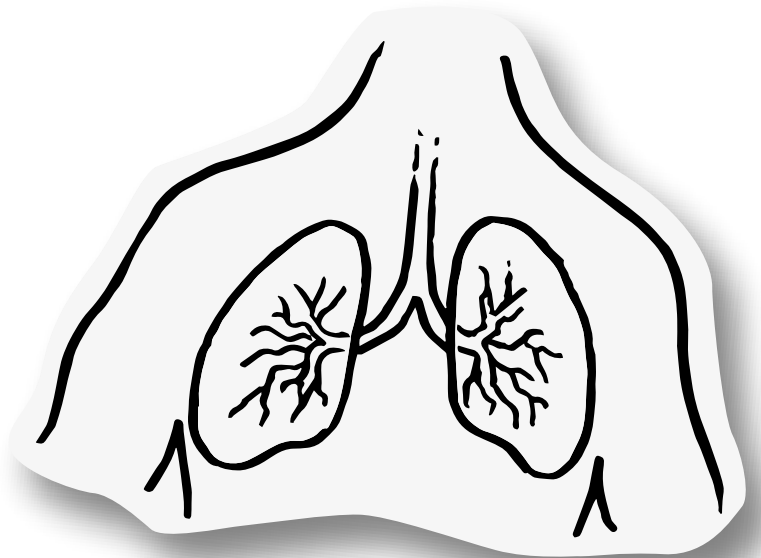
Breathing involves your respiratory muscles, which control how the lungs move. Specialists can test how well a person is breathing, during what's known as a respiratory assessment.

If the person with MND has to wait for an assessment, a nurse, physiotherapist or occupational therapist can advise on simple ways to help with breathing in the meantime.

If the tests show the person needs breathing support, the respiratory specialists will advise. Problems with breathing cannot be reversed and will continue to get worse, but therapy or equipment can usually help make breathing easier. This may include using a machine to help push air into the lungs. This is known as ventilation.

It is not the same thing as an oxygen machine. Oxygen is rarely used for MND, as it can be dangerous if used for long periods of time. Ventilation simply helps the person to receive an increased flow of normal air into the lungs.

A few people with MND have ventilation through a tube in the throat, called a tracheostomy. This enables a machine to take over their breathing.



This is known as invasive ventilation, which can require a lot of care. The person is likely to rely on this once it has been introduced.

The most common breathing support for MND is non-invasive ventilation, or NIV for short. This works through a mask that is worn over the nose, or nose and mouth.

At first, NIV may not be needed all the time. Some people just wear the mask overnight or for a few hours during the day.

Others need it for longer periods, as their breathing gets worse. They may get to a point where they rely on the machine all the time.

If the person doesn't want to use ventilation, or it doesn't suit them, medication can help them feel less breathless or anxious.

“

**Gramps used the mask at night, it helped him sleep and he didn't feel so tired in the day.**”





## Will the person get tired easily?

Many people with MND get very tired and may not have the energy to do as much as before. They may need to rest more during the day, or go to bed earlier at night.

*“Dad was so active before the disease, but that gradually stopped and it felt strange. I ended up questioning myself. Was it me? Had I done something wrong? But it wasn't that, just the effects of MND.”*

For someone with MND, energy is a little like having a bank account. It can run out quickly if they spend too much. If they overdo things in one day, they may need to wait until the 'bank account' recovers before they can spend any more.

This is understandable when you think how the disease may be affecting them:

- **if movement is affected, everything takes more effort**
- **if breathing is affected, they may not be sleeping well**
- **if they're finding it harder to swallow, they may not be eating and drinking enough.**

When someone with MND gets tired, other symptoms can feel worse. For example, walking might be more difficult or they may not feel like eating because it takes so much effort.

If the person knows when they get most tired, they can plan their day around this. For example, they may choose to be more active in the morning, then rest in the afternoon.

This can help you too. If you know when the person feels less tired, you can spend time with them when they have more energy.

## Do thinking and behaviour change?

MND can make it harder to do some things and the person with MND may get frustrated or upset. They are usually frustrated at MND, not you.

However, other changes to thinking and behaviour can happen for some people with the disease.

### Laughing and crying

The person with MND may laugh or cry more easily than they used to.

*“With MND, dad would cry a lot. This was difficult for us - we'd never seen him cry before...and when a carer did something wrong, even something serious, dad would just laugh. It felt wrong, as if the laughing wasn't real.”*

It's natural for someone's moods to be affected when dealing with a condition like MND and there may be times when they feel very down.

However, if they laugh or cry at really odd moments, it may be due to a symptom called **emotional lability**. This does not happen to everyone with MND.

This can make the person with MND laugh when they feel sad, or cry for no reason. It can be upsetting for them, as it's difficult to control. You may also feel upset or embarrassed when this happens, but they can get guidance and support from their health and social care team. Emotional lability does not necessarily mean there are other changes to the way they think or behave.



## Thinking and behaviour

Up to half of people with MND show changes to the way they think and behave because of the disease. In most cases this is mild, so it doesn't affect daily life very much. Sometimes it can be more severe and you may notice how their thinking and behaviour has changed.

**“His emotions and personality were changing. I know this happens for some people with MND, but you need to be told or it makes you think you've done something wrong.”**

If these type of changes happen, the person may find it difficult to take in new information or make decisions. This is known as cognitive change. Their personality can also be affected and they may even become more aggressive.

**“The disease made him behave in odd ways. His needs came above everything and everyone else.”**

Where changes to thinking and behaviour are severe, the person and those providing care and support will need extra help. This means professional carers may be involved at an early stage.

A small number of people with MND may get a type of dementia, called frontotemporal dementia (FTD). Changes to thinking and behaviour will be more severe with FTD and it can affect use of words and language. People may find it harder to follow conversations, find the right words or write words correctly. Memory is not usually affected, but people with FTD may find it difficult to concentrate and take in new information.

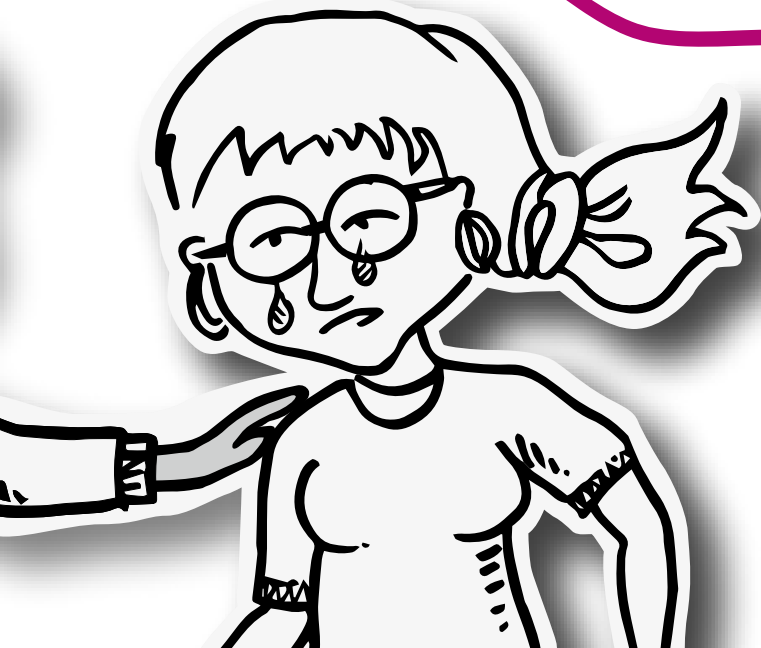
Dealing with a diagnosis of MND in the family is difficult. If thinking, emotions and behaviour are also affected, it can be very confusing and you may even feel scared. Talk to others in the family or someone from the health and social care team if you need support. You can also contact our Young Connect helpline:

Telephone: **0808 802 6262**

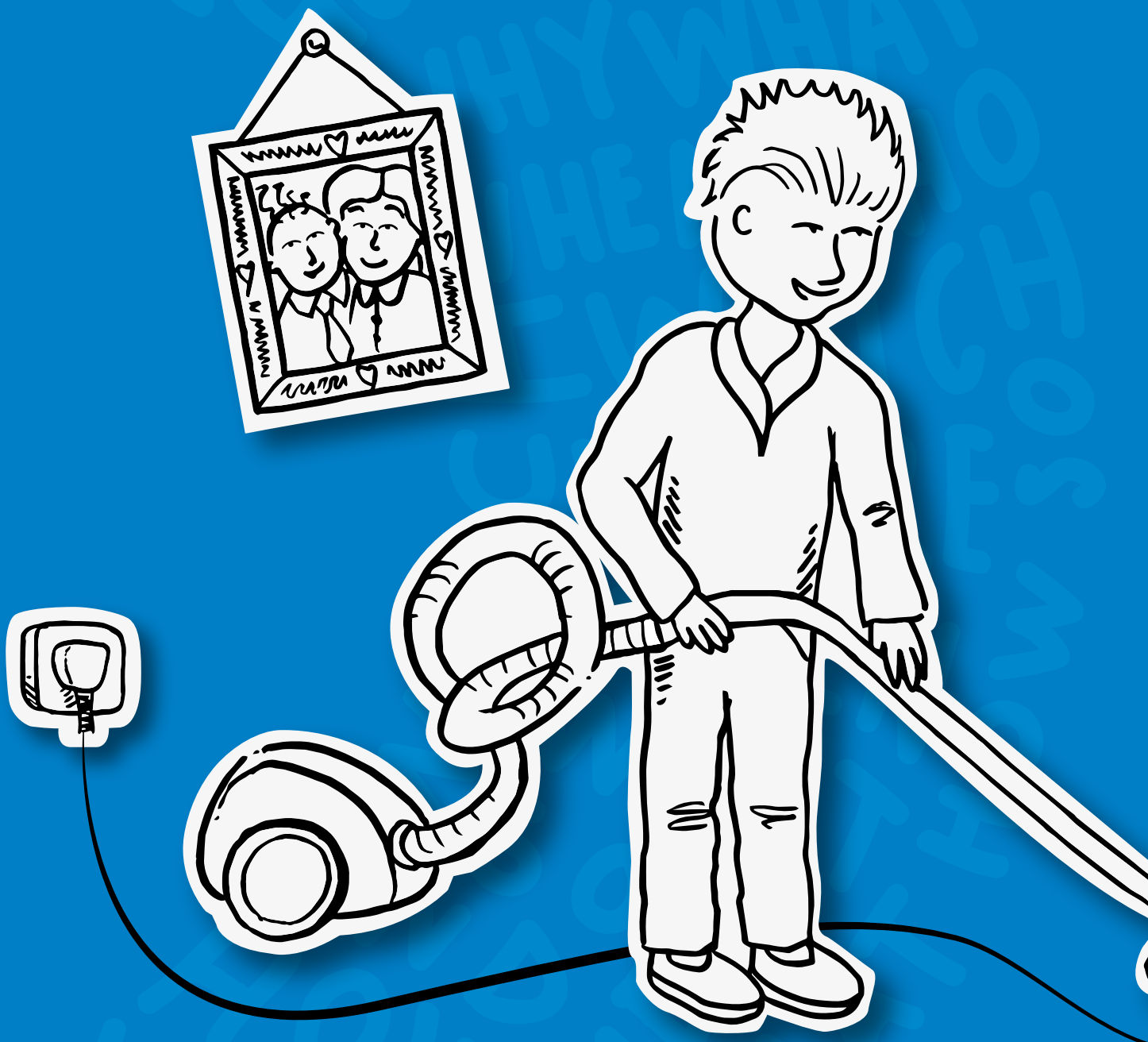
Email: **[youngconnect@mndassociation.org](mailto:youngconnect@mndassociation.org)**

Or contact our email for children and young people's services: **[cyp@mndassociation.org](mailto:cyp@mndassociation.org)**

For more suggestions about support, see **Section 6: Who can help?**



# 4 How will MND affect my life?



## How will my life change?

When someone is diagnosed with MND, the whole family is affected and people can react in very different ways. Everyone may need time to adjust.

As time goes on, the person with MND won't be able to do everything they did before. They will need more and more help as the disease progresses. Who does what at home will change and this could affect you, too. There may not be as much time for family activities if the person needs more support.

When someone has MND, they may decide to leave work. This means there may not be as much money available.

**“We were strapped for cash and mum had to go out and get part-time work even though she was also caring for dad and looking after us. My older brothers had to help out, to keep the house running.”**

Things around you at home are likely to change too.

Equipment will be introduced, to help the person get about or manage day-to-day tasks. Rooms may be converted to make everyday life easier. Mealtimes may also feel very different if the person has problems eating and drinking.

“

**I felt different to all of my classmates. They were busy gossiping and crying about boys and I had MND to deal with.”**

A range of health and social care professionals may get involved. As the person needs more care, lots of professionals may visit the house.

**“My mum used to say she should charge for all the cups of tea she made for other people. We never had any clean cups by the end of the day.”**



If your family own a car, that may also need to be adapted or changed to a vehicle with wheelchair access.

**“ I think I was trying to avoid what was happening and told myself he'd get better. So all I could do was think 'Why?' Why couldn't he work or drive anymore? ”**

**“ If we wanted to go out, we had to arrange for a special taxi or minibus to take dad - everything needed planning. ”**

Not only does life change, but keeps changing to meet the needs of the person with MND.

## What can I do to help?

If you help to support the person with MND in their care or daily routines, you are seen as a 'young carer'. You may find yourself helping more in the home, but also with personal care, such as helping the person to get dressed.

Sometimes getting involved in care can feel overwhelming and you may need to talk this through with everyone involved.

**“ I didn't think of myself as a carer - I just did what had to be done. I didn't really have a choice. ”**

You should not have to do things that feel uncomfortable. Even if you think there is no-one else who could do these things, you do have a choice. This can be looked at during a young carer's needs assessment. This is not something to get worried about, as this is designed to help you. Social care professionals work out what support you and your family may need and can arrange services to help.

See **How do I get my needs assessed?** in **Section 6: Who can help?**

You may want to contribute to care tasks. It may give you a sense of purpose and closeness to the person with MND. Many young people like being part of the 'care team'.

**“ I'd do lots just to make him feel better, like sticking his feet into a bucket of water and scrubbing them clean. ”**

If the person is only just beginning to need help, you may be wondering what you can do. It's natural to feel helpless sometimes, but there are many ways to support.

**“ I didn't really know what to do at first, but I'd watch mum. I studied how she did things, so I knew how to do them too. ”**

There may be things the person with MND would like you to do. Likewise, there may be things they don't want you to do. They may want to protect you or find it hard to let you help.

**“ He was proud and hated being helped, especially by us...he'd only ask if mum wasn't there and he really needed something. We were a last resort. ”**



You may have to tell the person with MND and other adult carers that you want to do something. Try to talk to them. This way you can all work better as a team and make joint decisions about who does what, and when.

There may be practical things you can do, like helping to prepare meals or shopping. You could take on regular jobs around the house or tidy up, so the person with MND is less likely to trip over things.

**“ I took my little sister up to bed a lot. Mum hates the thought she didn't do something for us, but we tried to help in small ways like this. ”**

You may have more or unexpected responsibilities because of MND. This can be difficult, but you may be surprised at how well you cope.

## What if I'm the main carer?

Being the main support for the person with MND is a big responsibility. If you find yourself in this role or there are no adults helping you to provide care, ask the professionals involved in the person's care for guidance. You should not have to manage care on your own.

**“ I used to feel awkward when people said 'You're doing so well.' With caring you do lots of things you never expected to do, but it's for someone you love. It's part of life, just what you do. ”**

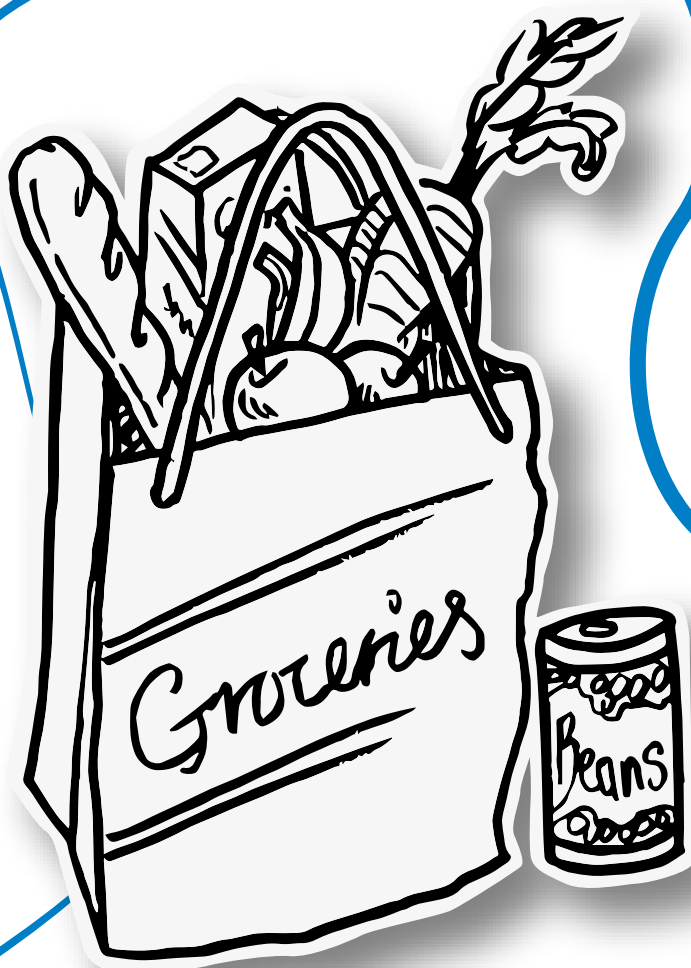
The person with MND can be assessed by adult social care services to consider their needs. You can also have a young carer's needs assessment to arrange support for you. You don't have to be the main carer for this to happen, just involved in providing support.

This is your right and as a young person, those assessing your needs have to ensure you get appropriate help.

For example, you may need professional carers to come in and help at home.

**“ We managed to get carers who came in regularly, which made a difference...having the same carers meant we all got to know each other and they were more like aunts and uncles. ”**

See also **What are my rights?** in **Section 6: Who can help?**





You may also be given time to see friends or join a club, or keep up with school or work.

Your assessment also provides an opportunity to find out about emergency contacts, local services and financial help or benefits that may be available. This information can be very important, especially if something unexpected happens.

To get an assessment arranged, contact social care services through your local authority. In Northern Ireland contact your local health and social care trust instead. If you're not sure how to do this, ask your family doctor or GP for help. You can also ask any health or social care professional involved in support for the person with MND.

See **Section 6: Who can help?**

You may also have a network of other people who can help out, such as relatives who live nearby or close family friends.

**“Everyone kept bringing meals round, which was so kind.”**

Sometimes you need to ask for help – family and friends may be very willing, but don't realise what's needed.

**“You don't want to ask, but you have to learn.”**

Sometimes you may feel resentful about taking on extra tasks or angry that the person with MND can't do the things they used to do.

**“It was our life at the time, so you just adjust to it, don't you?”**

At other times, you may find that you enjoy helping the person with MND and feel much closer to them.

**“I can go into survival mode really easily now. You learn to look after yourself and other people.”**

## Why do I feel the way I do?

It's normal to feel lots of emotions in everyday life – no-one can be happy all the time.

Emotions can sometimes be very intense. As a young person, you are growing physically and emotionally, and these changes can be confusing. This can feel even more challenging when MND creates change around you, too.

This may cause you to feel angry, sad, selfish or even guilty. These are natural responses to a difficult situation and there is no right or wrong way to feel.

Things may feel tense at home. Dealing with MND is challenging and emotions can change quickly. People may not be as patient as before.

Everyday worries can still affect you, too. You may feel anxious about homework, exams, or falling out and making up with friends at school.

Strong feelings are only to be expected. There may not always be a solution, but feelings come and go, which can sometimes make them easier to accept.

Your experience may be very different to someone else affected by MND, but try to work out why you feel the way you do. This is the first step to feeling more in control.

Later we will suggest ways to cope with challenging emotions, but here we look at why you may experience these feelings.

**“It was a weird time. I didn't feel like a child because I was doing all this stuff to help care for her, and then the next minute my mum and dad would say I was too young to understand and not tell me things. I think they were trying to protect me, but it was so frustrating and I'd get really angry.”**

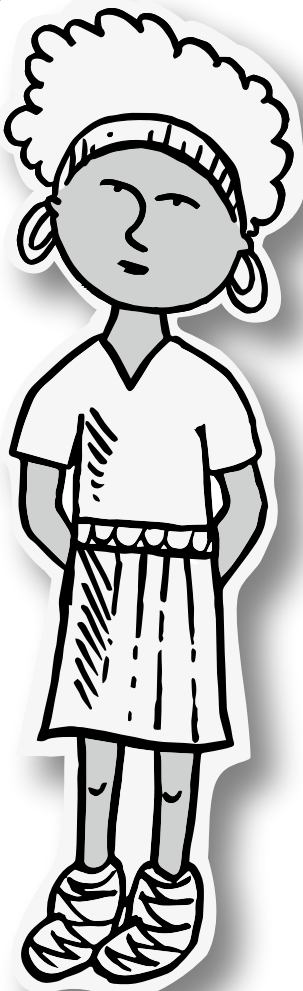
## Why do I get angry?

It's normal to feel angry with MND. You may feel angry because:

- it feels unfair that someone you love has the disease
- doctors can't cure the disease yet
- everything is different since MND
- relationships are changing
- other people don't seem to understand how you feel
- no-one seems to have time for your worries anymore
- something unimportant irritates you, but it's one thing too many and you lose your temper.

“ Sometimes I just wish I had my old life back, before everything changed. ”

But you can learn to manage anger. The strength of this emotion can even become a positive force to help you change something for the better.



## Why do I feel helpless?

MND is a rare disease and even some health and social care professionals haven't seen it before. It's not surprising if it leaves you feeling helpless, as:

- you won't be able to fix everything
- you may feel there is nothing you can do to change things
- things can happen unexpectedly, which can leave you feeling powerless
- everything is changing and feels new
- you doubt your own ability to cope.

Yet, you will find you are capable of far more than you realise. We may not like change, but we can all learn to adapt.

“ He'd fallen and I wasn't strong enough to lift him on my own, so just had to leave him there while I fetched someone else. I hated feeling so helpless when he needed help so badly. ”



## Why do I get embarrassed?

Young people sometimes feel embarrassed by adults, by the way they talk or the things they do. This can get worse when someone's ill, as it makes you feel your family is 'different'. Most teenagers just want to fit in.

**“I hated being in a small village at the time. I'd walk down the road and people would stop me to ask questions about what was happening. I just wanted to be invisible. As a young person, you don't always want to be noticed, you get self-conscious.”**

Some MND symptoms may make you feel embarrassed. For example, if someone is having difficulty speaking and their words sound odd, they may sound as if they are drunk. You may also find it embarrassing if they have problems with their saliva. Or, you may worry about what other people think if the person with MND uses a wheelchair.

**“Dad came to watch me in a school drama production as a surprise. Part of me was pleased, but peer pressure in your teens is such a weight. My instant thought was, 'Great, now everyone will be asking 'Who's the bloke in the wheelchair?'”**

It is normal to want to fit in with your friends and worry that MND in your family makes you different. You may worry about them meeting the person with MND.

**“I used to get really anxious about friends coming over. I'd worry what they'd think of all the equipment and changes to the house. Reaching your teens is a really difficult time for worrying about what your friends think.”**

Try to remember these feelings of embarrassment are natural and part of your own development. There is no need to feel ashamed or guilty about these feelings. You are not letting anyone down.

## Why do I feel worried or scared?

Everyone worries. It's normal to worry about the future, especially when something like MND affects your family. With things changing around you, you may find it scary to think about what happens next. Finding out about MND can help reduce feelings of fear, as you then know what to expect.

It is not selfish to think that MND is making an impact on your life, because it is.

**“Take a deep breath in every now and then and make the most of whatever is going on.”**

Acknowledging your worries can make them easier to deal with. Talk to those around you, who may be able to help. You may be surprised how much your family worry about you too.

**“It's hard to balance life and know when to ask our children for help and when not. As young adults they have had to help with and see things they shouldn't, but what is the alternative? There is great strain on them, but they are a credit to themselves. I wish I had more time for them.”**

## Why do I feel envious?

You may feel envious or jealous of friends who don't have to deal with MND.

**“ I used to get very upset when my friends could go out for bike rides with their dad and I couldn't. I don't know why bike rides meant so much then, but it seemed so important at the time. It's easy to be envious of friends doing normal family things.”**

You may find it difficult do things with your friends because you're needed at home.

**“ Sometimes we'd have these arguments and I'd slam the door and go out. I was sick of being told that I had to be a 'grown up'. I just wanted to be like all my friends. Sometimes I just felt like it was all too much.”**

Plans may need to change at short notice and this can be frustrating if you were looking forward to doing something special.

**“ Sometimes we'd have to cancel stuff because dad had an appointment or was really tired. My mum had this massive calendar on the wall with all the appointments in it.”**

You may have to get used to less attention than before.

**“ My little sister would try all sorts of tactics, like wearing knickers on her head. It was her way of saying 'Please will you just look at me?'”**

**“ Friends got a lot more attention from their parents and I wanted this too, as I'm a bit of a drama queen! I wanted attention 24/7, but I just had to get used to not having this.”**

An illness like MND can also be expensive. The person with MND may not be able to keep working and the main carer may also have to leave work to manage the care. It can be difficult if friends have the latest gadgets and fashion, when your family are struggling to get by.

**“ Money can cause arguments for many families, but MND creates such pressure. Our finances were stretched and I know mum felt guilty because she couldn't always give us what we wanted or needed as kids.”**



You may even feel jealous simply because another family is okay.

**“ I was so envious of people who didn't have to go through this. I didn't want it to affect me or happen to my dad. Why not some other faceless family? Why us? I know this was selfish, but I couldn't help it.”**

### Why do I feel guilty?

Sometimes you may feel guilty, maybe because you've been angry or embarrassed by the person with MND and then felt bad afterwards. Or because you get to enjoy an activity that the person with MND can no longer do.

**“ I felt guilty if I left mum to go out with my friends, but she liked hearing what we'd been doing and all the gossip.”**

You can't think about MND all the time. It's good to spend time with your friends. The person with MND would not want you to miss out on things or only think about MND.

You may even feel guilty because you think MND is your fault, but this is not true.

No-one is to blame for MND, so try to let these thoughts go or talk it through with someone you trust.

**“ Reason tells me it wasn't my fault, but my heart doesn't listen. I know, it's a bizarre thought, but it's so hard to make sense of it all.”**

### Why do I feel sad?

Finding out that someone close to you is very ill is unhappy news. Feeling sad is expected. As time goes on, you may also miss things you used to do together, if the person can no longer join in or gets too tired.

It's okay to feel this way. Everyone around you will probably feel sad too, so try not to hold it in all the time. When you show your emotions, it can give others permission to admit how they feel. Sharing can help everyone to feel more supported.

**“ You need someone to tell you it will be okay in the end. Not that there will be a cure or anything, but that you will find a way to get through the sadness and live your own life. Because you will.”**

### Is it okay to feel happy too?

Yes. This is natural. We can feel a sense of happiness in lots of different ways, whether over something that happens or because we are enjoying ourselves. You shouldn't feel guilty about being happy simply because someone else is ill. Good things can happen even in difficult times.

Being positive may help the person with MND to feel brighter, too.

### Tracking my feelings

If a difficult emotion only affects you now and then, it may be something you can manage. If it feels constant or extreme, you may need support.

See **Section 6: Who can help?**

If you feel up and down, it may help to track what's happening over a week or two. Tracking can help you *think* about your emotions, rather than just *feeling* them. You can use the following table to do this.

Not all of your emotions will relate to MND, but they are all important for you. We've included positive emotions, as it's important to note when you feel happy. Try to be honest when using this table, so you can see if there is balance between emotions that are challenging and those that feel positive.



You can use ticks or quick notes:

	I am feeling...	Most of the time	Sometimes	Occasionally or never
Challenging emotions	angry			
	guilty			
	sad or upset			
	drained or numb			
	confused			
	anxious or worried			
	stressed or pressured			
	annoyed			
	frustrated			
	embarrassed			
	envious or jealous			
	low or depressed			
	frightened			
	helpless			
	lonely			
Positive emotions	needed and involved			
	loving			
	loved			
	proud			
	satisfied			
	happy			
	interested			
	motivated			
	inspired or creative			
Other emotions				

If one or more of the challenging emotions are happening most of the time, ask yourself, 'Are these feelings extreme?'. If you feel distressed by them, you may need support.

See [Section 6: Who can help?](#)



## How do I cope with these feelings?

When someone close to you has MND, it affects the whole family. Everyone will cope in their own way and some days will feel easier than others.

The following suggestions may help you find ways to deal with difficult emotions.

### Getting involved and being prepared

The truth is, you can't stop MND. No-one can, but there are things that can make each day feel a little better.

Helping with chores, care tasks or just spending time with the person with MND can be positive. You may feel more like 'one of the team'.

**“By going through difficult challenges, you find out how to manage things. You wish you didn't have to learn things like that, but you do get more confident about supporting someone.”**

Sometimes adults try to protect young people by not telling them everything or shielding them from certain things. Ask for information and honest answers if you feel confused. If you know what is likely to happen, MND symptoms and care needs are less likely to come as a shock.

Ask others involved in care what to do in urgent or emergency situations. Even if you just find out where emergency telephone numbers are kept, you may worry less about possible problems.

### What if I react badly to something?

If you're reacting badly to things that normally wouldn't bother you, it can help to find a quiet place and think about what has caused you to feel this way. If you know the type of emotion you feel, it can be easier to control. This can help you manage these feelings when they start, so they don't take over.

**“I would act up, just because I could get away with it. It's easy to do. Try to treat your family with the same respect as before MND and allow the person affected to still be the parent or grandparent - or at least as much as they can be in the circumstances.”**

You can find guidance about emotional health for young people, including emotions such as anger and anxiety, at: [www.youngminds.org.uk](http://www.youngminds.org.uk)

See **Where else can I get help?** in **Section 6: Who can help?** for more organisations that support young people.

While time out can help you feel calmer, sometimes you may need to talk about what's happening with someone you trust.

**“Having someone to relate to outside of home is important, as they can tell you when you're out-of-line and you somehow take it better. You sometimes need that and you can't always take it from someone at home where all the pressure is.”**

There may also be an activity where you can work through your anger, such as a creative task or a physical sport.

**“Kickboxing was the one thing that helped me feel better. It was a release. My coach was aware of what had happened and helped me channel my anger and focus my energy in a structured way.”**

## Crying and laughing

**“ I didn’t cry in front of him because I thought I should be strong, but sometimes I’d go to my room and cry and cry.”**

Crying can help you release feelings of sadness and anxiety. There is nothing wrong with this. Laughter is a helpful way to release tension too. Even during sad times, there are still things that make us laugh. Don’t feel guilty about this. It’s not wrong to find something funny and the person with MND may feel more positive if you try to live life as normally as you possibly can.

**“ If MND has taught me anything, it is firstly that it is fine to laugh at the things you laughed at before. And secondly, any achievement, no matter how big or small, you know they’d be proud of you.”**

## Talking with someone you trust

**“ Letting things out is so important. Just tell someone if it gets bad and why you’re feeling that way. Don’t struggle with everything in silence.”**

Sometimes it’s important to let people know how you feel. Sharing these emotions can be very supportive and gives other people around you a chance to show how they feel too.

It helps to discuss feelings with your family, but you may need a trusted person you can chat with outside of home. This could be a teacher, family friend, relative or a youth leader.

**“ Someone I trusted told me it was okay to feel angry or show that I was upset. You can read things like that all day long, but it doesn’t quite sink in. He gave me permission to show my feelings, which really helped.”**

## Talking with other young carers

It can help to share experiences with others in similar situations to yourself.

Many areas have groups for young carers. They should involve trusted people to help, and often organise activities or trips. Most of these groups describe young carers as anyone under 18 who helps support someone who is ill or disabled. Look online for your local group or ask one of the following for guidance:

- your school or college
- your GP
- your local authority or council in England or Wales
- your local health and social care trust in Northern Ireland.

The MND Association also has branches and groups across England, Wales and Northern Ireland. Many of them hold family days or arrange fundraising activities. You may be able to meet other young people on these days, who share similar experiences to yourself.



## Talking with a counsellor or professional offering support

If emotions get really difficult, you may need some help. Talking about your feelings with trained professionals can help you find ways to cope and feel more in control.

***“I was acting up, being selfish, but the whole world felt unfair. There’s still a hole in the living room door where I punched it in anger.”***

Counsellors are people who are trained to listen and help you work through your worries. They can’t take away the problems and challenges you face, but they can help you think about ways to cope.

Some are counsellors by profession, but many other professionals also have this training and can support you, such as school nurses, some teachers, social workers and hospice staff.

Not only can counselling help in the present, but it can help prepare you for the future. By facing your worries now, you are better placed to prevent challenging emotions from building in the long term.

***“My younger brother is the most grounded now and he had a full year of counselling after dad died. The rest of us chose not to have this and we’re okay, but it gave him ways to think through problems and emotions.”***

If you would like counselling or similar support, an appointment is usually arranged in agreement with your parents or guardian. The following people can help find a suitable counsellor for your age group (there may be a waiting list and sometimes there may be a charge for the service):

- your family doctor
- the health and social care professionals who support the person with MND
- teachers, school nurses or college administrators
- staff at your local hospice.

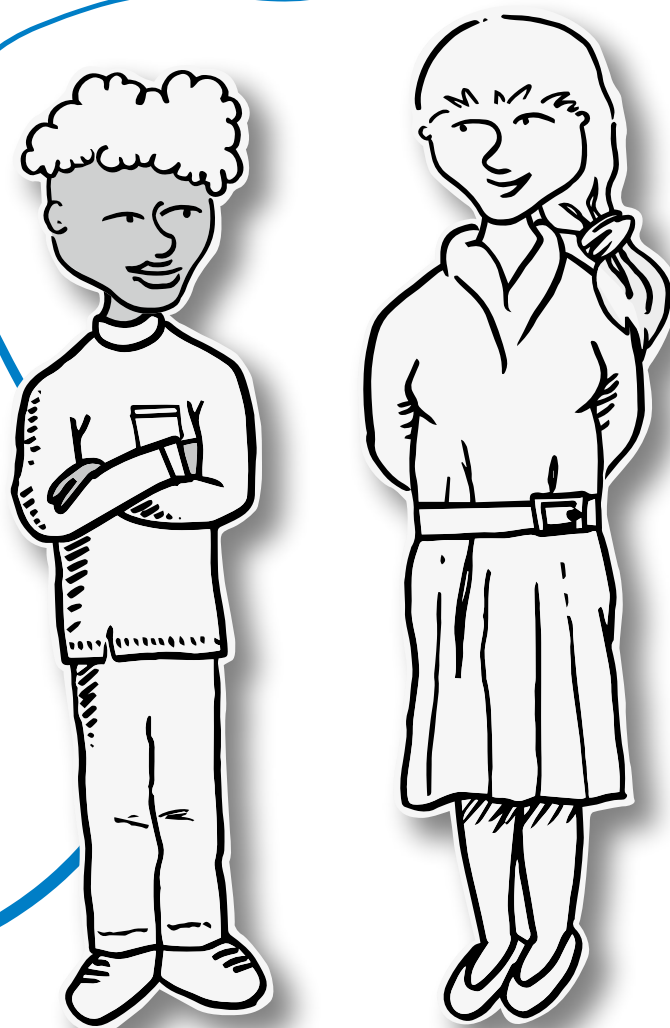
See also **What support can I get at school or college?** in **Section 6: Who can help?**

You can find out more about organisations offering support at the end of this guide.

See **Who else can support me?** in **Section 6: Who can help?**

If you don’t feel counselling is right for you, there may be other ways to work through feelings:

***“Maybe do some kind of activity with others who understand how you feel. Doing something positive helps to take you away from sadness or loss, and you feel you’re accomplishing something too. A singing group or doing something for charity, whatever the activity, it just needs to have a purpose. Then you rebuild a sense of who you are as a person and what you’re capable of doing.”***



## Time out to be you

We all have to adapt to change, as it happens around us all the time. Yet MND can change things very quickly. This makes it harder to cope with emotions.

Where possible, it can help to keep doing everyday things you used to do before the person was diagnosed with MND. If you are helping out a lot, this may not be easy, but try to find time for things that feel familiar. This could be as simple as watching a favourite television programme or being with your friends. Anything that distracts you from the more challenging emotions can give you time to feel a little calmer.

**“It’s important to do normal stuff like hang out with your friends, otherwise it’s not a normal life.”**

Keeping fit and healthy can also help you feel more positive. Eating a balanced diet is important, but exercise or sports activities can also help by:

- improving or maintaining fitness
- providing a sense of accomplishment
- giving you much needed time for yourself
- providing contact with friends.

## Can anything positive come from MND?

Although MND is a very difficult disease to cope with, good things can happen.

**“It’s not all doom and gloom. There are positives, you just have to look for them and appreciate them for what they are. Special moments, new skills, learning how to deal with difficult situations - these are all things you can carry with you in life.”**

You may be able to spend more time with the person who has MND than you did before. For example, if your mum or dad has MND and they decide to stop or cut down the hours they work, you may have more time at home with them.

**“I used to do my mum’s hair and nails. We spent a lot of time together, just the two of us. I’d paint her toe nails in multi-colours and we laughed a lot. Before she was ill she never had time to do silly things.”**

Many young people say that they become closer to the person with MND than before and appreciate the time they have together.

**“The thing that helped the most was spending as much time as I could with my dad to build some very special memories with him.”**

You might find that you learn new skills, such as cooking. While you may take on extra responsibility than your friends, it can help you become more confident and independent.

There may be times when you find it difficult to feel positive, but there are lots of people and organisations that can help you through these difficult times.

**“I did a parachute jump for charity last year, for the MND Association and the local hospice. It taught me that you can do something positive, even when the situation seems as bad as it can get.”**

## LET PEOPLE KNOW HOW YOU FEEL

### Messages from other young people affected by MND

Other young people wanted to send you messages of hope from their own experiences of MND:


“*Spending the last few years by his side and seeing him every day was really, really good. Learning how to look after another person who depends on you is a real achievement.*”

“*I would never want to let go of the emotions I’ve been through, because they’ve made me who I am. And I like who I am.*”

“*Now, no task is too big for me. I can still moan about the slightest thing though! But I get on with things, because I’ve learnt that sometimes you don’t have a choice.*”

“*Even in the most stressful times, when you’re having to do something that makes you feel uncomfortable, the person you’re helping is important to you. Support them as best you can.*”

“*You see it through new eyes as you change and realise the loss in different ways. It’s hard, but through all of this, you cannot let it stop you making your own choices and getting on with life.*”



“*I’m so proud of my mum who is my golden person, and my brother too, for all they went through. Dad instilled a sense of pride in me too.*”

“*I’m so proud of my mum and brothers - we’ve all come through so much and we’re still close as a family.*”

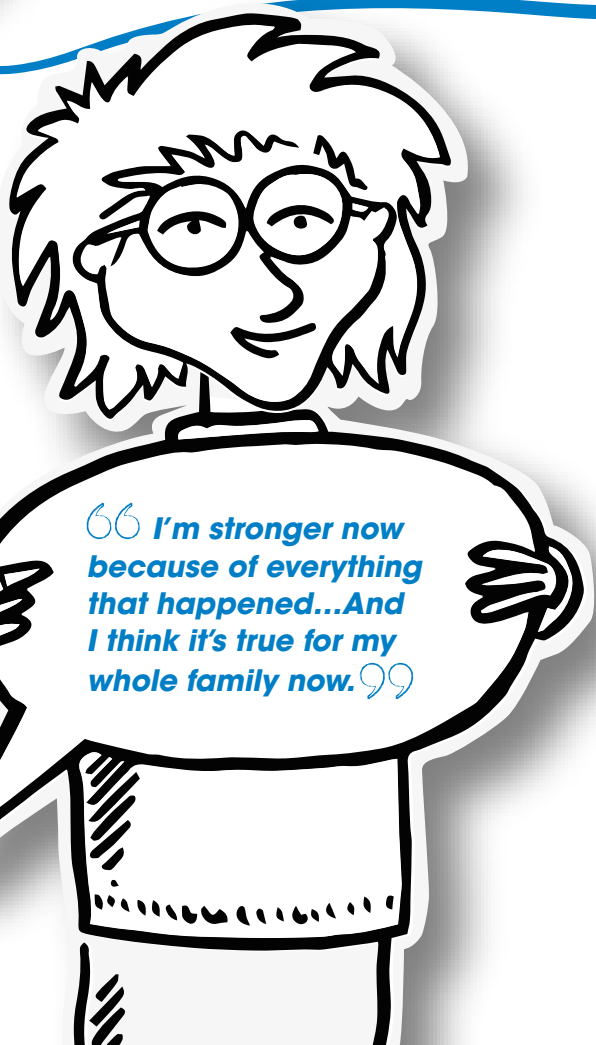


*“ I have a greater respect for other people now, a greater understanding. I’m more emotionally connected. ”*

*“ Mum’s poorly at the moment (not MND thank goodness!) and I’ve taken over at home for a while. I’m being the parent at the moment and I know how to do this because of helping to look after dad when he was so ill. ”*

*“ I don’t remember feeling proud of anything at the time. Now I look back and see how mum cared for dad and all of us at the same time and I think ‘How amazing was that?’ Back then, it was just our life and normal, but I’m proud now. ”*

*“ It’s hard to give advice to anyone else affected by MND, as it’s so different for everyone. But never underestimate how strong you can be. You might not think it at the time, but it comes out in you. ”*





## Do I tell my friends?

You may be worried about telling your friends what is happening at home. Some people find it easy to talk to friends about life at home. Others find it more difficult to open up. Do what feels right for you.

***“I would tell my close friends, but not the whole school. My close friends understand.”***

Sometimes, talking things through with a friend who is supportive can be helpful, but remember that MND is a rare disease. This means you may have to help them understand.

***“My friends had never heard of MND so I had to explain it all to them, which made me upset.”***

You may find this guide helps you to find the right words. Say what you feel ready to say. You can always explain more at a later stage if needed.

***“Sometimes I say I’m fine when I’m not, but I don’t want to talk about MND all the time.”***

You may just want to be with your friends and talk about other things, without having to think about MND. You don’t have to talk about MND if you don’t want to. Try not to feel guilty when taking a break, as the person with MND would not expect you to constantly think about the disease.

***“You have to do normal things with your friends to make you feel normal.”***

Friendships can change when you have to deal with difficulties at home, especially if you help to care for the person with MND and you’re needed at certain times.

***“My friends are all really nice most of the time, but I think they get fed up when I can’t do something because I’m needed at home.”***

If you live with the person with MND you may get anxious or embarrassed about bringing friends home. It can seem a lot for a friend to take in, for example:

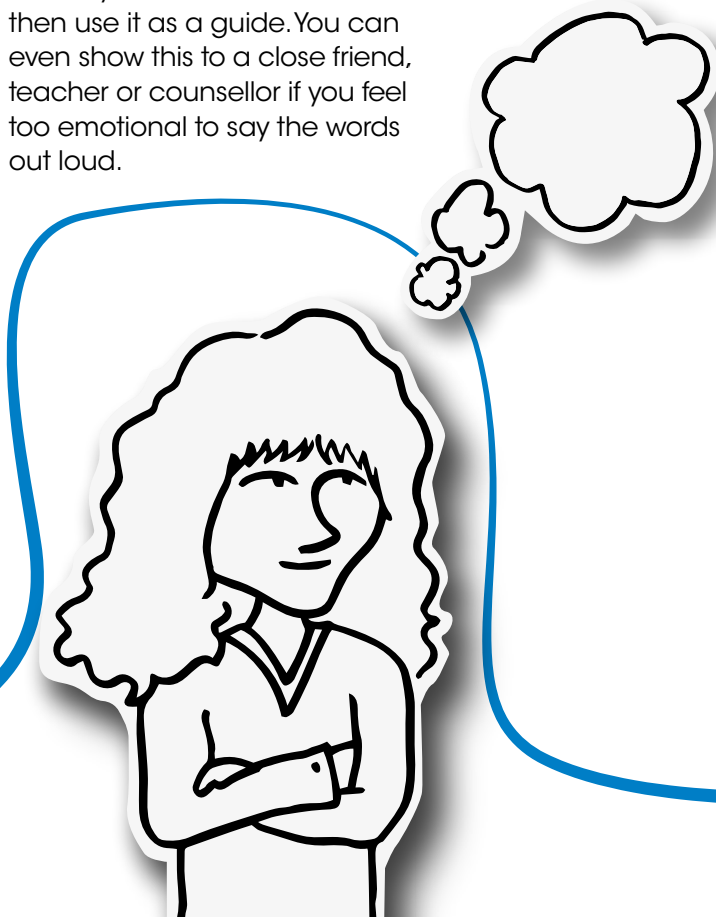
- **the person with MND may be in a wheelchair or find it difficult to speak**
- **there may be lots of equipment to help the person with MND at home**
- **care tasks may have to come first, before anything else can happen.**

***“Other young people found it difficult. Some knew how to react, some didn’t. I was going through an emotional time and not everyone was mature enough to handle it well.”***

Yet most people are very understanding and often interested too. As time goes on, you will probably find that:

- **your closest friends accept your situation**
- **it feels easier to share experiences with them**
- **you need their support to help you ‘feel like you’.**

You may find it helpful to use the next page to write down some of the things you might want to say. If you need different headings, you could create your own version. You can then use it as a guide. You can even show this to a close friend, teacher or counsellor if you feel too emotional to say the words out loud.



## Someone close to me is living with motor neurone disease (MND)

This disease can affect how a person walks, talks, moves, eats, drinks and breathes. It can be different for each individual.

**The person with MND is my: (for example, mum, dad, grandma, grandpa...)**

**At the moment, MND has affected them in the following ways:**

**For me, this means:**

- I help out more at home
- I don't have as much time to spend with friends
- I sometimes feel emotional, quite quickly
- I sometimes need extra time for school homework
- I may need to respond to a call from home when out or at school
- There are changes at home, including equipment to help

**If you're reading this, you can help me by:**

# 5 What will happen in the future?



## How can I collect and keep good memories?

Collecting memories is something many of us do, to help us remember family and friends, happy times or special occasions.

When you know that someone's life may be shorter than expected, collecting memories can feel even more important.

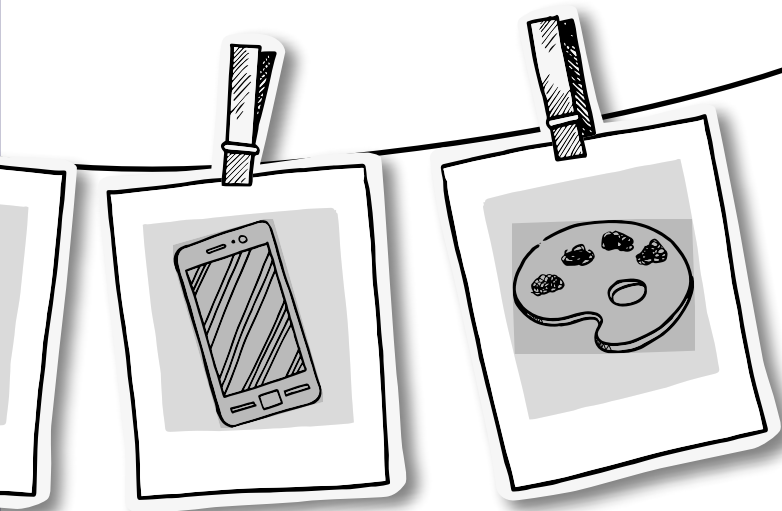
There are lots of ways to do this, such as:

- **keeping a diary or journal**
- **using old and new photos to fill a special album**
- **making a memory book, to include photos, notes, tickets from events and so on**
- **creating a memory box or memory jar, to fill with special objects (you don't need to buy an expensive container - it can be a simple shoe box that you can decorate)**
- **using a smart phone, tablet or digital camera to record sound or video clips, if this feels right for you and the person with MND**
- **seeking out online memory websites, which allow you to post information, photos and tributes - these can be private and confidential (you don't have to make them public if you don't want to).**

It's important, of course, to think about how the person with MND feels when collecting memories. They might find certain things very emotional, so try to talk through what you'd like to do first. This way you can find out how and when they might like to get involved.

Whichever way you collect and keep your memories, you can revisit them whenever you like. It can be helpful if you take time together to look at things that are important to you and the person with MND. For example, if you both look through old photos, you can ask questions about the time or event. This may make the photo more meaningful in the years ahead.

We provide memory boxes for young children and young people at the MND Association. These include activities to help you keep mementos. If you would like to know more, contact: [cyp@mndassociation.org](mailto:cyp@mndassociation.org)



“

*My dad used to go into the hospice every week. He did lots of paintings and they helped him paint even when his arms got really weak. I still have one of his pictures in my bedroom. I like looking at it before I go to sleep.”*



“

***I only have one video clip where he was mucking about trying to see how a web cam worked. He's just joking, but this clip is so important to me now. I think it would be great to have more of this.***”

### **Audio and video memories**

Some online memory and tribute websites also allow video clips and offer suggestions about how to collect memories.

Technology has made it easier to capture sound and video recordings, for example, using smart phones or computer tablets. Try to make sure the person with MND is happy for this to happen, but it can be a good way of remembering a special time.

The person with MND may start having problems with their speech, which can get worse. This may make it more difficult for them to communicate on a sound or video recording.

“***His speech went so quickly, a video would have included him slurring and I don't want to hear him like that again. It might take me back to a sad place. I guess if he'd been able to do a video before all the changes, that would have been lovely...or family videos from before the illness.***”

If you would like to video the person before they find it difficult to use their voice, you don't need to wait for a big occasion. Ask if it's okay to record while you sit and chat. They may even wish to record a special message for you. You may find these clips comforting in the future.

As you get older, you may wish you knew certain things about the person with MND. You might want to draw up a list of questions to ask them, such as:

- **What is your favourite film, book or music?**
- **Do you have a favourite saying?**
- **What's your best story from when you were at school?**
- **What would you say to me if I got married?**
- **What's your best advice about finding work?**

Think about things you might want to know. You could ask funny questions as well as serious ones. You could even video this, like a short interview. Memory and tribute websites suggest questions to ask. An example of this type of website is [www.recordmenow.org](http://www.recordmenow.org)

See **Where else can I get help?** in **Section 6: Who can help?** for contact details.



If it feels uncomfortable to ask questions yourself, write them down so the person can write or record answers in return.

If you do collect memories, it can be nice to include family and friends. They may wish to add a message, picture or object of their own that means a lot. You may wish to share these with the person who has MND, if they wish to see them.

**“ I have a memory box and shelves in my bedroom with photographs and keepsakes. It's important to keep things. ”**

If the person with MND has experienced changes to the way they think or behave, collecting memories may be a little more difficult to manage. You may wish to collect photos from before they were diagnosed and remember them in this way.

You may even find it comforting to wear something that reminds you of the person with MND, especially on special occasions, like birthdays. You may even have something they gave you, which can become important.

**“ I have my necklace. It was the last gift dad gave to me and I never take it off...I have added two extra disks to the chain, one was a gift from my mum and one from my brother. I like to carry my family around with me wherever I go. ”**

## What happens when someone dies?

As there is no cure for MND, the person won't get better. The disease can progress in different ways and at different speeds, and this uncertainty can be hard to deal with. You may worry about how things will happen in the future.

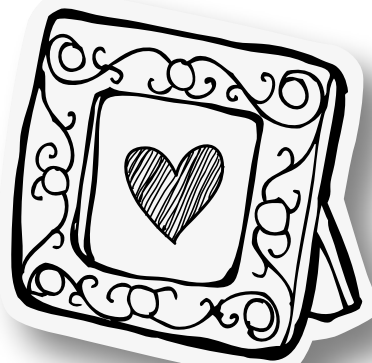
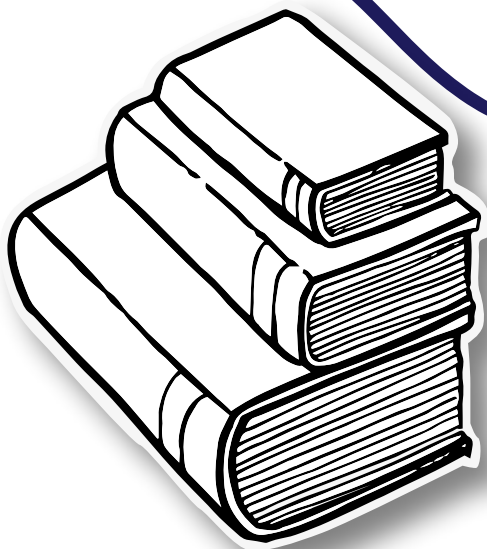
The person will find it more and more difficult to do things for themselves and you may find it upsetting to see them struggle with things they used to be able to do.

**“ My mum was bright, strong and funny. Watching her get worse was heartbreaking. ”**

As someone becomes weaker with MND, they may decide to spend time in a hospice or a hospital where they can get expert medical care. Doctors and nurses will do all they can to make the person as comfortable as possible.

Sadly, people do die from MND and you may worry about how this will happen. For most people, it's a peaceful process. The person falls into a deep sleep and their breathing slows down, until it gradually stops. Doctors can prescribe medicines so the person is not anxious or in distress when this happens.

**“ I had read that people choke to death and all these awful things. It wasn't anything like that. Mum fell into a sleep. I sat with her and her breathing became slower, with fewer breaths. Then she was gone. ”**



When someone dies, it can make you feel very sad. At first, you may spend a lot of time crying and find it overwhelming. This is part of the grieving process and is very normal.

It is also natural to feel a sense of relief when the person dies. You may be relieved because:

- **the event you feared is over**
- **the person you loved does not have to cope with MND anymore**
- **daily life will no longer be shaped by the challenges of MND.**

You shouldn't feel guilty for these thoughts.

**“When Gramps died a bit of me was relieved. Partly because I knew that he was at peace, but partly because I thought things would get back to normal.”**

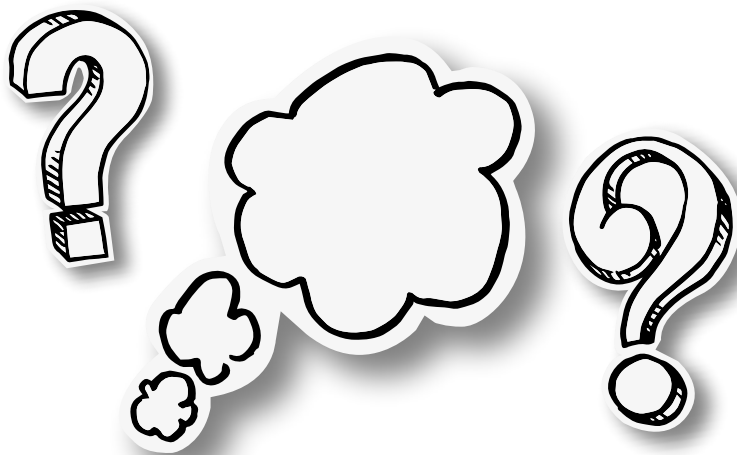
People react in different ways when someone dies. Some people find it difficult to show their emotions and 'bottle things up'. There is no right or wrong way, but it can be helpful to talk about how you feel with someone you trust.

There are many organisations that can give you support when someone dies. Some are listed at the end of Section 6 in this guide. You might want to talk to your friends about how you're feeling, or to a member of your family.

You may find it difficult to talk about the person who has died at first, but as time passes this usually becomes easier.

Eventually you will be able to think about the person who has died without getting too upset. You will be able to remember happier times as well as the sad.

**“Remembering the good times makes me feel more happy.”**



## Do I go to the funeral?

You may be able to choose whether or not to attend the funeral, unless there are particular religious, cultural or other family reasons not to.

If you choose to go, it may help you begin to accept the finality of death. It can also be an opportunity to gather with family and friends to say goodbye to the person who has died.

However, if you think it will be overwhelming, you may decide not to attend the funeral. Do what feels right for you. You can find your own way to say goodbye. Everyone reacts and copes differently.

**“I had a meltdown and said I didn't want to go to the funeral anyway. My brother did the same the night before and said he wasn't going, but we both did. It was the thought of it that was so difficult.”**

There are lots of ways to get involved in the funeral arrangements, whether you attend or not.

For example, you could:

- **write something for someone to read aloud during the service**
- **pull together a collection of photographs to display**
- **choose a music track to play**
- **ask for a memento, photo or drawing to be placed in the coffin.**

**“I made a card and letter to go in her coffin. I'm glad I did it and happy because I feel like it will always be with her.”**

You might want to talk about your feelings with your friends, family or someone you trust.

See **Who can help?** in **Section 6.**

### **What happens after the funeral?**

You may find things get very quiet after the funeral. There may have been lots of professionals coming to visit the house when the person with MND needed support, but that all stops. You may have seen lots of relatives and family friends both before and at the funeral. Once this is over, you are unlikely to have as many visitors.

**“ Mum had to pick up the pieces after the funeral. Not many stuck around after that. People seemed to disappear as if all our problems must be over now, but they don't just go away. ”**

You may also find people don't know how to talk about the person who died. They may worry about upsetting you and conversations may feel uncomfortable for a while. This will get easier in time as everyone adjusts.

**“ I used to end up apologising to people - and still do now - when I had to explain dad had died. They'd get so upset when I told them. I'd find myself saying 'I'm really sorry', which is daft! ”**

When someone close to you dies, your own life has changed. You may feel different to before and your emotions will probably come in stages. For example, you may go through a time when you feel angry. This is very common and a natural way to feel.

**“ Mum once said to me 'You're not the only one to have lost your dad!' Selfishly I replied, 'Well you haven't lost your dad, so yes I am.' Now I'm older I know how awful it must have been for her to lose her husband and have to deal with everything, including me. But I couldn't relate to anyone else's feelings at the time. ”**

“

**You see it through new eyes as you change and realise the loss in different ways. It's hard, but through all of this, you cannot let it stop you making your own choices and getting on with life. ”**

You are likely to reach a point where you can accept what has happened. You may still have times when you feel very sad, but it becomes easier to cope with the sadness.

Grief allows the mind and body to adjust to losing someone. How this happens for you may be very different to someone else, but there is no right or wrong way.

**“ Dad is wherever I want him to be... He's all around me...I know he's not here, but I have so much love for him and I'm half him, so I bring his energy with me all the time. ”**

If you need further support, contact our MND Connect helpline, which includes a Young Connect service. The team can provide information, direct you to services or simply listen:

Telephone: **0808 802 6262**

Email: **youngconnect@mndassociation.org**

Or contact our email for children and young people's services: **cyp@mndassociation.org**

# 6 Who can help?



Lots of different health and social care professionals get involved when someone is diagnosed with MND. You may meet them if you go with the person to an appointment. Professionals sometimes make home visits, too.

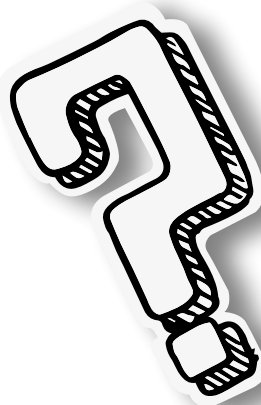
The following information looks at:

- **who can help the person with MND**
- **where the person with MND can get help**
- **who can help you as a young person.**

The table on the next page explains who is likely to provide care or treatment for the person with MND. These professionals often provide help to carers, young carers and families as part of their support.

The disease affects everyone differently, which

means the person you know may only see some of these people.



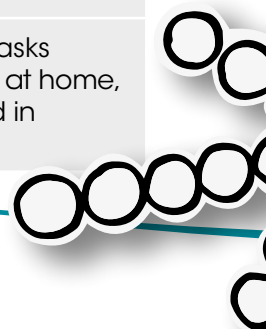
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*There were lots of nurses and professionals coming into the house. This was nice in a way, as there were other people around and chatting. 99*



## Who can help the person with MND?

Who gets involved?	What do they do?
Neurologist	A doctor who works with the brain, spinal cord, nerves and muscles. They are experts on conditions such as MND.
Consultant	As well as a neurologist, someone with MND may see other doctors or consultants. For example, they may see a respiratory consultant about breathing support.
Multidisciplinary team	A team made up of different types of professionals, who work in a co-ordinated way to help someone. With the consent of the person who is ill, they share information about the case and sometimes hold appointments in small groups to work together.
MND co-ordinator	The main contact at MND care centres or networks (and sometimes available in other neurological teams). The co-ordinator acts as a link between services and professionals to help the person with MND get treatment and care.
Community or district nurse	A nurse who works closely with the GP and often makes home visits as the disease progresses. They can help with checking and treating symptoms, prevention of pressure sores and arranging some items of home nursing equipment.
Speech and language therapist (SLT)	A therapist who helps with speech and communication problems, or difficulties with eating and swallowing. They can assess someone, provide therapy, and advise about communication aids.
Dietitian	An expert on food and drink, who can help someone with MND maintain a healthy weight and advise on how to eat and drink as safely as possible. If needed, they can also explain how to take in food and fluids in other ways, such as tube feeding. A dietitian often works closely with speech and language therapists.  See the heading <b>Can the person still eat and drink</b> in <b>Section 3: What is living with MND like?</b>
Occupational therapist (OT)	A therapist who helps someone remain as independent as possible if they have disabilities. They can advise on equipment, changes to the home or finding different ways to do things. They may be able to supply some equipment free of charge.
Physiotherapist	A therapist who can advise about suitable exercise and show carers how to provide support with this, if needed. Exercise cannot reverse damage from MND, but can strengthen muscles not yet affected and help joints to move more easily. This can reduce stiffness and pain.
Respiratory team	A team who are experts in breathing. They can assess the person with MND and offer guidance, therapy and treatment. This may include the possibility of ventilation (breathing support from a machine).
Care worker	A professional carer who can help the person with MND with daily tasks such as getting up, washed and dressed. They can help the person at home, at certain times of the day or night. Care workers are also employed in residential and nursing homes.



Palliative care team	A team that works to improve life for people with life-shortening conditions. They provide a wide range of support, including symptom control and guidance on emotional and practical needs.
Pharmacist	A professional who provides medication as prescribed by a doctor. They can also advise on the best type of medication to use, such as liquid medication for ease of swallowing.
Complementary therapist	A therapist who can provide support such as massage, acupuncture or reflexology. A wide range of complementary therapies exist. Complementary therapies do not provide a cure for MND, but they can ease symptoms for some people and help them relax. These therapies do not replace conventional medicine, but work alongside it.
Wheelchair services	These professionals assess the type of wheelchair needed and help arrange for one to be provided.
Social worker or care manager	A social worker or care manager usually helps with needs assessments for people with MND and carer's assessments for carers, including young carers. These assessments provide information and can lead to care services being arranged. They can also provide personal support and guidance.
Benefits adviser	An adviser who helps with queries and claims for financial support and benefits. The MND Association has a Benefits Advice Service, see: <a href="http://www.mndassociation.org/benefits-advice">www.mndassociation.org/benefits-advice</a>
MND Association regional staff	Professionals who work for the MND Association. They can offer guidance. Many have expert knowledge about MND and work closely with local service providers to ensure care and support is available at the right time.
MND Association visitor (AV)	<p>Our volunteers, who provide information and support for people living with MND, their carers, family and close friends. Where an AV is available, they can help by phone, email or home visit.</p> <p>If an AV is not available, our helpline, MND Connect, includes a Young Connect service. The team can provide information or simply listen:</p> <p>Telephone: <b>0808 802 6262</b>  Email: <a href="mailto:youngconnect@mndassociation.org">youngconnect@mndassociation.org</a></p> <p>See also later heading <a href="#">How can the MND Association help me?</a></p>

## Where is this help provided?

People with MND can be supported in various ways, including:

- **by appointment, to discuss problems or get assessed, which may happen at home, or at a clinic, hospital or hospice**
- **with treatment or therapy, where there is no need to stay overnight**
- **with treatment or therapy where they stay overnight or for a short time**
- **with care at home from care workers or nursing staff**
- **with care in a nursing home, hospital or hospice.**

The table below describes the different locations where someone may receive care or support. Not everyone will need help from all these places, but some people with MND need different types of help as the disease progresses.

## Where can the person with MND get help?

### What is provided?

As the need for care support increases, extra help may be necessary. Care workers can help with personal care and housework. Nursing staff can help with medical care if necessary.

The person with MND will see lots of professionals, but their GP is an ongoing contact. The GP surgery can help keep track of medical records, process repeat prescriptions, add the person to care registers and help with referrals to specialists.

The MND Association helps to fund MND care centres and networks across England, Wales and Northern Ireland. These are dedicated MND clinics where people come together to improve the standard of care for people living with MND. They also give guidance to carers and families.

Neurological services offer similar support to MND care centres and networks, including expert knowledge of MND and standards of care. The person with MND may attend a local neurological clinic if it's closer to home than the nearest care centre.

The person with MND may visit a hospital for a treatment, such as help with their breathing. They may also go into hospital if they need urgent medical care.

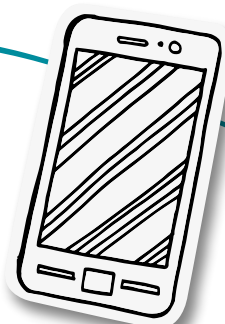
**Home**

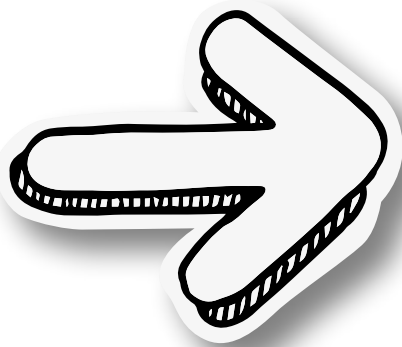
**GP surgery**

**MND care  
centre or  
network**

**Local neurological  
clinic or specialist  
MND service**

**Hospital**





*“Gramps and nana thought the hospice was great. Gramps used to go and they’d cut his hair and trim his moustache - it gave nana a break for the day.”*

#### What is provided?

Hospices offer a wide range of services, including counselling, practical advice, emotional support and sometimes even activities, such as art sessions, to help people relax. They can answer questions about future care and make sure people with MND are as comfortable as possible.

People often worry about going to a hospice because they think it’s just a place where people die, but the support on offer can help everyone involved have a better quality of life. Some people do choose to spend the last few days of their life in a hospice, because the staff can offer expert care.

Respite care can provide carers with a short break for a few hours, or a longer break for a week or two. This can be very helpful if a carer is getting tired or needs time to do something else. This type of care is not necessarily in a set ‘place’ as it can happen at home, in a day centre, hospital, hospice or nursing home.

Day centres are run by care staff and volunteers, often through a hospice or day therapy service. Activities and therapies may be on offer, along with the chance to share experiences with other people who have long-term illnesses or disabilities. Day centres also give carers a chance for a break or time to get other things done.

A residential care home where the person can be cared for day and night by trained professionals. This is sometimes necessary if their care becomes complicated and they need lots of medical support.

Our branches and groups offer opportunities across the UK to meet up with others living with or affected by MND, where experiences, tips, information and support can be shared.

**Hospice**

**Respite care**

**Day centre**

**Nursing home**

**MND  
Association  
branch or group**

The list below gives you suggestions of people who can help you. No matter what challenges you face or how you are feeling, the most important thing to remember is that support is available.

## Who can help me as a young person?

Person or group	What they do?
Lead teacher	These teachers are appointed by a school to lead in a particular aspect of school life. A lead teacher is usually the main contact for students who are young carers. Emotional support in schools is often called pastoral care.
School nurse	A school nurse can provide you with support and pastoral care, or refer you to other health and social care help if needed.
Education Welfare Officer (EWO)	An EWO identifies problems with school attendance, but also looks at possible solutions. They can help your family get benefits for school meals, transport or clothing. They also have knowledge of other local services and professionals.
Counsellor	<p>A trained professional who listens if you need to talk about your emotions and helps you find ways to manage your feelings.</p> <p>Children and young people affected by MND or Kennedy's disease can now access swift professional counselling through our collaboration at the MND Association with the children's charity, Barnardo's. This service can be accessed online or over the phone. To start the referral process, contact: <a href="mailto:cyp@mndassociation.org">cyp@mndassociation.org</a></p>
Social worker or care manager	A member of staff from adult social care services, who can provide support and guidance. They can also assess the support you may need, especially if you're a young carer, and help arrange appropriate services.
Children and Adolescent Mental Health Services (CAMHS)	If you need professional help to cope emotionally with daily life, you and your family may be referred to CAMHS by your GP. The CAMHS team can help where something traumatic has happened, such as a diagnosis of MND in the family. If there is a long waiting list or another service may suit your needs better, you may be referred to a different organisation.
Carer's centre	A local carer's centre can provide information about services for carers in your area, including young carers. Contact your local authority or in Northern Ireland, your local health and social care trust, to find your nearest centre.
Health and social care professionals	The health and social care professionals who support the person with MND can help you, too. When you meet them, don't be afraid to ask questions if something is worrying you.

“ I used to see Marilyn at the hospice. She'd listen to how I was feeling and I could tell her things 'cos I knew she wouldn't get upset or tell anyone else. ”





## What support can I get if I'm a student?

You may find school or college gives you time to just be you.

“**School allowed me to be normal and go in and be a nobody, which was brilliant. It was a safe haven for me.**”

However, there may be times when you fall behind with your studies or attendance. This could be due to what's happening at home or because you feel worried. You may even find yourself getting emotional at school or college, which can feel difficult to manage.

“**I didn't want to cause trouble, I just didn't know how to control all the emotions I was feeling.**”

You may want to keep your home life private, but it can help to let your school or college know why you are finding things difficult. If you keep everything inside, people around you may not understand or even realise anything is wrong.

If you are unsure how to get help, ask someone you trust for advice. This could be your mum or dad, guardian, a teacher, or another adult you find easy to talk to.

### What services do schools offer?

As well as educating, schools also support a range of practical, emotional and behavioural needs. Known as 'pastoral services', this support is provided by teachers and school nurses, or even other pupils as mentors.

“**You are supposed to tell your form teacher stuff, but I don't like him, so I talk to the science teacher instead and she's really understanding.**”

Ask your school how they can help. They may provide a pastoral care plan after talking through your needs with yourself, and your parents or guardian. This will explain:

- **how they can support you in a way that feels right for you**
- **who to contact if you feel worried or upset about anything while at school**
- **ways to help you feel more secure at school.**

The school nurse is a useful contact, who can:

- **support you**
- **speak on your behalf if you need them to do this**
- **look at how support can be given if there is an emergency at home**
- **refer you to wider support services if needed.**

It can be really helpful if your parents or guardian discuss what is happening at home with your preferred contact at school. If possible, this should happen at the beginning of each academic year, or when you move to a new school. This helps make your needs known, even if you have different teachers.

“My younger brother struggles in his new school because they’re not really aware of him losing his dad. It was some time ago, so even if they do know, it’s like it’s all over. But it stays with you and his teachers could be more supportive. I wish certain things could be put in place to help him when he feels bad.”

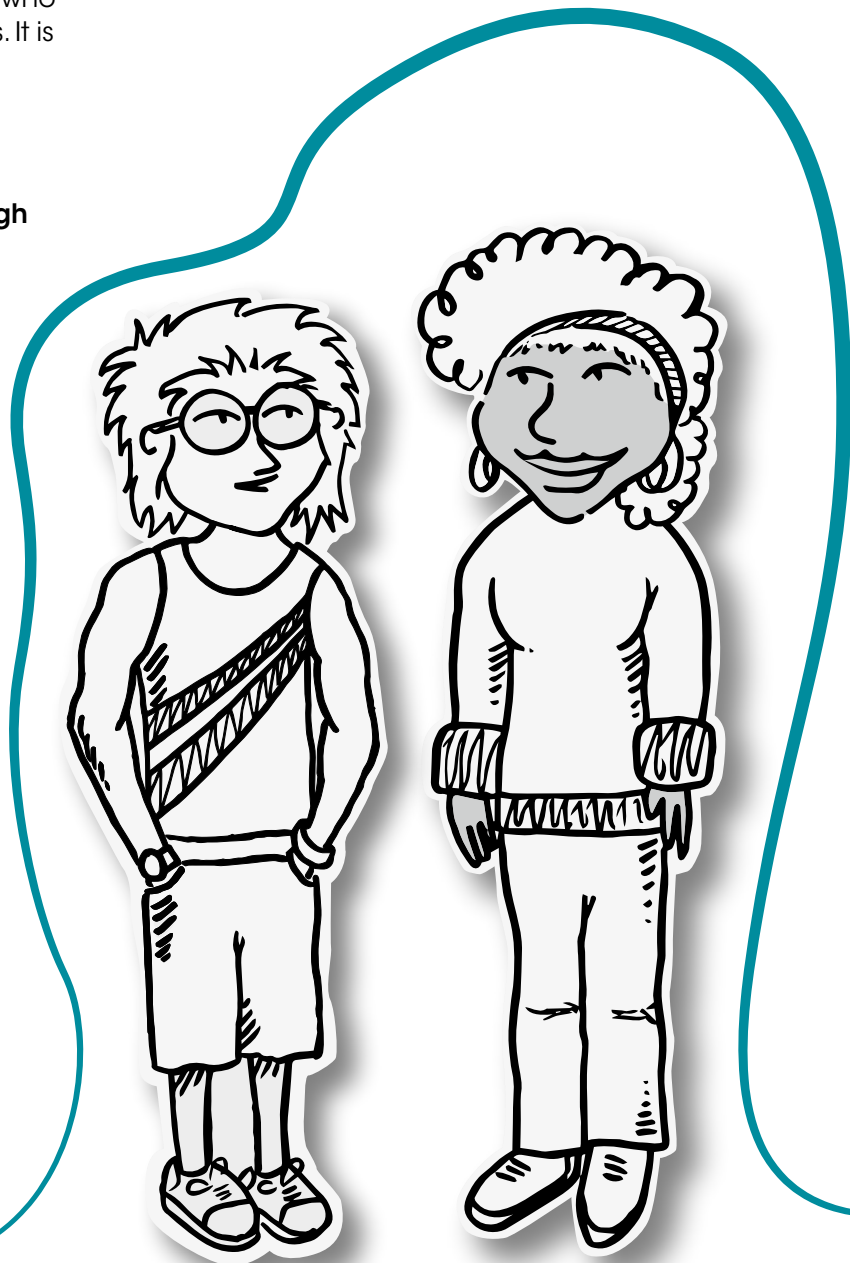
A training programme to help school nurses become Young Carer Champions has been set up. This is supported by the Department of Health, Carers Trust and others, to help young carers and their families find the services they may need. You can see more by searching for *school nurses* at: [professionals.carers.org](http://professionals.carers.org)

There is usually a lead teacher at each school who is nominated as main contact for young carers. It is worth finding out who this is.

Teachers can help by:

- allowing extra time for homework
- arranging possible support services through the school, such as counselling sessions
- providing information about external support services in the local area
- introducing a young carer to other young carers in the school for peer support
- advising about school commitments and homework, especially if an emergency happens at home.

“At school you hope no-one even mentions MND, but at times you also want teachers to be aware and give you a bit of leeway. Like not having a go if you haven’t got your homework done on time. It’s difficult for them though. They’re supposed to treat you the same and keep things as normal as possible. It’s a bit of a balancing act I guess, but there are times you need help.”



## Young Carers in Schools programme

This is an initiative across England to make it easier for schools to support young carers. Run jointly by Carers Trust and The Children's Society, as 'Young Carers in Focus' partners, it provides:

- **guidance for school staff and teachers to help them identify and support young carers**
- **opportunities for teachers, young carer services and health and social care professionals to network and share knowledge**
- **the Young Carers in Schools Award, enabling schools to gain recognition for good practice.**

Ask if your school is involved or search for *young carers in schools* at: [www.carers.org](http://www.carers.org)

## What services do colleges offer?

If you attend a college or university there is usually a mental health adviser or counselling service available.

You may also be entitled to 'reasonable adjustments,' such as extra time in exams and extensions on coursework.

Ask your tutor or college administrator to see what can be offered in terms of support. If there is a students' union, they may also be able to help with information and guidance about local support services.

“

***My eldest brother dropped out of university after dad died and just couldn't cope at the time.*** ”

## What support can I get if I work?

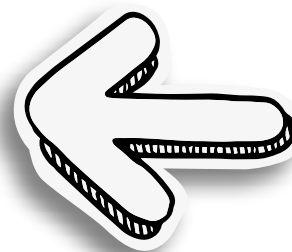
If you are employed part-time or full-time, you may worry about your job being affected by the demands of caring. In most cases, employers are willing and able to help. They may be able to:

- **adjust working hours around the caring role**
- **allow flexible working, so your hours can change when appropriate**
- **provide some form of carer's leave (this may be unpaid, but could be useful in urgent situations).**

Ask the person who manages you or your human resources department for advice.

## What are my rights?

As a young person, you have rights. This means you are legally entitled to help in particular situations.



The United Nations Convention on the Rights of the Child (UNCRC) is an international human rights treaty that grants all children and young people (aged 17 and under) a set of rights. All UK government policies and practices must follow these rights.

Some of the rights included in the UNCRC are important to UK laws that support young carers. For example, children have the right to:

- **a childhood**
- **an education**
- **health and health services**
- **be heard, listened to and believed**
- **be protected from physical and psychological harm**
- **privacy and respect**
- **have their views taken into account when decisions are made that affect their lives.**

Further detail can be found at: [www.unicef.org.uk/what-we-do/un-convention-child-rights/](http://www.unicef.org.uk/what-we-do/un-convention-child-rights/)

This means that, as a young carer, you have the right to information, choice and wellbeing. As part of this, you can have your needs assessed. This leads to a care and support plan, which may include:

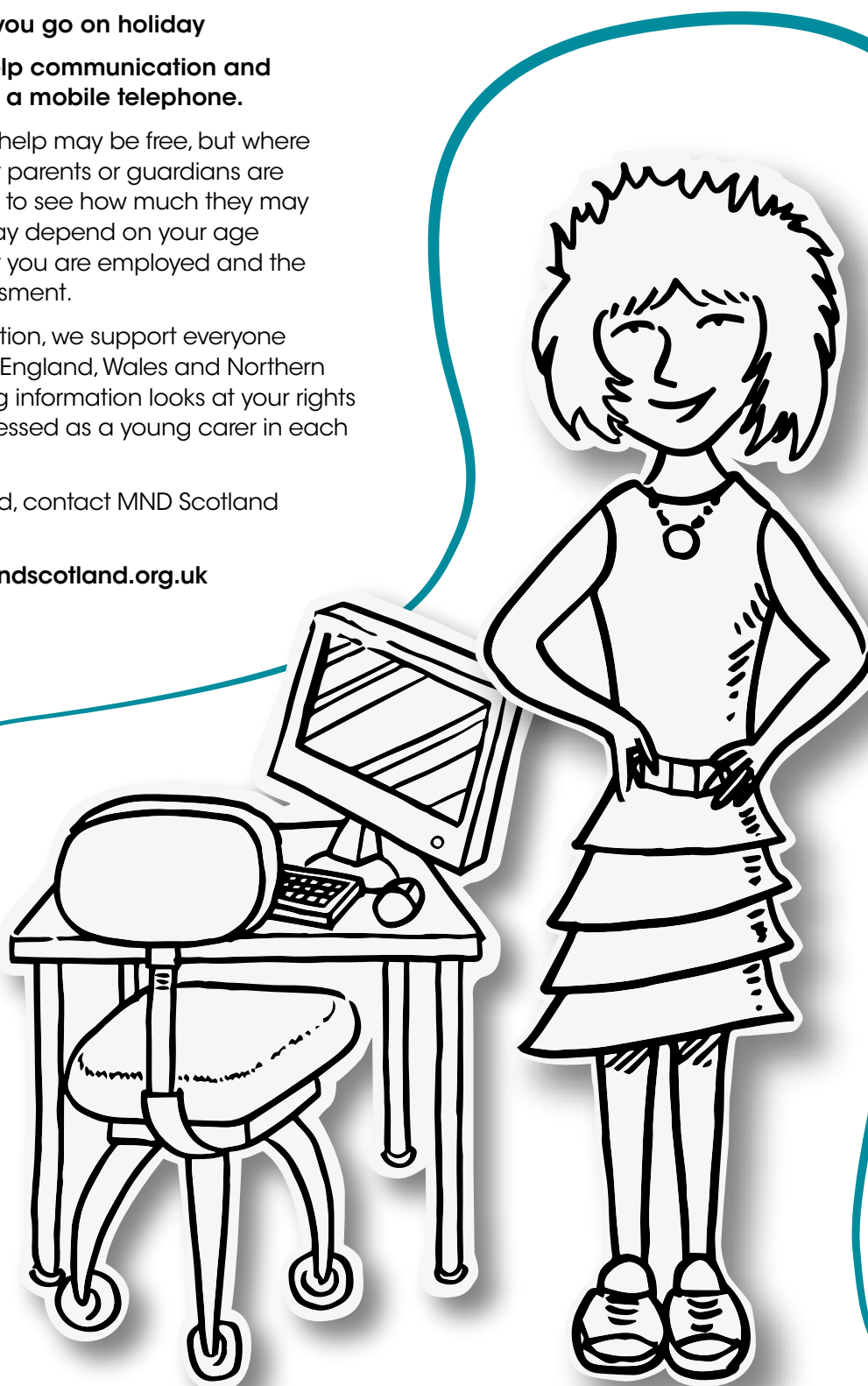
- **practical help in the home**
- **support for recreational activities**
- **support to help you go on holiday**
- **equipment to help communication and contact, such as a mobile telephone.**

Some services and help may be free, but where costs do apply, your parents or guardians are financially assessed to see how much they may need to pay. This may depend on your age (under 16), whether you are employed and the results of your assessment.

At the MND Association, we support everyone affected by MND in England, Wales and Northern Ireland. The following information looks at your rights and how to get assessed as a young carer in each of these regions.

If you live in Scotland, contact MND Scotland for guidance:

Website: [www.mndscotland.org.uk](http://www.mndscotland.org.uk)





## How do I get my needs assessed?

The person with MND is likely to be assessed by adult social care services, to work out the support or services that may help them. When this happens, the assessor will realise that you, and possibly other children or young people, are involved. They should then consider an Early Help Assessment. This uses a 'whole family approach' to look at:

- **the help your family may need**
- **what may change in the future**
- **whether you need a young carer's needs assessment.**

### Young carers' rights in England

In England, all young carers under the age of 18 have a right to assessment regardless of who they care for, what type of care they provide or how often they provide it.

An assessment can be requested through your local authority, but should be offered if there is an 'appearance of need'. For example, you may be identified as a young carer when the person with MND has their needs assessed or an older relative has a carer's assessment.

The assessment looks at why you are involved in care tasks, what may need to change and ways to help your family avoid the need for you to take on too much responsibility.

### Young carers' rights in Wales

If you are a young carer under the age of 18 with significant caring responsibilities, you would be recognised as a child in need in Wales. As such, local authorities have a duty to assess you, to see how to support you and your family.

This would be done through a Children Act Assessment. If you are 16 or over, you can request a full carer's assessment if you wish.

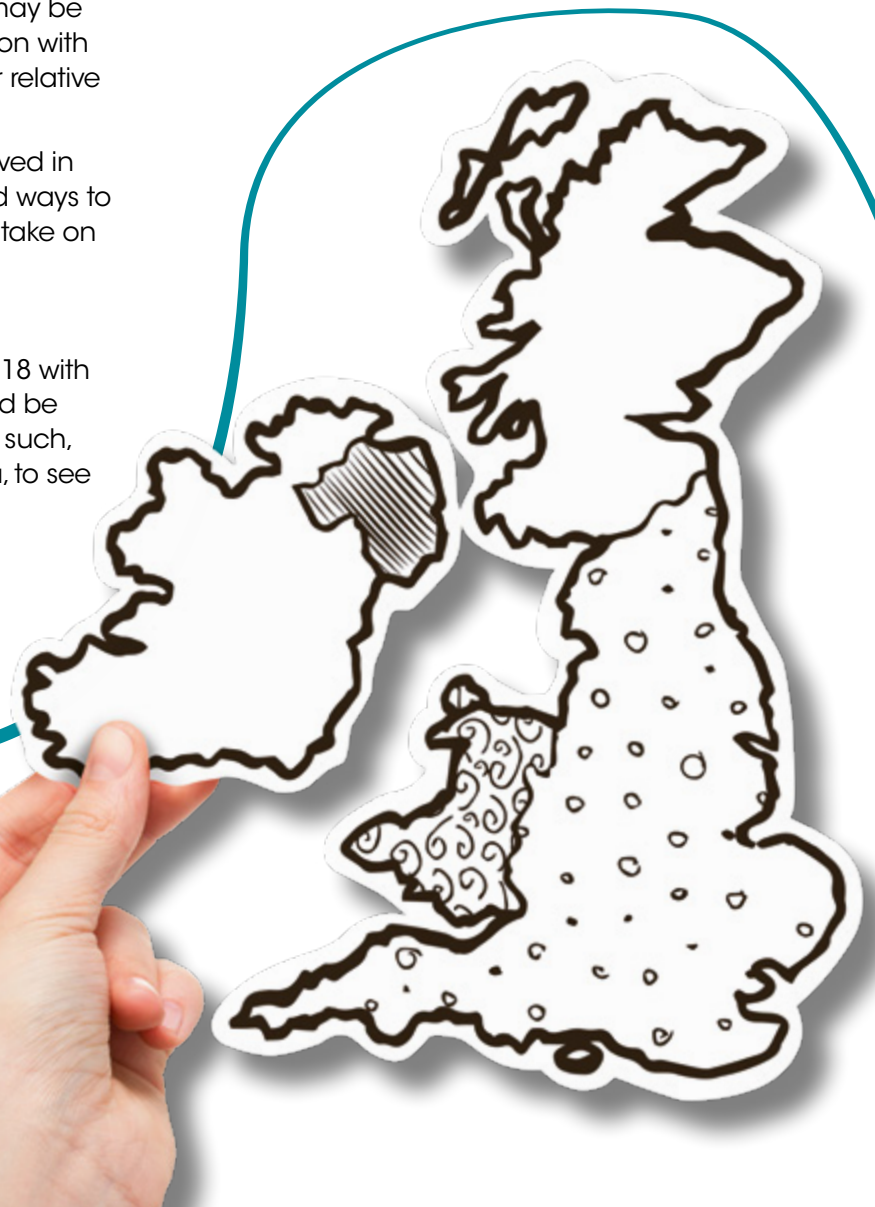
The aim of your assessment is to ensure you achieve or maintain a reasonable standard of health and development.

### Young carers' rights in Northern Ireland

In Northern Ireland, young carers up to the age of 18 are assessed using a process called *Understanding the Needs of Children in NI* (sometimes known as UNOCINI). You can request an assessment through your local health and social care trust.

If you are a young carer aged between 16 and 18, you can ask for a full carer's assessment if you wish, but it may be in your best interests to use the process mentioned above.

When assessing your needs in Northern Ireland, the aim is to help you avoid levels of care responsibility that could impact on your health and wellbeing.



## How can the MND Association help me?

If you have any more questions or need support, contact our email for children and young people's services: [cyp@mndassociation.org](mailto:cyp@mndassociation.org) Or Young Connect, which is offered by our main MND Connect helpline. The team can provide information or simply listen:

Telephone: **0808 802 6262**

Email: [youngconnect@mndassociation.org](mailto:youngconnect@mndassociation.org)

The helpline team can also introduce you and your family to our services, as available in your area.

Our services include:

- our website at: [www.mndassociation.org](http://www.mndassociation.org) including pages for children, young people, parents and guardians at: [www.mndassociation.org/cyp](http://www.mndassociation.org/cyp)
- information about living with MND, which can be downloaded at: [www.mndassociation.org/publications](http://www.mndassociation.org/publications) or ordered in hard copy through the helpline
- **regional branches and groups, where you can meet other people affected by MND**
- **our volunteer Association visitors, who offer support and guidance by phone, email or home visit**
- **our regional staff, who can help with external services if things get complicated**
- **MND care centres and networks across the UK, which we help to fund**
- **equipment loan or MND Support Grants to help the person with MND where there is a delay or health and social services cannot supply**
- **direction to external services for specialist help, as appropriate.**

## MND Support Grants for young people

Our Support Services team offer grants to help young people affected by MND. Up to £250 can be awarded to a young person in any one year. The grant can be used to help your quality of life. For example, you could use it to help fund:

- **a laptop or smart phone**
- **a day out with your family to build a special memory**
- **decoration of your room to create a calm environment.**

Contact us for details. Or a member of your family or a health and social care professional can contact us for you:

Telephone: **0808 802 6262**

Email: [support.services@mndassociation.org](mailto:support.services@mndassociation.org)

## Where else can I get support?

You may need specialist support as a young person. The organisations and websites shown here provide help for your age group.

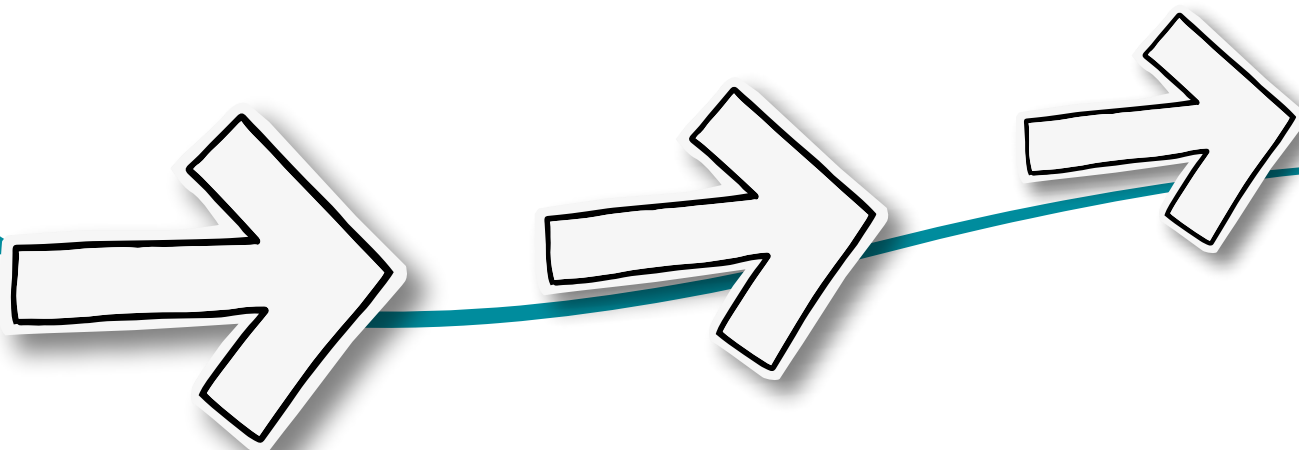
We cannot be held responsible for their web content or products, but they may help you start your search for further support.

There are many more organisations that can help, including services in your local area. If you and your family are in touch with one of our Association visitors, they may know what's available in your region. Your local authority, council or health and social care trust can also advise.

If the details shown here have changed, our Young Connect helpline can assist:

Telephone: **0808 802 6262**

Email: [youngconnect@mndassociation.org](mailto:youngconnect@mndassociation.org)



## Barnardo's

A charity supporting children, young people and young carers across the UK. Children and young people affected by MND or Kennedy's disease can now access swift professional counselling through a collaboration with us at the MND Association. This service can be accessed online or over the phone. To start the referral process, contact: [cyp@mndassociation.org](mailto:cyp@mndassociation.org)

Telephone: **0208 550 8822** (England)

**029 2057 7074** (Wales)

**028 9067 2366** (Northern Ireland)

Email: through the website contact page

Website: search for *young carers* at:  
[www.barnardos.org.uk](http://www.barnardos.org.uk)

## Bullying UK

Help on bullying issues, with advice for children and young people.

Telephone: **0808 800 2222** (confidential helpline)

Email: through the website contact page

Website: [www.bullying.co.uk/advice](http://www.bullying.co.uk/advice)

## Child and adolescent mental health services (CAMHS)

Specialist NHS children and young people's mental health services, offering assessment and treatment when children find it emotionally hard to cope with daily life. If family, friends or GPs are unable to provide the necessary support, CAMHS may be able to assist. As a child, you need to be referred by a professional – your GP or school can help with this. You can search online for *Child and adolescent mental health services* in your area or your local NHS trust website should have the details. If you live in Northern Ireland, you can ask your local health and social care trust for CAMHS details.

## Child Bereavement Charity

Support for families, children and young people during bereavement.

Telephone: **0800 0288840**

Email: [helpline@childbereavementuk.org](mailto:helpline@childbereavementuk.org)

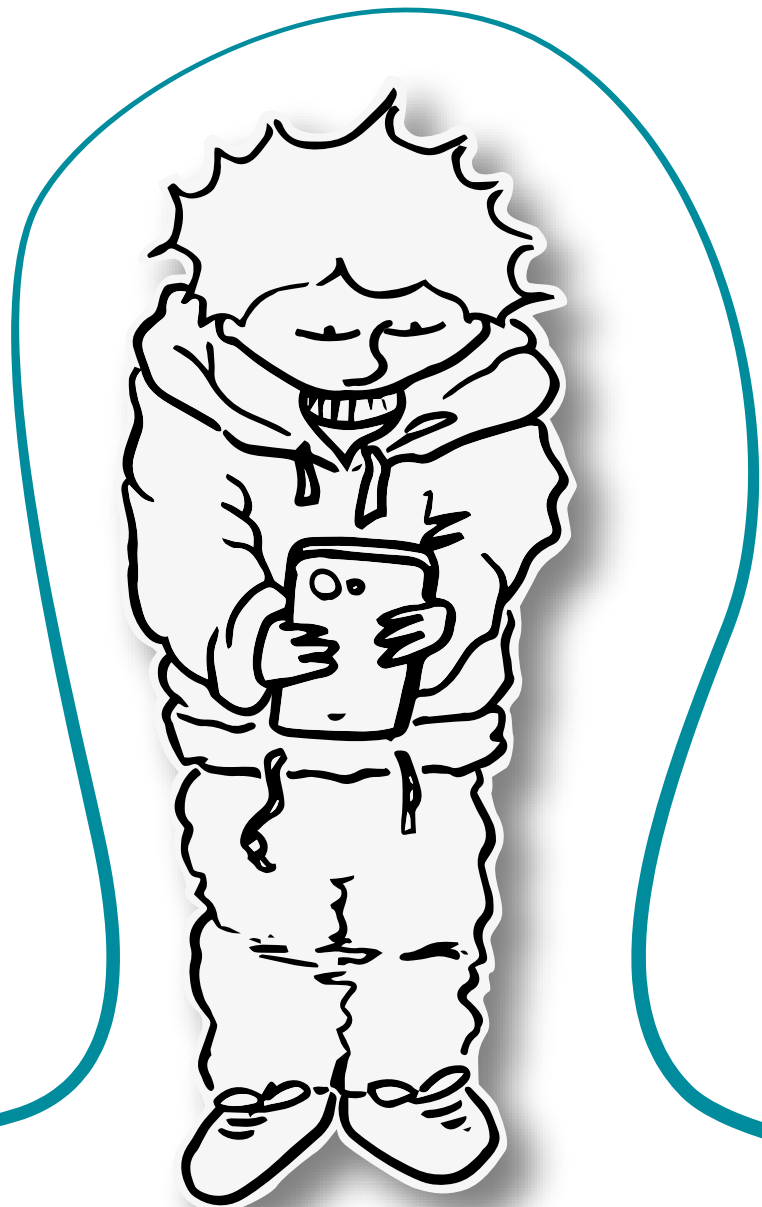
Website: [www.childbereavementuk.org](http://www.childbereavementuk.org)

## Childhood Bereavement Network

This organization can direct you to support for bereaved children, young people and families across the UK.

Email: [cbn@ncb.org.uk](mailto:cbn@ncb.org.uk)

Website: [www.childhoodbereavementnetwork.org.uk](http://www.childhoodbereavementnetwork.org.uk)



## Childline

Counselling and a free 24-hour helpline for children or young people in distress or danger.

Telephone: **0800 1111**

Email: through website confidential login (does not need your real name)

Website: **www.childline.org.uk**

## The Children's Society

Support and services for children and young carers, including guidance about the annual Young Carer Festival.

Telephone: **0300 303 7000**

Email: **supportercare@childrenssociety.org.uk**

Website: **www.childrenssociety.org.uk**

## Hope Support Services

A charity that helps young people when someone close is diagnosed with a life-shortening illness.

Telephone: **01989 566317**

Email: **help@hopesupport.org.uk**

Website: **www.hopesupport.org.uk**

## RecordMeNow

A free, downloadable app, for people to leave video messages after their death, for children and family members. The question-prompting, video-recording app can be used easily on a computer with webcam or downloaded as an app. It includes suggested questions to answer, which are based on research with bereaved young people.

Email: through the website contact page

Website: **www.recordmenow.org**

## Winston's Wish

Support for bereaved children, young people and their families.

Helpline: **08088 020 021**

Email: **ask@winstonswish.org**

Website: **www.winstonswish.org**

## Young Minds

An organisation providing guidance about the emotional wellbeing and mental health of children and young people. They do not operate a helpline for young people, but can advise parents and guardians.

Parent helpline: **0808 802 5544**

Textline for young people: Text YM to **85258**

Website: **www.youngminds.org.uk**

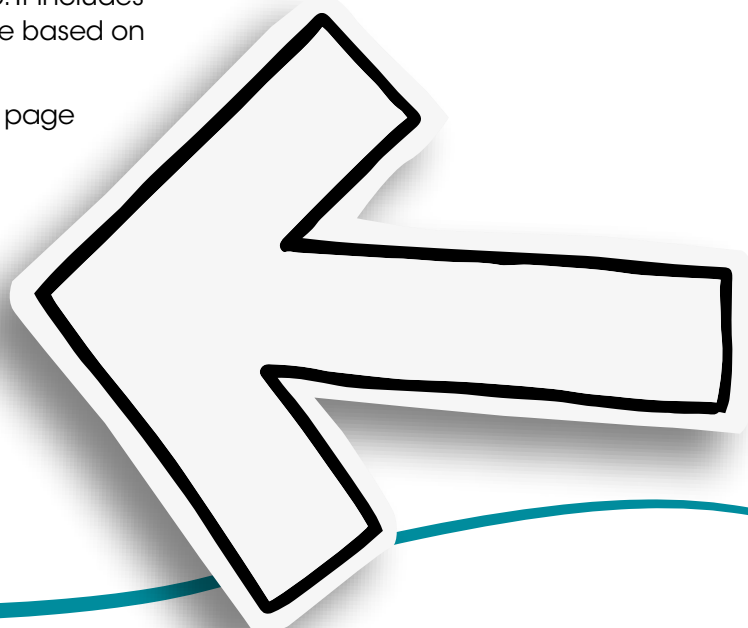
## Youth Access

A national membership organisation for young people's information, advice, counselling and support services.

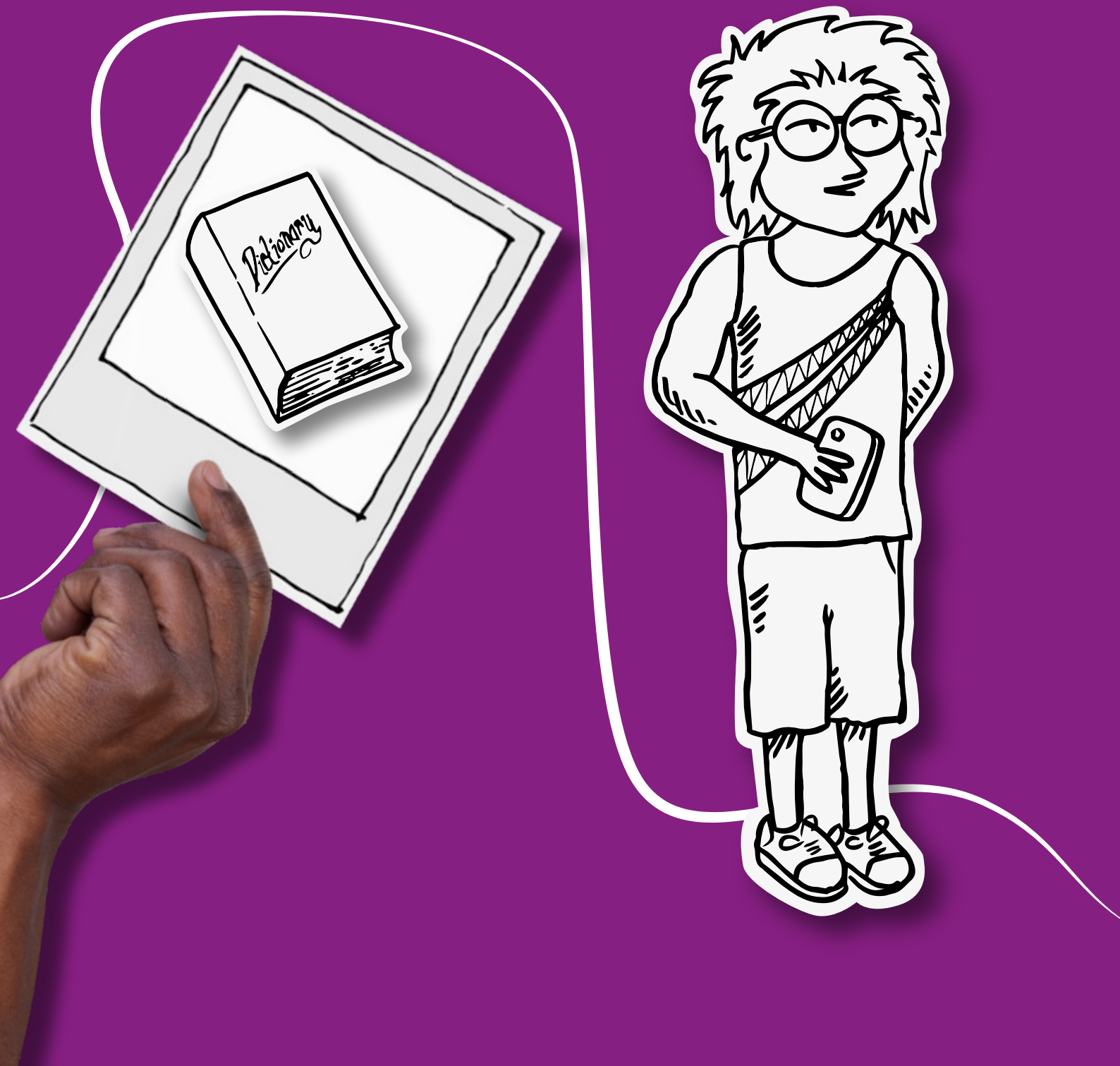
Telephone: **020 8772 9900**

Email: **admin@youthaccess.org.uk**

Website: **www.youthaccess.org.uk**



# 7 What do all the medical words mean?





## What do all the medical words mean?

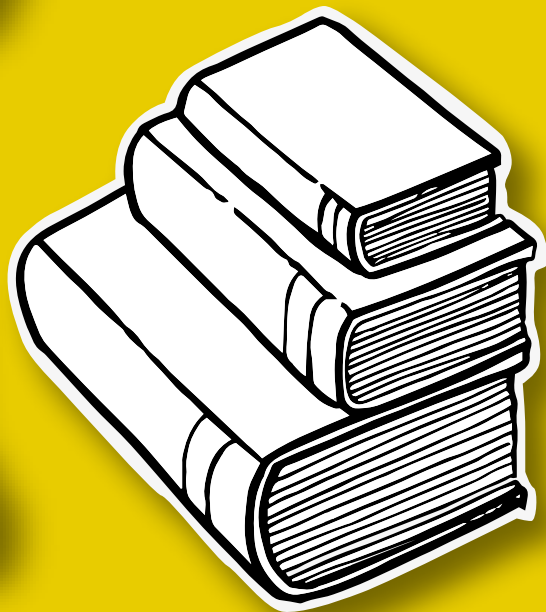
Here is a list of some of the words you might hear when people talk about MND, with an explanation of what they mean.



Medical words	What they mean?
Bulbar muscles	The muscles in the mouth and throat that help us to chew, swallow and speak.
Cognitive change	Changes to the way people think and behave.
Diagnosis	When a doctor says what is wrong with someone who is ill.
Emotional lability	A symptom of MND that causes people to laugh or cry for no reason.
Fatigue	Extreme tiredness.
Frontotemporal dementia (FTD)	A small number of people with MND may get a type of dementia, called frontotemporal dementia (FTD). This affects thinking, behaviour, use of language and the ability to take in new information.
Gastrostomy PEG/RIG/PIG	An operation to put a feeding tube into the stomach if someone has difficulty eating or drinking. PEG, RIG and PIG are short terms used to describe the different types of gastrostomy.
Hospice	A type of hospital for people who have a disease that cannot be cured.
Invasive ventilation (using a tracheostomy)	Breathing support from a machine. Using a tube inserted into the windpipe, through the neck, this type of ventilation 'breathes' for the person with a flow of natural air.
Motor neurone	A nerve that carries a message from the brain to tell a muscle what to do.
Non-invasive ventilation (NIV)	Breathing support from a machine. It helps increase the flow of natural air into the lungs through a mask over the nose, or nose and mouth.
Progressive illness or disease	An illness or disease that changes over a period of time. This usually means the symptoms will get worse.
Respiratory muscles	Muscles that help us breathe by expanding and relaxing our ribcage, allowing our lungs to fill and empty of air as needed.
Symptom	A feeling or physical change caused by an illness or disease.

# 8

# References & Acknowledgements

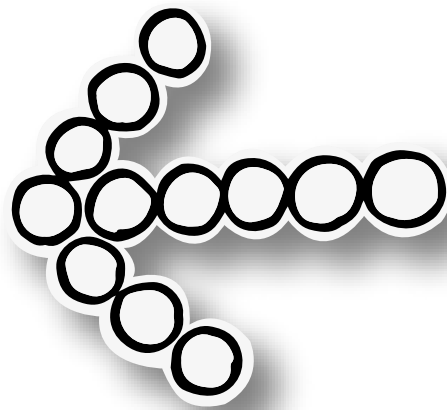


## References

A list of the evidence used to develop this guide is available on request. Please send your request by email to: [infofeedback@mndassociation.org](mailto:infofeedback@mndassociation.org)

Or write to us at:

Care information feedback, MND Association,  
6 Summerhouse Road, Moulton Park,  
Northampton, NN3 6BJ



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### For their expert guidance and review:

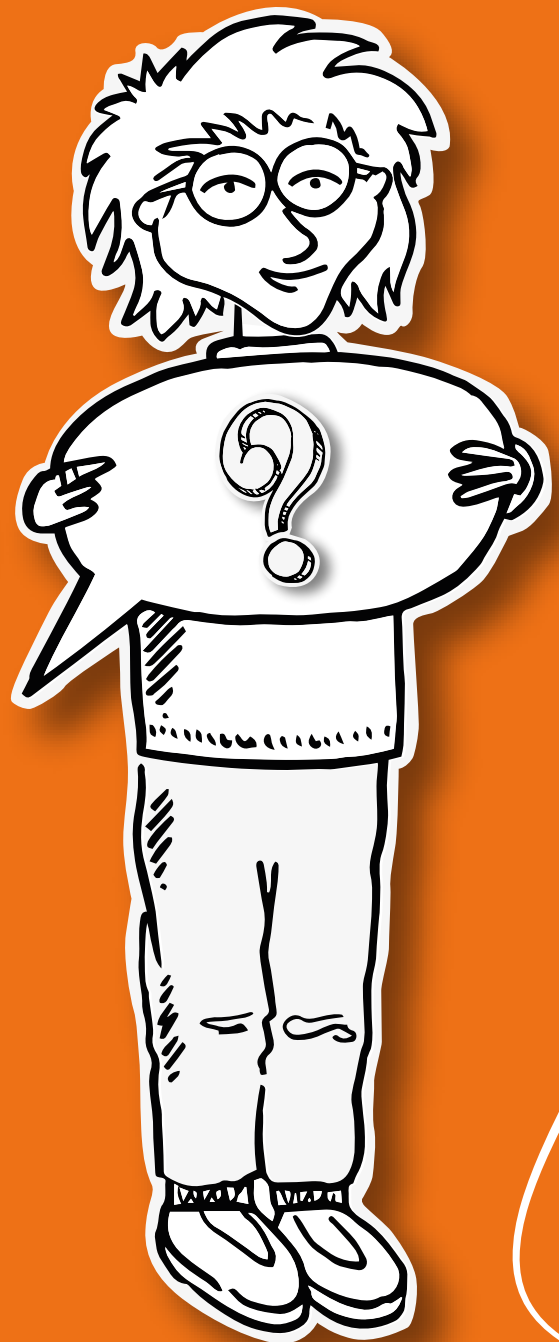
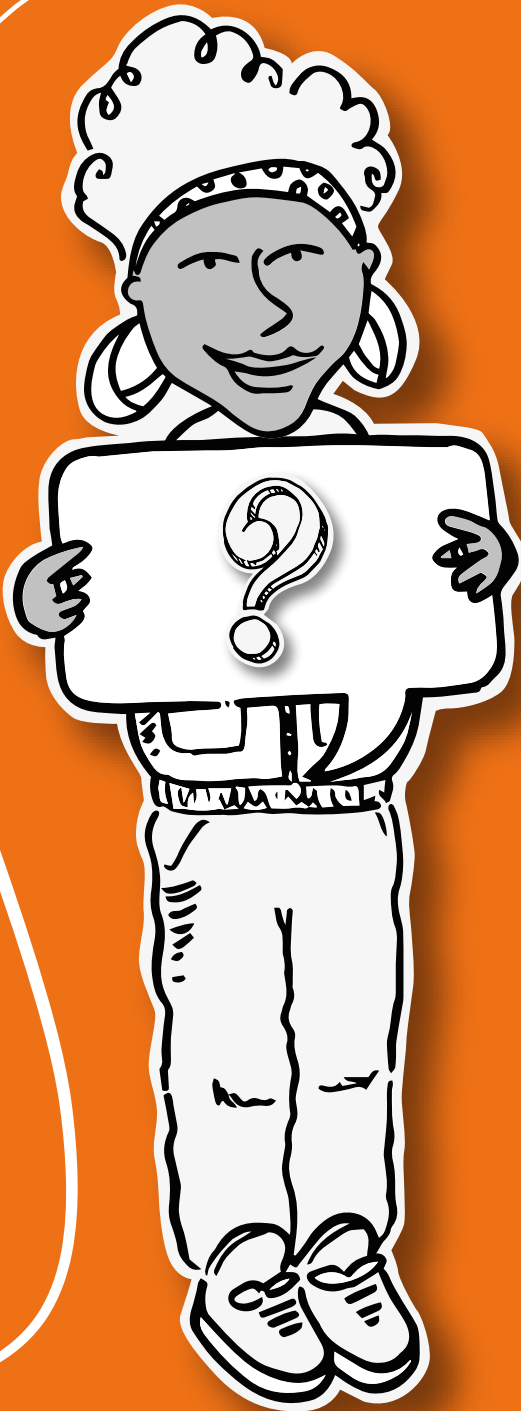
Teresa Badger, Teacher and Student Welfare Manager, The King's School, Wolverhampton

Penny from the Online team, Carers Trust, London  
Winston's Wish, the charity for bereaved children



9

What do you think?



Let us know what you think of *So what is MND anyway?* We'd love to hear what you think we did well and where we can improve the content for young people affected by MND. You can complete

this page and tear it out, to send to the address shown at the bottom of the form. Or you can fill in this form online at: [www.smartsurvey.co.uk/s/sowhatisMND](http://www.smartsurvey.co.uk/s/sowhatisMND)

**1. Which of the following best describes your interest in this information?**

- I'm living with MND
- I'm a young person or young carer
- I'm close to someone with MND
- I'm a carer for someone with MND
- I'm a health or social care professional

**2. Do you think the information is clear and at the right level for young people?**

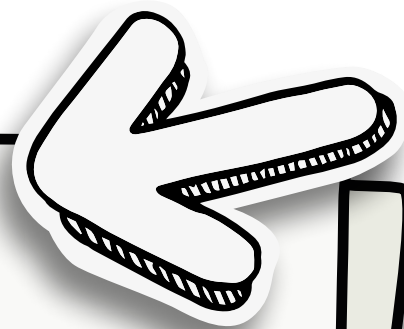
- Ideal    Okay    Quite difficult    Very difficult

**3. Is it easy to find the section you need?**

- Ideal    Okay    Quite difficult    Very difficult

**4. Did you find the information useful?**

- Very useful    Quite useful    Of no use



Continued...





**5. Do you feel this information will help young people affected by MND with any of the following?**

(tick all that apply)

- awareness that no-one is to blame for MND or its effects
- more awareness about what to expect as the disease progresses
- more ideas on how to help the person with MND
- ways to get support as a young person affected by MND
- awareness of how to collect good memories with the person who has MND

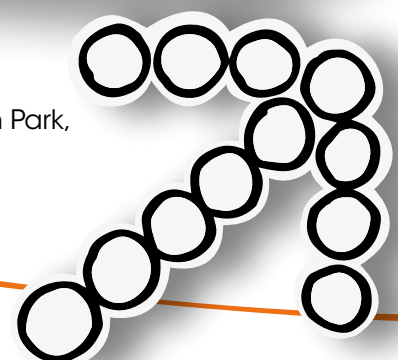
**6. Is there anything you would have liked to be covered in more detail?**

**7. Do you have any other comments or suggestions?**

(please print this page and continue on opposite page if needed)

**Thank you**

Please return your completed form to:  
Care information feedback, MND Association, 6 Summerhouse Road, Moulton Park,  
Northampton, NN3 6BJ



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Version: 1

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