

So, **What is MND** Anyway?

A guide for younger people



MND Scotland Factsheets

Copies of these factsheets can be downloaded from our website at
www.mndscotland.org.uk

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Services We Provide

Specialist Care and Equipment Loan



Our Care Team and Equipment Loan Services work to ensure people with MND receive the best available support at the right time. We have an MND Specialist Care Team who visit people affected by MND at home to provide information, assess their needs and pull in the right kind of help at the right time from other agencies. Primarily they liaise with health and social care professionals, including the person's GP, to help communicate client needs and offer specialist guidance for particular problems.

Our equipment loan and delivery service has over 300 specialist items to help people cope with a variety of challenges as their symptoms progress. The service is essential when delays occur in the provision of equipment by the NHS or local authority social work departments.



Information



Our information officer manages a collection of pamphlets, books, journals and DVDs about MND and related issues. These are available for anyone to borrow, particularly patients, their families and health and social care professionals. The information officer can also answer your queries by researching specialist sources.

Research Funding

MND Scotland provides funding for research. We are currently committed to a minimum investment of £600,000 over the next 5 years.



Education

We run Family Information Evenings across the country to help family and friends find out more about MND. We also organise in-service education days for allied health professionals and study days for professionals who aim to develop specialist knowledge of MND to provide the best possible care.

Counselling

We train and coordinate a special team of volunteer counsellors covering the whole of Scotland. The aim is to help people come to terms with the emotional stress and pressure of living with a terminal condition and its aftermath.



Welfare and Benefits

Our Welfare and Benefits officer is available to offer advice and information about a range of financial and practical entitlements to help and support you.

Small Grants

MND Scotland provides small grants of up to £600 per year to help defray exceptional costs that can come when living with MND. For further information on how to apply ask your MND Care Specialist about this scheme.



Other Services



We also offer other limited services, such as Befriending (Tayside and North Fife only) and some Complementary Therapies in areas where volunteers are available and willing to provide these services. To find out what is available in your area ask your MND Care Specialist or contact MND Scotland directly.

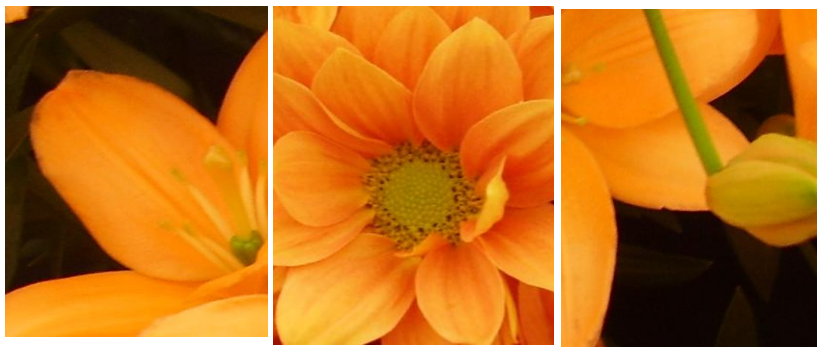
Introduction

This booklet tries to set out some facts about Motor Neurone Disease and to make them easily available to teenage readers. So if you have been given this booklet to read it may be a member of your family has been told they have Motor Neurone Disease (MND) and your parents want you to know what this means.

This booklet is intended to help you to understand things that might be concerning your parents and to give you the facts about motor neurone disease.

There are many different problems that motor neurone disease can cause. However, it is important to remember that not everyone is affected in the same way and that some people will never develop some of the problems mentioned here. Some people with MND never lose the use of their hands, others never lose the use of their voice and others remain able to walk. Just because something is mentioned here it doesn't mean it will definitely happen to the member of your family who is affected by MND.





So, What is MND

Anyway?

Motor Neurone Disease (MND) is an illness that usually affects people over the age of forty. In Scotland the average age of someone who develops MND is about sixty-five, but sometimes people under the age of forty can develop the illness too. MND is quite a rare disease and hardly ever happens to anyone under the age of twenty. It is also much less common than cancer or heart attacks.

When someone develops MND something goes wrong with the nerves that carry messages from the brain to the muscles. As MND develops fewer of these messages get through to the muscles causing their movements to become weaker and weaker until, eventually, some muscles seem to stop working.

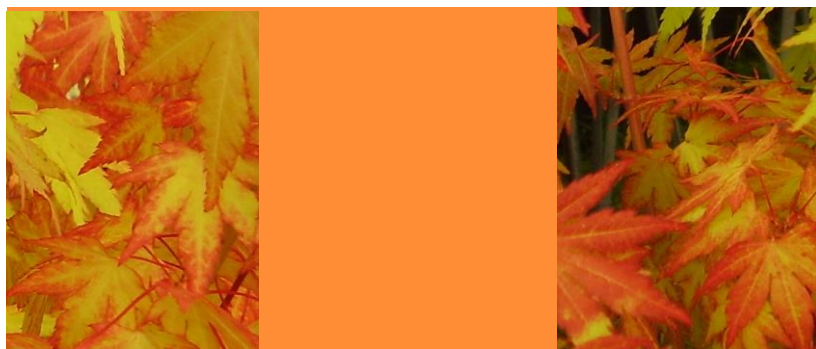
There are many possible reasons why someone could develop these symptoms and it can take a lot of time and detective work by doctors to decide what the real cause

of the problem is. Sometimes it can take a year or more of going backwards and forwards to hospital appointments before the doctors can decide that the cause is Motor Neurone Disease.

When we become ill there is often a period of time over which the illness develops, we don't go from being healthy one minute to being ill the next. There is a period of time while the illness is developing but we don't show any signs of it.

Usually someone who is developing MND notices that something isn't right with one or more of their muscles. Often this is because they now have trouble doing something that they could easily do before.

MND can start in any muscle in the body. There is no one fixed place where it always starts. For some people the first signs of MND could be in walking. For others it could be in swallowing; while others might have problems in lifting things. In theory any muscle could be the first one to tell someone they are developing a problem.



How do People Get MND?

For a very small number of people, about five in every hundred cases, MND runs in the family. These cases are known as “Familial MND.” When this happens MND is passed on by a faulty gene that can be inherited from a parent who carries the disease-causing gene.

When MND affects a family like this it is usually well known to the family. Since there is a fifty-fifty chance of inheriting the faulty gene from a parent who has it, on average half of their children will carry the faulty gene. If this gene has been in the family for generations there will already be a number of known MND cases in the family.

Several different genes are known to cause MND in different families. However, the families that have these known genes are only about half of all the families affected by familial MND. Unfortunately this means if someone is looking for a genetic test to see if they have the gene that affects their family there is quite a high chance that the family’s gene is not yet known.

In ninety-five out of every hundred cases, MND is an illness which is not known in their family. Their cases are described as sporadic cases since we do not know why they have developed the disease. Neither can we predict who the sporadic cases will be.



Inherited MND and sporadic MND are identical, so it is not possible to tell from symptoms alone whether the person inherited it or developed it sporadically. The only way to tell what kind of MND someone has is to look at their family history and to see whether other blood relatives have developed MND in the past. If there is no family history of MND the disease is unlikely to be inherited or passed on.

It is easier to find faulty genes among members of the same family than it is to find them in a random group of strangers. This is because members of the same family will have many genes that are the same.

When a disease like MND is passed on by a faulty gene then everyone with the disease will have one copy of that gene and a second copy of the healthy gene. Most of the family members, without the disease, should have two copies of the healthy gene. What the scientists looking for genes need to do is to screen the genes of those with the disease against those without the disease. They are looking for those genes where everyone with the disease

has a certain pair of genes that are different, while most of the others will have a matching pair for that gene..

New discoveries are helping us to understand more of what is going on in MND. When new genes are identified as being responsible for familial MND researchers often test tissue samples from previous patients who had sporadic MND to see if any of them have had changes to the same gene. In all cases they have found some sporadic patients with the same genetic mistakes.

As new genes involved in familial MND have become known the doctors have gone back to their records and made lists of the symptoms shown by people who had this faulty gene. This work is still in its early stages but already we are seeing that changes to one gene are linked with MND tending to start in the legs. Changes in another are linked with MND tending to start in the arms, while those to a third gene are associated with it tending to start in the neck or back.

It is hope that this kind of research will, in the future, allow doctors to test people who have MND and so have a better idea of how the disease will affect that person once they know which genes are involved in that person.



Why Do Muscles Show A Problem With Nerves?

Muscles only work when they receive messages from the motor neurones telling them what to do. To make any movement you need to decide what you're going to do. The messages then leave your brain and travel down your spine. From your spine the messages are passed on to the correct motor neurones that work the muscles you need to use to make that movement.

A movement rarely uses only one muscle; often there are several muscles involved. For example; to throw a ball can involve muscles in your back, your shoulder, your arm, your hand and your fingers. All of these muscles need to get slightly different messages at slightly different times for you to swing your arm and let the ball go at the correct time. If you decide to throw the ball fast and hard the movements are different from when you decide to throw the ball gently.

Although you're not aware of the exact messages you send through your motor neurones to your muscles, your brain sends slightly different messages depending on the decisions you make. If you decide to throw the ball gently to your left, you automatically make a different movement than if you want to throw it as hard as you can to the front.



When someone has MND some of these messages might not leave the brain. This is because the motor neurone responsible for carrying the message from the part of the brain that controls a certain muscle has been damaged. In other cases the damage can happen to the neurones that carry the messages from the spine into the muscle.

In the most common form of MND the person develops both of these kinds of problem. This form is called ALS, short for Amyotrophic Lateral Sclerosis.

You might hear the phrases “Upper motor neurone damage,” and “Lower motor neurone damage,” being used in relation to the person with MND. Lower motor neurones carry messages from the spine to the muscle. Upper motor neurones are the ones that are found in the brain.

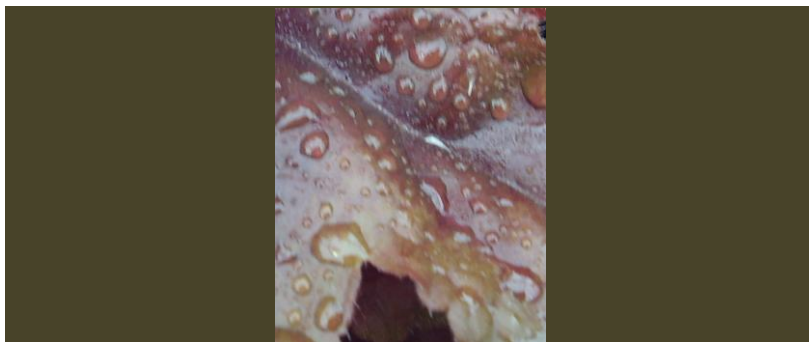
If you have done biology at school you might already know something about reflexes or “reflex arcs.” A good example of a reflex is found in the pupil of your eye. When you are in bright light the pupil is small, and when you are in dim light the pupil is large.

This opening of the pupil is controlled by a reflex which tries to keep the amount of light entering the eye within the best range for seeing. Too bright a light and the pupil closes down to let less light in; too dim a light and it opens up to let more in.

In a reflex like this a message is sent from a sensor. This tells the motor neurones to work a muscle or a set of muscles. In the eye the sensor senses the brightness of the light coming in. If it's too bright it tells the muscles controlling the pupil to close the pupil until the amount of light is just right. The sensor then senses things are right and stops sending messages asking for change.

Another well known reflex is the knee-jerk reflex which causes the lower leg to jerk forward when the knee is firmly tapped below the kneecap.

Much of our movement is controlled like this so that when we decide to walk somewhere we do it without thinking in detail about HOW we do it. We make a decision about how fast we will walk and in which direction we will walk. We don't need to think in detail about which muscles to use, when to use them, how hard to work them or in which order they need to be worked. We trained our



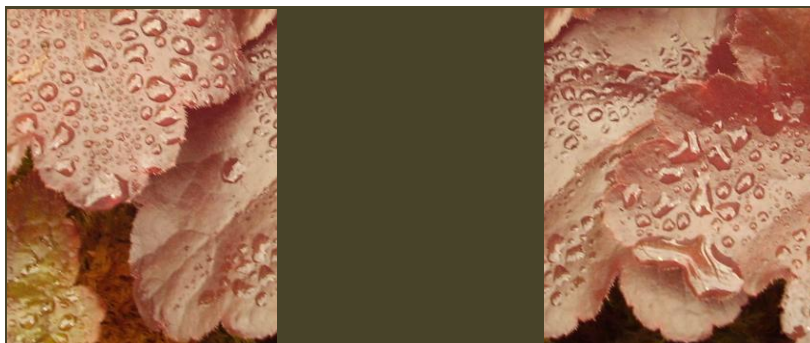
reflexes to do all these things in the right order when we were small children and first learned how to walk, talk and throw things.

Since lower motor neurones are involved in all reflexes there is a gradual loss of reflexes in muscles whose lower motor neurones are damaged by MND. Without the stimulation provided by these neurones the muscle gradually wastes away.

When upper motor neurones are lost the brain can't send messages to the lower motor neurones they control. It's a bit like having a piece of wire missing from between the switch and an electric lamp. The switch works, the lamp can work, but the message doesn't get from one to the other.

The disconnected lower motor neurones respond to this lack of messages from the brain by growing new connections to try to reconnect with the brain.

Due to these new connections the different nerve cells involved in the reflex arc start sending messages to each other, which causes their muscle's tone to increase.





Muscle tone is a measure of how ready the muscle is to work. Someone who exercises a lot will have muscles that are firm and ready for action. Someone who doesn't exercise much will have muscles that are softer and need to take up a lot of slack before they begin to work. Sometimes this increase in muscle tone caused by MND is so great that a muscle can pull an arm or a leg into an awkward position.

Muscles normally work in pairs. Think about the muscles in your upper arm. The one on the front brings your lower arm up to the shoulder when it does work. The one on the back of your upper arm extends your lower arm away from the shoulder when it works.

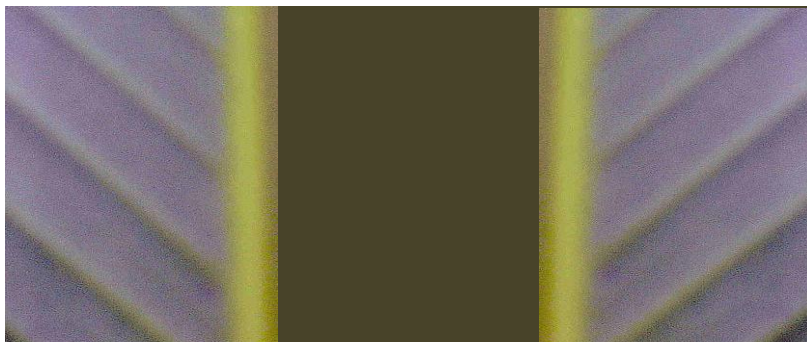
If you try to work both of these muscles at the same time your arm becomes locked and rigid. Sometimes in MND upper motor neurone damage causes the tone of both muscles of a pair to increase; so much so that it causes both muscles to seem to work at the same time. When this happens, and the limb becomes locked and stiff, the name for it is "Spasticity". A "Contracture" happens when only one of the muscles in a pair is involved and causes the joint to bend awkwardly.

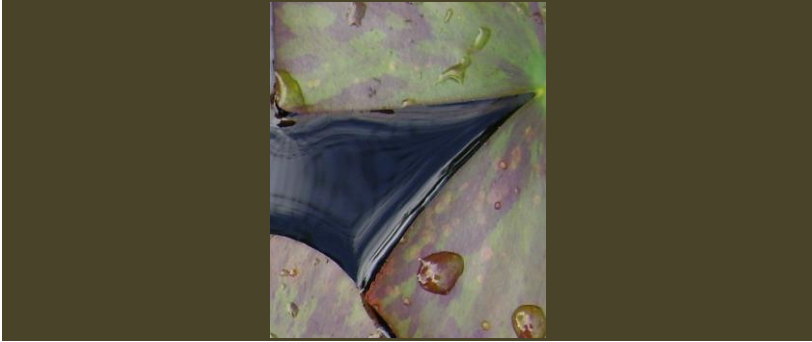
For muscles which have lost their lower motor neurone connections the damage is mostly seen as weakening and wasting. Muscles which still have lower motor neurone connections but have lost their upper motor neurones become stiff to the point of near uselessness.

We use muscles to do so many activities of life that when they stop working it can be very serious. It can even be life threatening.

In MND the damage starts by affecting one muscle or a group of muscles. Over time the damage spreads to affect other nearby muscles as well as those in other parts of the body. This is why the old-fashioned name for MND was “Creeping Paralysis.”

In the early stages the family doctor may have been involved in trying to work out what the problem is with the person who has MND. Even if he or she thought it might be MND the family doctor would still have sent the person to see a neurologist. Neurologists specialise in diseases of the nervous system and would be involved to be absolutely sure of the diagnosis.



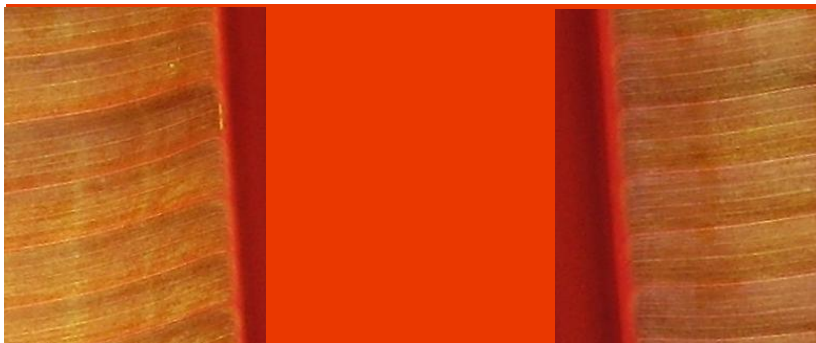


To settle on what is wrong the neurologist would have found reasons to exclude other diseases of the nerves. “It can’t be this, because..... It can’t be that, because...” and so on.

The neurologist would also send the person for different kinds of tests to help with the investigation. There is no test that can definitely say “This is MND,” but there are tests that can say, “This probably isn’t MND.”

MRI and CT scans give a picture of inside the body, a bit like an X-ray. These pictures can rule out other possible causes of the problems such as tumours or damage on the spine. Blood tests can rule out infections which might cause similar symptoms. A special kind of electrical test can compare how well damaged and healthy muscles can carry an electrical signal. If a muscle has lost a lot of its nerves it is less able to carry this signal.

Ultimately, though, making a correct diagnosis depends on the skill and experience of the neurologist in putting together all the different bits of the jig-saw puzzle of symptoms.



When MND Affects the Limbs

The person with MND might gradually lose the ability to do some things that everyone normally takes for granted. The most obvious of these is walking and standing. If the leg muscles are affected this weakens them. This weakness might show itself first by the person tripping, or having difficulty in getting up out of a chair. At the same time the person might need to rest for a while after walking any distance.

With time the leg muscles may become so badly weakened that the person might not be able to climb stairs and may only be able to walk short distances on the flat with the help of sticks. The weakness usually increases until the person is not able to walk very far and might need to use a wheelchair to get around.

It is important to remember not everyone is affected by MND in the same way and that some people's legs are never affected by the disease.

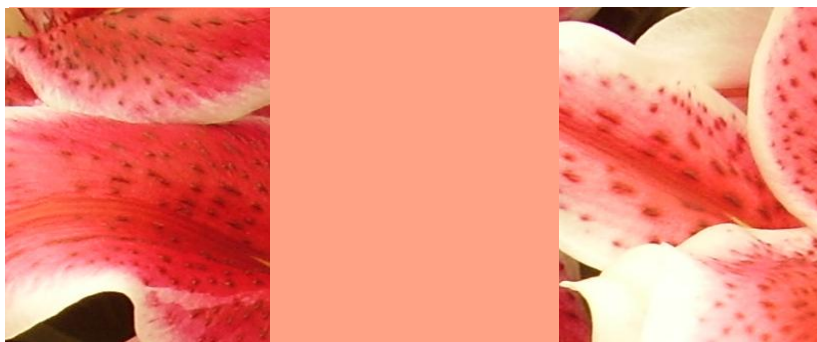
In some people the disease can affect the muscles of the arms, hands or fingers. This can cause problems in lifting or carrying things, but it can also cause other problems you might not think of. Getting dressed or undressed, cooking, feeding yourself, even changing the channel on the TV all need hands and fingers. And what do you do with an itchy nose if you can't raise your arms?

Again, not everyone affected by MND loses the use of their arms, but it does happen quite often.

Loss of the use of the arms and legs can have other effects. For example, it can make it difficult to sit up or turn over in bed. Someone who can't do this for themselves will need help from others to change from an uncomfortable position.

Blood is sent around the body by each beat of the heart, but the heart needs help from the muscles to have the blood sent back.

Once blood has passed through the narrowest blood vessels, where it unloaded its cargo of food and oxygen, it finds itself sitting in a vein, waiting to be sent back to the heart.





Unlike on the journey out from the heart, where the pulse of pressure from each heartbeat pushed the blood along; the pulse is so weak in the veins it has trouble moving the blood at all.

To help send blood back to the head veins have valves that allow the blood to flow only towards the heart. The valves divide the vein into sections. When muscles work they squeeze on the veins that run around and through them, putting pressure on the blood and squeezing it into the next section. With this help from the muscles the blood is then sent back to the heart.



If the muscles no longer work this extra help to return blood isn't there and stale blood can gather in the muscles. This blood is short of oxygen which can cause painful cramps in the muscles.

Liquid also escapes from the blood vessels into the tissues of the body. This helps to take food and oxygen away from the blood and into the cells of the body. This liquid is returned to the heart and bloodstream by the Lymphatic system.

Just like in the veins the lymphatic system is divided into sections by one-way valves and it needs help from the muscles to push fluid from one section to another. If the muscles aren't working then this liquid isn't removed from the tissues of the body and can gather there causing swelling.

Both cramps and swellings can be side effects of weakened muscles in MND.

Physiotherapists can sometimes help deal with these side effects by massaging the muscles and by teaching the family how to help the person do range of movement exercises. These exercises are designed to help the person to stay supple but can also encourage blood flow.



What they call “Bulbar Symptoms”

In about a quarter of people who develop MND their first symptoms affect their ability to speak, to swallow or both.

The muscles that control our lips, tongue and throat are controlled from the “bulbar” part of the brain. This area is found at the lower back of the head. If problems appear in muscles controlled by this area they are sometimes called “bulbar symptoms.” “Bulbar symptoms” means the person with MND has problems with their speech or swallowing.

About eight out of every ten people whose first symptoms are in another part of the body will eventually develop problems with speech or swallowing.

Speaking Difficulties

In the early stages the person's speech might be a bit slurred and slow, as though they had drunk too much alcohol. They might even begin to speak through their nose a bit. This can make their voice sound different from how it was before. In time the person might have so much trouble in forming words that it becomes difficult to understand them.

When you live with someone affected in this way the changes to how they speak happen slowly. You and others in the house will probably learn to understand their changed way of speaking. This can be true, even when people not in the family can't make out what the person is saying. Eventually most people, whose speech is affected, need to find other ways to communicate. Often this is done by writing things down, but other ways of communicating are possible.

A number of these methods for alternative communication are mentioned later in this booklet.





Swallowing Problems

Swallowing problems are a bit more difficult to deal with. We swallow hundreds of times a day to eat, to drink and to get rid of saliva from our mouths. If we can't swallow we can't take in food or liquid this way, and neither can we swallow our saliva. The obvious solution to this is to spit the saliva out. Except, if the lips and tongue are affected and can't be controlled then spitting can also be a problem.

Swallowing problems can start in a number of ways. For some people their jaw muscles can become too weak to chew their food. Someone affected this way needs to change to a diet of soft foods that don't need much chewing.

If their tongue isn't working properly other people might have difficulty in getting the food to the right position to be swallowed. Still others might be able to chew and start to swallow, but the food just sits in their throat, not going down properly and taking far too long to do so. This can lead to choking and coughing up the food.

Sometimes changing the texture of the food can help people to continue to swallow safely for a while. Changing the texture usually involves liquidising the food in a blender then adding food thickeners to get it to the correct “thickness” for the person. The thickened food should be solid enough to hold together when being swallowed so that none goes down the wrong way, but thin enough to allow weak throat muscles to push it down easily. The ideal thickness is often described as being a bit like thick custard.

When we swallow a flap of tissue covers the windpipe to stop food and liquid going down the wrong way. When this muscle is weak, the seal across your windpipe as you swallow isn’t strong enough to prevent food or liquids from entering. This causes coughing and spluttering to get rid of the food and stop it from entering the lungs.

If any food or liquid enters the lungs it can be very dangerous for the person. Food or liquid in the lungs can cause a serious illness called “aspiration pneumonia.”

People with MND who develop swallowing difficulties are often offered the possibility of having a feeding tube fitted so they don’t need to swallow anything.





The operation to fit this tube involves making a small cut that goes from the outside of the body right into the stomach. A special plastic tube is passed through this hole and is held in place by a plastic clip on the outside. On the inside there is usually a small balloon built into the rim of the tube. Some stitches help to hold the stomach against the body wall until the wound heals.

Once the tube is in place the balloon can be filled with salt water from the outside to stop the tube from accidentally popping back out. Depending on how the operation to fit this feeding tube is done it can be called either a PEG or a RIG. Most people just call them PEGs.

After the operation the person can be given all their food, drinks and medicines through this tube. The food is specially prepared in liquid form and is not like normal food.

Sometimes a feeding tube will be fitted when the person doesn't yet need to use it. This is done when it is thought that the person might be too ill later on to have the operation.

When someone can't swallow their saliva and can't spit it out they will often drool a lot. This can be embarrassing to see, but is even more embarrassing for the person.

There are a number of ways drooling can be reduced. Sometimes the person can be given patches that contain drugs to reduce saliva production. These patches are stuck on the skin and usually last for about three days. For some people a single patch is too strong and it can dry up their mouth completely. If this happens pieces might sometimes be cut off the patch to reduce the dose.

For other people patches don't always work and they might need to use a portable suction unit. Suction units have a tube that goes into the mouth in the same way as the suction unit your dentist uses. Extra saliva can then be sucked away to make the person comfortable again.



Breathing Problems

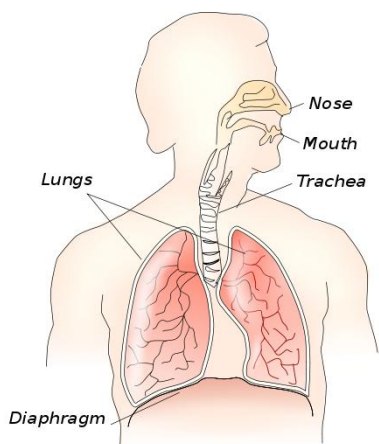
Many people with MND develop breathing problems, often towards the end of their illness.

Breathing allows us to take in oxygen from the air around us and to get rid of carbon dioxide made by our bodies. When we do a vigorous exercise, like running, we suddenly use up a lot more energy than normal. This causes an increased demand for oxygen from those parts of the body doing the exercise.

To supply this extra oxygen we breathe faster. At the same time we are fueling this energy demand by combining digested food with the oxygen. This releases energy we can use and makes carbon dioxide that we also need to get rid of.

This exchange of gases is driven by the muscles that control breathing. When we breathe we take oxygen into the body and send carbon dioxide out of the body,

Like the other muscles of the body these breathing muscles are controlled by motor neurones that can be affected by MND. If the breathing muscles are affected then the person with MND might not be able to take in a large enough breath to meet their needs.



The muscles we use to breathe are mainly the large dome-shaped muscle called the diaphragm and the muscles between the ribs. The diaphragm separates your chest from your stomach and other guts. When we are really breathless we might also use muscles in our shoulders and neck, which is why your

shoulders heave after really heavy exercise.

When we sleep most of our body muscles become paralysed to stop us from thrashing around and damaging ourselves. This includes the rib muscles. As a result we breathe using only our diaphragm when we are asleep.

Sometimes the diaphragm and rib muscles are only just providing enough oxygen for the person with MND during



the day. If this happens, then at night the person will not take a large enough breath due to the rib muscles not working.

Most people spend the day in an upright position, even people who are ill like to sit up in bed. This has the effect of letting gravity pull our stomach and gut contents down towards our legs and away from the diaphragm. This makes it easier for the diaphragm to work as it does not have to push the stomach out of the way.

At night, when we are lying on our backs, gravity pulls everything down towards the bed. Like a water filled balloon sitting on a table, our guts try to spread out in all directions inside our body at night. This causes them to push out against the skin at our sides and against the diaphragm from the inside.

This extra pressure from your guts means the diaphragm has to work harder to push them back at night than it does during the day. As a result a weak diaphragm can't move so far as it can when someone is sitting upright. Add that to the ribs not moving and the biggest breath someone can take while asleep is much smaller than any breath they can take during the day.

Someone who is only just getting enough oxygen during the day will run short of oxygen when asleep. When this happens our brains react to the low oxygen levels in the blood by making us wake up.

As soon as we wake up our rib muscles start to work and we take in a couple of deep breaths causing the oxygen levels in the blood to become normal again. Most people go back to sleep right away and don't remember having wakened up.

When this happens to someone with MND they can waken up every couple of minutes and not remember any of it in the morning. At the same time they haven't had the deep sleep we all need. This can make them very difficult to waken in the morning. During the day the person can be very sleepy and can drop off to sleep again quite often.

If this broken sleep continues for a long time the person can develop problems in concentrating and remembering things.

If night time breathlessness goes on too long the person may start to waken up with headaches in the morning.





This is because if we can't get enough oxygen into the body, then we most likely can't get rid of enough carbon dioxide. When carbon dioxide builds up to dangerous levels in the blood it causes headaches.

Another problem caused by weak breathing muscles is that the person can't cough too well. Not being able to cough easily means that it becomes difficult for someone to clear their lungs properly. Phlegm can then build up in their lungs making breathing even more difficult. This can allow bacteria to get a hold and lead to chest infections which can be serious.

Some people with MND choose to have their breathing helped by a ventilator when they sleep. A ventilator usually has a pump to deliver the right amount of air for each breath the person needs. A hose connects the pump to a breathing mask. When the person breathes the pump blows air into their lungs. To make sure that the air goes into the lungs the mask needs to fit their face tightly. If the mask isn't tight enough, the air will escape.

At night, as the person breathes the pump kicks in and pushes air into their lungs. This gives them a bigger breath than their diaphragm alone can provide. The

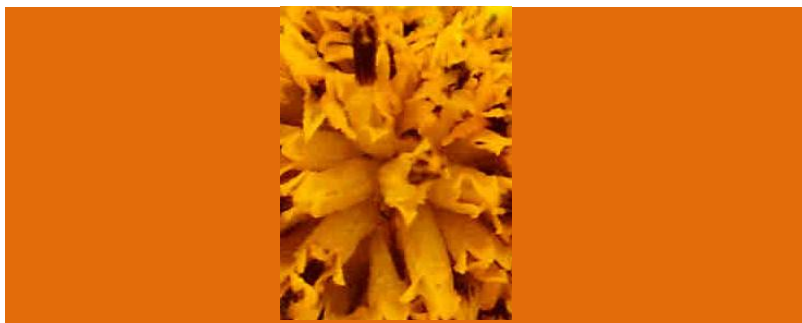
ventilator helps make sure that they get a full breath every time. This usually helps the person to get a proper sleep as it gets around the breathing problems they have.

MND is what we call a “progressive” disease. Progressive means that it only gets worse. Someone who has problems with their breathing at night will probably discover they sometimes need to use their ventilator during the day. Most often this use will slowly increase until the person needs to use the ventilator for most of the day.

Unfortunately having a mask strapped tightly to your face for the whole day, every day, causes problems.

Where the mask makes tightest contact with the face it stops blood getting into the tiny blood vessels underneath the mask. The areas of skin these blood vessels supply will find themselves short of food and oxygen and will start to die off, leading to the development of sores

Over time these sores can grow bigger and become more painful. If the sores become infected this can lead to other serious problems.





For many people having to wear a mask that makes contact with these sores can be too uncomfortable. As a result the person might decide that they need to stop using the mask.

Once someone reaches this decision the result is inevitable. If they can't have the extra help from the ventilator, then they will not get enough oxygen and neither will they get rid of enough carbon dioxide. These two things together can cause the person to become unconscious. Eventually the build up of carbon dioxide in the person's blood will act like an overdose of anaesthetic and they will stop breathing.

Who Are all These People?

MND is a complicated disease that can affect different parts of the body in different ways. It can cause problems with the movement of arms and legs leading to other problems with every-day life. Eating, drinking, breathing and speaking can all be affected. As a result there may be a lot of people around to help care for someone with MND.

In the very early days of the illness the person might only see their family doctor and a neurologist at the hospital.

Once the neurologist has made a diagnosis of MND they normally pass the person's details onto the local MND Scotland Care Team Specialist.

The MND Scotland Care Team Specialist usually visits the person's house to see how suited it is for someone living with MND. At the same time they also find out what other help is needed. In the early days following a diagnosis of MND the care team specialist will try to pull together the right group of people to support the person and their family at that time.

One of the first people to be involved is often an occupational therapist. An occupational therapist, or OT, is a specialist in helping people to work out new ways of doing things that their illness is preventing them from

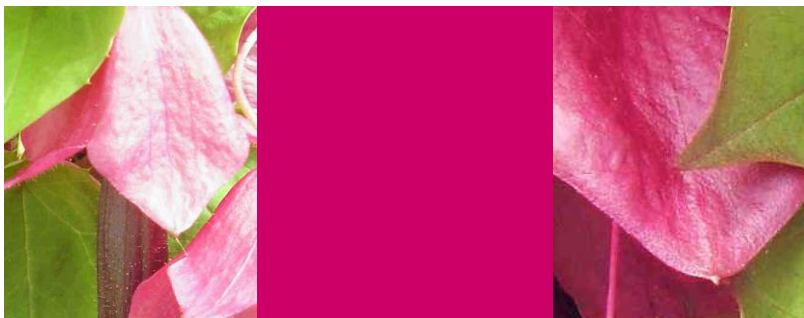
doing. OTs have access to a range of specialist equipment that can help the person to cope better. These might include handrails to help with steps, stairs, baths or showers. They can also help with specialist types of tap-turners, different kinds of handles and locks for doors and windows. There is a whole range of other equipment to help people cope with the disabilities MND can cause.

A physiotherapist might sometimes be involved to give advice about how best to keep the body supple. They can also help to deal with things like muscle cramps and mobility problems.

When speech is affected by MND a speech and language therapist (SLT) might be involved. The SLT can recommend which communication aids are best for the person and their circumstances. If things change then the SLT might come back to make new recommendations.

It is also the Speech and Language Therapist who makes recommendations when someone has problems with swallowing. The kinds of advice the SLT can offer includes the best way to position the head and chin and





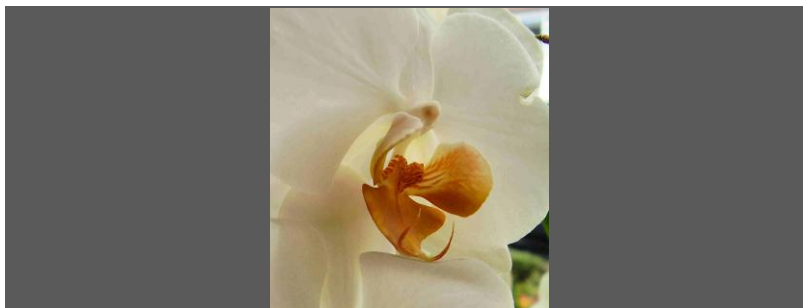
what kind of diet is best for the person. If the SLT feels a changed diet is needed then they will probably also involve a dietician.

The dietician will give detailed advice of what the modified diet should contain. It is also a dietician who prescribes the liquid food when someone is being fed through a feeding tube.

As MND progresses and the person is less able to get out of the house the family doctor might need to do more home visits. A district nurse might also start to visit to make sure everything stays healthy. If the person is now having trouble attending the hospital the MND Care Team Specialist might also visit more often than before to make up for not seeing them there..

Depending on the person's particular needs other people might also be involved, such as social workers, carers, and specialist nurses like palliative care nurses or specialist respiratory nurses if the person is using breathing support.

Due to the variability of MND not everyone mentioned will always be involved in every case, but in most cases most of them are.



Living with MND

For some people affected by MND living with the condition is a struggle. As the disease affects more of their body they can be short tempered and irritated by what they see as their body failing them.

On the other hand, many people with the condition appear to adjust to it relatively well and might actually be unexpectedly cheerful in the face of such a dreadful condition.

Quite how someone will react to being told they have the disease is not easily predictable, however most people seem to develop a positive attitude after a period of deep reflection and consideration.

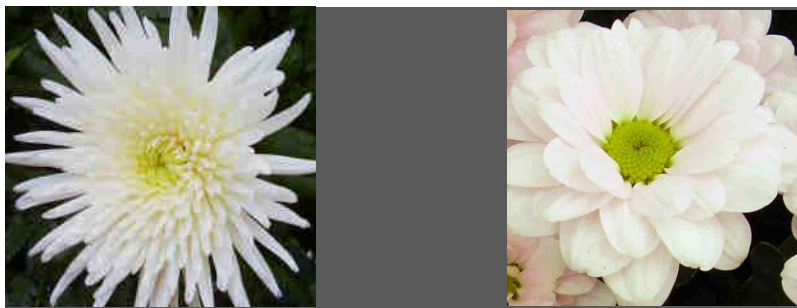
For most people MND has no effect on their mind, but about one in three can eventually develop difficulty in

finding the right words. Usually it is the names of things they are unable to get and they might describe things rather than naming them.

About one person in six, can have behavioural changes that can make them difficult to please. There is a large range of behavioural changes known to affect people with MND. Thankfully very few people develop all of them.

Amongst the more common changes seen in this small group of people is what is often seen by others as an increase in selfishness. The person can appear to become concerned only about what they want and can be very demanding of others. Sometimes a person affected by changes in behaviour can fail to recognise the emotions or moods of others and simply not see the effect their own behaviour is having on those around them.

Some people can develop an over-fondness for sweet foods. This could cause them to eat a whole cake or a whole packet of biscuits in the one sitting.





Other people sometimes continue with activities that are no longer needed.

For example, someone who has lost their voice and who is writing out a message asking for something can feel they need to complete the message, even after the other person has guessed the message and the thing has been brought to them

In particular, when bulbar symptoms have developed, some people can have difficulty controlling their emotions. Very often they think that their uncontrolled tears or laughter are a sign of developing madness and don't mention this. If this symptom, called emotional lability, does develop it should be mentioned to the MND Care Team Specialist as there are drugs available to help control it.

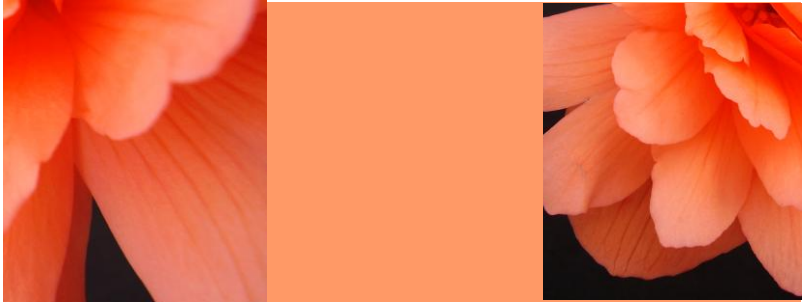
The vast majority of people affected by MND do not have these problems and cope with the disease in their own way. Often they stay remarkably up-beat, despite the damage caused by the disease.

How Long is Someone's Life Expectancy?

Anyone who works with people affected by MND very quickly learns that the first rule of MND is that there are no rules. The disease is so variable that there are exceptions to every rule and it isn't possible to give cast-iron guarantees about life expectancy. In general, though, most people who are affected fall within the following rough guidelines.

MND includes several different conditions. The least common of these is called Primary Lateral Sclerosis (PLS). PLS accounts for between one and two in every hundred of all diagnosed cases of MND. It is a disease involving only the upper motor neurones, so doesn't normally cause wasting of the muscles. This is because the reflexes and the lower motor neurones remain intact. Most people diagnosed with PLS can expect to live a near normal lifespan.

Progressive Muscular Atrophy (PMA) affects between eight and ten people out of every hundred new cases of MND. PMA is a disease of lower motor neurones only and so causes the muscle to waste away. This is due to lack of stimulation. Most people who have PMA can



expect to live for five years or more from the first symptoms.

MND which starts in the throat or mouth is sometimes referred to as “bulbar onset ALS” (see page 17). Bulbar onset ALS has a usual life expectancy of six months to three years from the first symptoms for most affected people. Although in some people the disease can progress frighteningly fast, cases are known of people who have lived with the condition for ten years or more.

ALS which starts in the limbs has a usual life expectancy of three to five years from the first symptoms for most affected people. For a small number of people the disease can be so slow that they can live for twelve years, or even longer, after diagnosis.

Sadly, we have no real way just now of predicting who will have a long-lived illness and who will have a short illness. It is hoped that once we learn more about the different causes of MND these will give better guidelines as to how each individual case might develop.

Alternative Communication Strategies

About three-quarters of people affected by MND eventually develop problems that can affect their speech.

Sometimes weak breathing muscles mean that the person with MND cannot make their voice loud enough to be easily heard. For people affected this way there are portable voice amplifiers that can help. These are usually small enough to be carried on a belt around the waist.

For others who have trouble controlling the muscles of their mouth and tongue the problem is shaping the words. As speaking becomes more difficult for them they might use a number of different communication methods depending on their other abilities. Some people just write things down, while others like using devices such as



mobile phones with text prediction. Sometimes specialist speech generating machines can help, but these machines often need the person to be able to press keys on a keyboard to make the words.

There are also 'apps' available for smart phones and i-Pads to convert text to speech. Again the person still needs to be able to select the letters to make the words.

When using a keyboard is not possible there are other possibilities. The easiest of these systems work by displaying symbols on a grid on a touch sensitive screen. The idea is that the person touches different symbols in turn and builds up a sentence that way. For example one symbol might stand for "I want" and another might mean "a cup of tea." So with two taps on a screen the person can make the sentence "I want a cup of tea" and the machine will say it for them.

When the person is unable to touch a screen these programs can usually also be used in what is called a "Scanning Mode" in which symbols or letters can be highlighted in turn. As each symbol lights up the user can press a button using any part of their body that can still move, to select the symbol or letter they want. In this way the person can create words and sentences. This is not fast and it can sometimes take a long time to have a conversation.

Other ways people communicate when they can no longer speak included looking or pointing at letter boards, codes based on eye blinks or even someone speaking part of the alphabet and the person blinks when they get to the right part.

One method depends upon you and the person both knowing what letters come after each of the vowels in the alphabet. They naturally divide it up into manageable sections. You would start by slowly saying "A..." "E..." "I..." "O..." "U..." and the person would nod or blink or make some sign as you say the one they want. Let's say they nod at "I". You would slowly then say that bit of the alphabet from "I" onwards, "I..." "J..." "K..." "L..." "M..." "N..." and gradually build up, letter by letter, what they want to say.

The ultimate in alternative communication techniques is eye-gaze controlled equipment. These work by cameras tracking what the user is looking at on the screen; so if you stare at a program icon for more than the minimum set time the computer will open that program. Do the same to letters on an on-screen keyboard and you can type messages. However the cost of these machines is not cheap.

Alternative communication methods are not fast and often require a lot of patience by everyone involved if they are to be used successfully. However, do bear in mind that someone with MND might find communication very difficult if they are easily fatigued.



Lastly...

**You are
not Alone**

Motor Neurone Disease can be very upsetting for everyone involved. This is why MND Scotland offers a free counselling service amongst its range of services. If you think talking to someone might help you then telephone us on 0141 945 1077 and ask to speak to someone about counselling.

If you are under eighteen years old permission will be required from a parent or guardian before you can actually begin a course of counselling.



For further information on our support or services contact us at

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