

# Chiari malformation



Brain & Spine  
Foundation

A guide for patients and carers

The **Brain & Spine Foundation** provides support and information on all aspects of neurological conditions. Our publications are designed as guides for people affected by brain and spine conditions – patients, their families and carers. We aim to reduce uncertainty and anxiety by providing clear, concise, accurate and helpful information and by answering commonly asked questions. Any medical information is evidence-based and accounts for current best practice guidelines and standards of care.

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## Introduction

This booklet provides information on Chiari malformations. It focuses on Chiari malformations in adults, describing what a Chiari malformation is, associated conditions, possible treatments including surgery, and how lifestyle can be affected. Chiari malformations affect each person differently and your doctor or consultant will be in the best position to offer advice and information to meet your individual needs. Sources of further support and information are listed in the Useful contacts section (see page 35). References are available on request.

# Common questions

## What is a Chiari malformation?

The term 'Chiari malformation' is used to describe how in some people their brain sits inside their skull in an unusual way. In individuals with a Chiari malformation, a part of their brain extends below the opening at the base of the skull, (which it normally wouldn't), and protrudes into the space at the top of the spine.

Some people with a Chiari malformation may not have symptoms. Others however may experience headaches, neck pain, and other neurological symptoms; as well as problems relating to the flow of fluid around the brain and spinal cord e.g. hydrocephalus, syringomyelia.

The **cerebellum** is the lowermost part of the brain, and plays a role in controlling balance and co-ordinating movement.

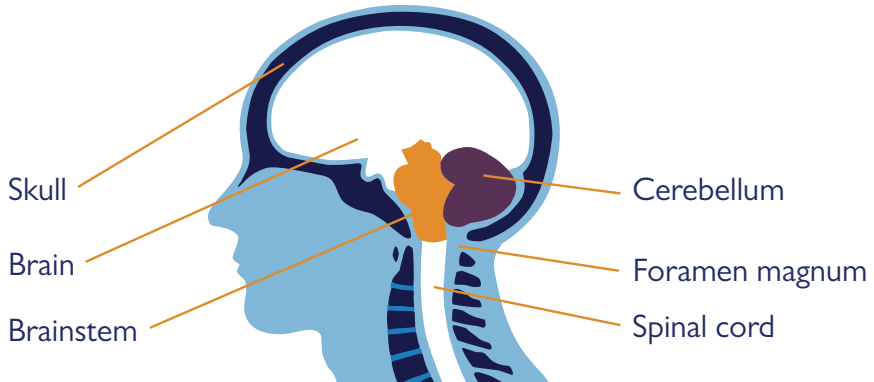
The **brainstem** is the part of the brain that connects with the spinal cord. It relays information between the brain and the body, and is also involved in vital functions such as breathing.

The **foramen magnum** is the opening in the base of the skull.

The **posterior fossa** is the space in the back of the skull where the cerebellum usually sits.

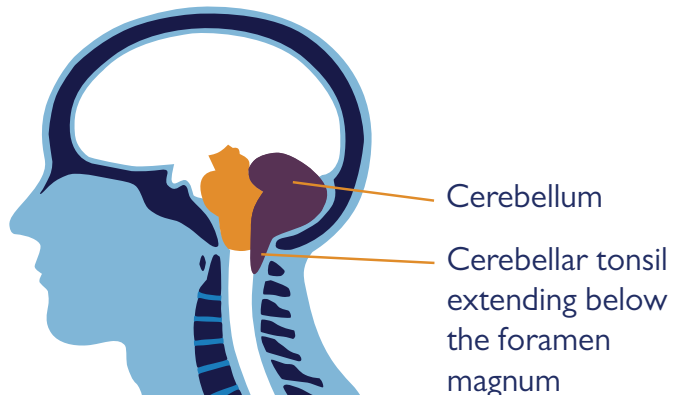
Usually the part of the brain called the cerebellum and the top of the brainstem are located in a space within the skull above the foramen magnum – the opening at the base of the skull.

### Diagram of the brain



If this space, sometimes referred to as the posterior fossa, is abnormally small or if something is pushing down (hydrocephalus or a tumour) or pulling from below (tethered cord or some spinal conditions), then part of the cerebellum and brainstem may extend down through the foramen magnum and into the top of the spine. This is what is called a Chiari malformation.

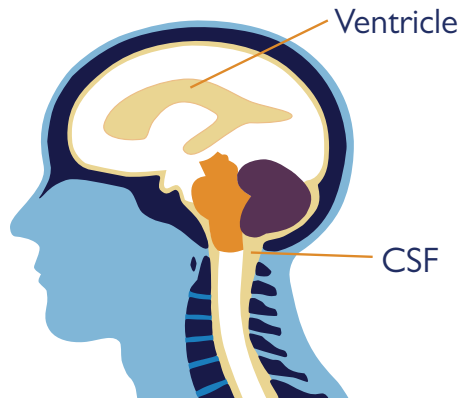
### Diagram of a Chiari malformation



A Chiari malformation may disrupt the flow of cerebrospinal fluid (CSF) to and from the brain, and this can affect the overall pressure within the head. This may lead to hydrocephalus, and may also contribute to the symptoms people experience.

**Cerebrospinal fluid** (CSF) is a clear, colourless fluid that surrounds the brain and spinal cord. Its main functions are to protect the brain by acting as a shock absorber, to carry nutrients to the brain, and to remove waste.

Diagram showing CSF



CSF is produced in spaces within the brain called ventricles. The CSF then flows from here and moves around the brain and the spinal cord.

Chiari malformations are named after Hans Chiari, the pathologist who first described them. Previously they could also be called 'Arnold Chiari' malformations, although 'Arnold' has now largely been dropped from the name. Another name sometimes used is 'hindbrain hernia'.

## Are there different types of Chiari malformation?

Chiari malformations are divided into types. Your specialist will tell you which type you have, based on your symptoms, physical examination and scan results.

### Type I Chiari malformation

This is the most common type. Type I malformations involve the cerebellar tonsils (the lowest part of the cerebellum) extending down below the foramen magnum and into the spinal canal.

### Type II Chiari malformation

This type is less common than Type I, but is more serious. Type II malformations are usually identified in childhood, because this is when symptoms often develop. Type II malformations involve the cerebellar tonsils and part of the brainstem (the lowest part called the medulla or medulla oblongata) extending downwards below the foramen magnum and towards the spine.

The **medulla**, also called **medulla oblongata**, forms the lower part of the brainstem and is involved in regulating functions within the body, such as heart rate and blood pressure.

Type II, III, and IV are all associated with spina bifida and other congenital abnormalities of the brain and spine ('congenital' means present at birth).

### **Type III and Type IV Chiari malformation**

These types are very rare and much more serious than types I and II.

They affect children and symptoms appear at birth and during infancy. In

Type III, the cerebellum and the brainstem are forced out of an abnormal opening in the back of the head and neck. In Type IV, the cerebellum doesn't develop fully before birth.

### **Type 0 or 0.5 Chiari malformation**

These forms of Chiari malformation were only defined recently and

remain controversial. The terms describe people who experience 'Chiari-

like' symptoms, but whose cerebellum does not extend beyond the base

of the skull as far out as is usually necessary to diagnose a Type I Chiari

malformation (5mm or more on an MRI scan). In these instances it

may still be possible that the flow of CSF is obstructed (blocked) at the

foramen magnum. Research is being done to find out more about these

symptoms and the best treatment options for these people.

### **Type 1.5 Chiari malformation**

Some specialists have started to use the term Type 1.5 Chiari

malformation to describe people with a form of Chiari malformation,

which is more advanced than Type I but doesn't completely fit the

criteria for Type II. Again this is controversial and not universally accepted.

Researchers are looking into these cases to better understand these

patients and how best to treat them.

### **Complex Chiari**

Some specialists describe a 'complex Chiari' as being when the cerebellar

tonsils are extending out of the base of the skull and the patient's head is

also at an abnormal angle and position on the spine. This can be associated

with hypermobility syndromes ([see Ehlers-Danlos syndromes on page 13](#)),

but again is not universally accepted.



## What are the symptoms?

Often, people with **Type I** Chiari malformations may not experience any symptoms. If people with Type I malformations do experience symptoms they may be similar to those experienced by people with Type II malformations (see below). Headaches and neck pain are especially common.

Usually, people with **Type II** Chiari malformations do experience symptoms, and will have done since childhood. The main symptoms people with Type II malformations may experience are:

- headaches (usually at the back of the head and often made worse by coughing, sneezing, straining or bending over)
- neck pain
- dizziness and balance problems
- unusual feelings in the arms or legs (numbness or tingling)
- muscle weakness and paralysis (a loss of muscle function)
- visual problems and involuntary movement of the eyes (nystagmus)
- swallowing problems
- hearing loss and ringing in the ears (tinnitus)
- feeling sick (nausea) and being sick (vomiting)
- sleep problems

Less commonly, some people may also experience depression. Further research is needed to fully understand the relationship between Chiari malformation and depression. For help with depression or feelings of anxiety speak to your GP.

Children with **types III and IV** Chiari malformations experience severe neurological symptoms, which are not covered in this booklet.

## What causes Chiari malformations?

In most cases, Type I Chiari malformations are congenital. This means that people are born with the abnormality. For these people, their Chiari malformation is related to them having a small posterior fossa (the space in the skull that holds the cerebellum).

Type I malformations can also be acquired. This means that the condition develops sometime after birth. In these cases, a Chiari malformation can be caused by a build-up of pressure in the brain (for example as a result of hydrocephalus or a tumour) or by a problem with the spinal cord being held down (known as a tethered cord). Although very rare, Type I Chiari malformations can be caused by an injury.

Type II Chiari malformations are congenital. They are caused by abnormalities in the structure of the brain and spine which develop in the womb before birth. This may be due to genetic factors or other influences, such as a lack of vitamins and minerals during pregnancy. Type II Chiari malformations are associated with spina bifida ([see page 13](#)).

Types III and IV Chiari malformations are very rare and caused by developmental problems before birth.

## How common are Chiari malformations?

It is hard to know exactly how common Chiari malformations are.

It has been estimated that 1 child in every 1000 is born with a Chiari malformation. However, because some people don't develop symptoms until adulthood or don't ever develop symptoms, it's likely that the condition is more common than this.

Chiari malformations seem to be more common in women than men.

## Are Chiari malformations hereditary?

The risk of a child inheriting a Chiari malformation from a parent is very small. Researchers are looking into which gene or genes may be responsible. It is possible that children born with a Type I Chiari malformation may have inherited a faulty gene or genes from a parent.

Screening of the family members of a person with a Chiari malformation is not usually done. As many people with a Chiari malformation have no symptoms and treatment is usually only required if symptoms are causing problems, screening should only be considered if family members have symptoms that suggest they may have a Chiari malformation and might also benefit from treatment.

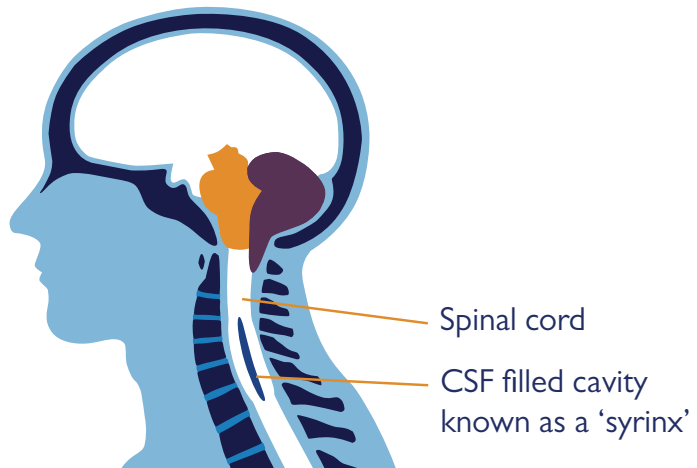
# Conditions related to Chiari

There are a number of conditions that are 'associated' with Chiari malformations. This means that it is common for people to experience these conditions along with a Chiari malformation.

## Syringomyelia

People with Chiari malformations may often develop a condition called syringomyelia. This is when collection of cerebrospinal fluid (CSF) forms in the spinal cord. This fluid-filled space is known as a syrinx. It usually forms in the neck (cervical) area, but can extend further down the spinal cord.

### Diagram of a syrinx



It's not clear why people with a Chiari malformation sometimes develop a syrinx. It's likely to be a result of the Chiari malformation blocking or disrupting the flow of cerebrospinal fluid (CSF) at the foramen magnum.

Over time, a syrinx can grow and press on the spinal cord which may injure or damage it. If the spinal cord is being pressed on, symptoms can include

numbness, muscle weakness, pain, stiffness, unusual sensations (burning or tingling), changes in sensation (loss of pain or temperature sensitivity) and bladder and bowel problems. In extreme cases, it can cause paralysis.

Syringomyelia can be treated by surgery to treat the underlying cause (the Chiari malformation), or by surgery to directly drain the fluid from the cavity within the spinal cord using a shunt ([see page 27 in our section on Surgery](#)).

Syringobulbia is the term used when a syrinx extends into the brainstem. This can affect the nerves in the head, and can cause weakness in the facial muscles, dizziness, involuntary movement of the eyes (nystagmus) and changes in sensation in the face (loss of sensitivity to pain or temperature). As with syringomyelia, the treatment is to drain the fluid from the syrinx.

## Hydrocephalus

Hydrocephalus is when there is a build-up of fluid in the brain. The excess fluid leads to increased pressure in the brain which may cause damage to the brain tissue. People with Chiari may also develop hydrocephalus, and the condition is more common in people with Type II Chiari.

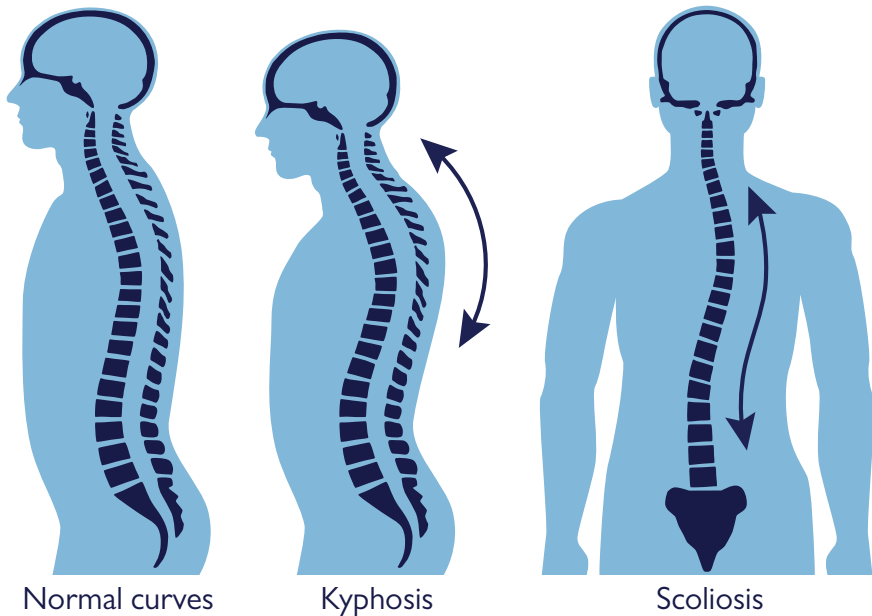
In the past, hydrocephalus was sometimes referred to as 'water on the brain' (the word hydrocephalus comes from the Greek words for 'water' and 'head'). However, the excess fluid is cerebrospinal fluid (CSF), not water.

Hydrocephalus can either be a primary condition (no other underlying cause or condition) or a secondary condition (when it develops as the result of another cause or condition). Hydrocephalus associated with Chiari malformation would be classed as secondary. Hydrocephalus can be treated with surgery to move the fluid out of the brain ([see page 27 in our section on Surgery](#)). ([You may also like to read our fact sheet on Hydrocephalus and shunts, for further information.](#))

## Curving of the spine

Abnormal curving of the spine can occur in people with Type I Chiari malformation or syringomyelia, but is more common in those with Type II Chiari. The spine may curve to the left or right (scoliosis) or it may curve outwards (kyphosis).

### Diagram of curves of the spine



Curving of the spine can cause back pain and stiffness.

The exact link between Chiari malformations, syringomyelia and curving of the spine is not clear. In some people, treating the Chiari malformation and syringomyelia may stop any abnormal curving of the spine from getting worse.

## Spina bifida

People with Type II Chiari malformation may also have a form of spina bifida. Spina bifida is a condition where the spinal column and the spinal canal don't completely close up before birth. The coverings of the spinal cord and sometimes the spinal cord itself can bulge out through the gap.

## Tethered cord syndrome

This is a condition where the bottom end of the spinal cord is abnormally fixed or held down to the tailbone (sacrum) at the end of the spine. This stops the cord from moving naturally and can lead to it getting stretched and damaged.

Although the condition is usually discovered in childhood, some people may not develop symptoms until they are adults. These symptoms may include problems with the bladder, bowel or with sexual function. The condition can be treated with surgery ([see page 28 in our section on Surgery](#)).

## Ehlers-Danlos syndromes

Ehlers-Danlos syndromes (EDS) are a group of connective tissue disorders. Within our bodies, connective tissues provide stability and support and are present in the ligaments, tendons, cartilage, organs, skin and bones.

There are different types of EDS, but in all types the connective tissues are weaker. This can cause problems such as joint hypermobility (joints bending or moving further than they should) and stretchy, fragile skin.

EDS and Chiari malformation are known to occur together; although the relationship between the two conditions isn't clear.

Individuals with EDS may benefit from an upright MRI scan in order to diagnose Chiari malformation, however this service is not widely available and access may be limited.

People with EDS and Chiari may experience more severe symptoms, such as headaches and neck pain, if the muscles and ligaments in their neck aren't providing enough support for their head. The treatment of these patients might involve physiotherapy, pain management and sometimes surgery.



# Tests and investigations

To make a diagnosis, doctors will perform a thorough neurological examination. The key tests to diagnose Chiari malformations are **CT scans** or **MRI scans**. Both scans check for abnormalities in the structure of your brain and spine.



Type I Chiari malformations are sometimes discovered by chance when a person is having scans to investigate a different problem. This is called an incidental finding.

## CT scan

A CT scan (computerised tomography scan) is a special type of X-ray that takes pictures of the brain and spine from different angles.

During the scan you will be asked to lie on a scanner table while the scanner rotates around your head and neck. It is a quick and painless examination.

## MRI scan

An MRI scan (magnetic resonance imaging scan) uses strong magnetic fields and radio waves to produce pictures of the brain and spine that are more detailed than a standard X-ray.

During the scan you will lie flat on a bed that slowly moves into a long tube. The scan is painless but the scanner is very noisy. Earplugs or headphones (often both) are provided. The headphones allow the hospital staff to talk to you while you are in the scanner.

Some people find the confined space in the scanner tunnel claustrophobic. If you think you will feel anxious or uncomfortable in the confined space of the scanner tunnel you should tell the staff before the scan. You should also tell them if you unexpectedly feel anxious just before you are due to enter the scanner tunnel.

Scan results often talk about **tonsillar ectopia**. This is a medical way of saying that the cerebellar tonsils are not in the usual position, and are extending down into the spinal canal. Tonsillar ectopia is measured in millimetres (mm).

A diagnosis of Chiari malformation is usually made when the cerebellar tonsils are extending more than 5mm below the foramen magnum (the opening at the base of the skull). However, this measurement is not always a good indicator of the symptoms a person will have.

Some people may have no symptoms despite their cerebellar tonsils being significantly out of place. Others may have lots of symptoms even though it is not expected from the scan results.

(You might be interested in reading our fact sheet, *Brain and spine scans*, for further information.)

# Possible treatments

Not everyone with a Chiari malformation will need treatment. Many people may worry that if a malformation has been discovered then it must need to be treated. However, if you are not experiencing any symptoms there may be no need for treatment.

For people who do experience symptoms, treatment options may include medication and surgery. The best treatment for you will depend on the severity of your symptoms and your scan results, which your specialist will discuss with you.

## Medication

Pain relief medication can be given to relieve headaches and neck pain. Your doctor may prescribe muscle relaxants to ease any tension in the muscles that could be contributing to your pain.

If painkillers are an effective way to manage your symptoms, you may not require any more invasive treatment.

However, if you find that your pain is getting worse or you are developing new symptoms you should go back to your doctor.

## Surgery

If your pain cannot be managed by medication or you are experiencing other symptoms then your doctor may suggest surgery as a treatment option. See our section on Surgery ([page 23](#)) for more information on surgery as a treatment for Chiari malformation.

# Managing your pain

Treatment may improve your headaches or neck pain; however, it may not completely cure them. You may need to find ways of managing your pain yourself.

In order to manage your pain it also helps to understand it. There are many other factors besides injury and illness that can influence pain. For example, stress, anxiety and low mood are known to have a negative impact on pain. Poor sleep can also play a part, as can poor diet, lack of exercise or pushing yourself too hard. Working out what factors may be contributing to your pain can be tricky. It may help to keep a **pain diary**. Noting down when you have pain flare-ups may help you to spot what factors could have been involved.

Some people find that using hot or cold packs can provide some relief for headaches and neck pain. You may wish to try relaxation techniques, such as meditation, yoga or mindfulness, to see whether reducing stress can help with your pain. More information and advice on diet, exercise and sleep can be found in the next section of this booklet.

If you feel you would benefit from more support, your GP or specialist can refer you to an NHS pain management programme. Pain management programmes support people to develop techniques and strategies to deal with their pain. The programmes are delivered in a number of small group sessions. The aim is not to cure pain, but to give people the tools they need to feel more in control.

You may also wish to explore other organisations and online resources that offer information and support around long-term pain (see [Useful contacts and Further reading sections](#)).

# Living with Chiari

Some people will have waited for many years before getting their diagnosis. Although the diagnosis can feel frightening, it may also be a relief to finally have some answers and a better idea of what the future may hold.

You may have good days and bad days, so it is important to listen to your body and be patient with yourself.

It will be worthwhile to practise coping strategies for symptoms such as pain, fatigue, and memory/concentration problems. (Further support on coping with memory problems, pain and fatigue can be found on our website.)

Looking after both your physical and your mental health will also stand you in good stead. Diet, exercise, sleep and taking some 'me' time are all vital to your overall wellbeing.

Particularly on bad days, don't be afraid to ask family and friends for help. Talking to the people around you will help them to better understand your condition and what they can do that will help you.

If you are working, it can be worthwhile talking with your employer about how to ensure your working environment and work patterns are both safe and supportive.

Many people also find it helpful to talk to others who are living with a Chiari malformation. Talking to other people who have had similar experiences and who are facing similar challenges may help you to feel less alone. Details of organisations and support groups for people affected by Chiari malformation can be towards the end of this booklet.

For information on recovering from surgery and what to consider when returning to activities after surgery, please go to page 29.

## Sport and exercise

As a general rule, it is always best to avoid any exercises that you find make your symptoms worse.

Exercise has multiple health benefits. It helps keep muscles strong, joints flexible and prompts the brain to release chemicals (endorphins) which improve mood and act as natural painkillers. Regular exercise is important for maintaining a healthy weight and for your general health.

Low impact sport and exercise, such as walking and Tai Chi, may be the least likely to make any symptoms worse. These activities will all tone and strengthen the muscles, and Tai Chi may also improve balance. Both Tai Chi and yoga have the added benefit of reducing stress for many people.

After a diagnosis of Chiari malformation, it is best to speak with your neurologist or neurosurgeon about returning to sports should this be something you wish to do.



## Diet

It's really important to try to eat a healthy, balanced diet. A poor diet can lead to a weakened immune system and obesity. Being overweight is dangerous for your overall health and puts extra strain on your body.

Research has shown that the Mediterranean diet has lots of health benefits. This diet avoids processed foods and is rich in fruits, vegetables, nuts, whole grains, fish and healthy oils (such as olive oil).

You should also make sure you drink plenty of water, as dehydration is known to cause headaches and tiredness. Try to aim to drink six to eight glasses of water a day.

## Sleep

Not getting enough sleep can have an impact on your mood and cause you to feel irritable. It may also make you more sensitive to pain.

There are a number of very simple things you can do that may improve your chances of getting a good night's sleep. Sleep experts sometimes refer to this as 'sleep hygiene'.

- Go to bed and get up at the same time everyday (even at weekends).
- Make sure your bedroom is a calm space that's quiet, dark and tidy.
- Take time to relax or wind-down before bed (have a bath or meditate).
- Choose food or drink that is rich in the amino acid tryptophan, such as a milky drink.
- Avoid stimulants, like caffeine and nicotine, before going to bed.

If your Chiari malformation is causing symptoms like headache and neck pain, a soft pillow that is not too deep may be more comfortable. Specially shaped pillows are available online, although a travel pillow may be a good alternative. This may be particularly helpful whilst you are recovering from surgery and your wound is still tender.

## Driving

You are still allowed to drive if you have a Chiari malformation, but the law says that you must tell the DVLA about your health condition ([see Useful contacts on page 35](#)).



If you are on any medication, always check that it is okay to drive whilst taking it.

## Air travel

There is no problem with travelling by plane if you have a Chiari malformation, but [see page 32](#) for more information if you are travelling after surgery.

## Chiari malformations and pregnancy

In women with a Chiari malformation, symptoms can worsen during pregnancy and childbirth. Sometimes this may affect the type of delivery recommended and the type of anaesthetic (spinal, epidural, general anaesthetic). It is worth asking your specialist for guidance.



# Surgery

If your pain cannot be managed by medication or you are experiencing other symptoms your doctor may suggest surgery.

The most common type of surgery to treat Chiari malformations is known as **decompression surgery**. Surgery will be considered and discussed on an individual basis and is not suitable for everyone.

The aim of decompression surgery is to create more room for the bottom of the brain and the brainstem, and to make it easier for the cerebrospinal fluid (CSF) to flow around the brain and the spine.

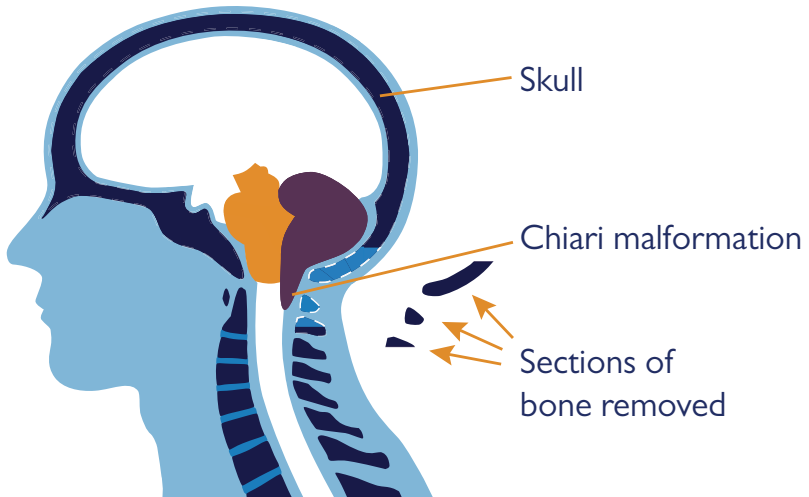
## What does surgery involve?

The surgery is done under general anaesthetic, which means the patient is asleep throughout the procedure. The surgery is performed by a neurosurgeon who is an expert in operating on the brain and spine.

The neurosurgeon will make a cut down the back of the head and neck. The skin and muscles are pulled back, and the surgeon cuts out and removes a small piece of bone from the back of the skull at the base. Parts of the top one or two vertebrae (spinal bones) may also be removed to help create more space.

Sometimes the neurosurgeon will also cut open the thin covering that surrounds your brain and spine (called the dura) and sew in a patch to make it bigger. This is not always necessary or suitable for everyone.

## Diagram of decompression surgery for Chiari malformation



The cut along the back of your head and neck is then closed up and you will be moved to the recovery room.

Initially after surgery you may need to stay in a high dependency unit, before going to a neurosurgical ward to further recover.

Lots of people do find they get headaches, neck pain and nausea when they are recovering from their surgery. You will be given medication in hospital to ease these symptoms.

Decompression surgery is a major operation and you are likely to stay in hospital for several days afterwards. However, the length of your stay in hospital will depend on how well you are recovering.

## What are the risks?

As with any form of surgery, there are potential risks. Your neurosurgeon will discuss them with you before your operation. Whilst they are uncommon, possible risks of decompression surgery include:

- stroke or bleeding (haemorrhage)
- nerve or spinal cord damage (causing weakness, numbness, pain or paralysis)
- speech problems
- difficulty swallowing
- memory loss or problems with thinking
- balance problems
- infection / meningitis
- hydrocephalus (see page 11)
- syringomyelia (see page 10)
- seizures
- CSF leak
- pseudomeningocele (a collection of cerebrospinal fluid [CSF] around the surgery site)
- no improvement, recurrence, or worsening of symptoms
- a risk to life

## What happens after surgery?

Although some symptoms may remain after surgery, most people who have surgery do find that their symptoms improve afterwards. Even if they do not improve a lot, surgery aims to prevent existing symptoms from getting worse.

Symptoms that most often improve following surgery are headaches and neck pain. Symptoms that were being caused by the abnormal pressure on the brain are the next most likely to improve. These include problems with speech, coordination and balance. If scar tissue develops, it is possible that symptoms could return.

After the operation, you will need to take it very easy for several weeks. Your body needs time to heal and it will be at least a month or two before you start to feel close to normal again. Recovery time will be different for everyone, and it may be up to six months before you are able to do any strenuous (very tiring) activity.

## Further surgery

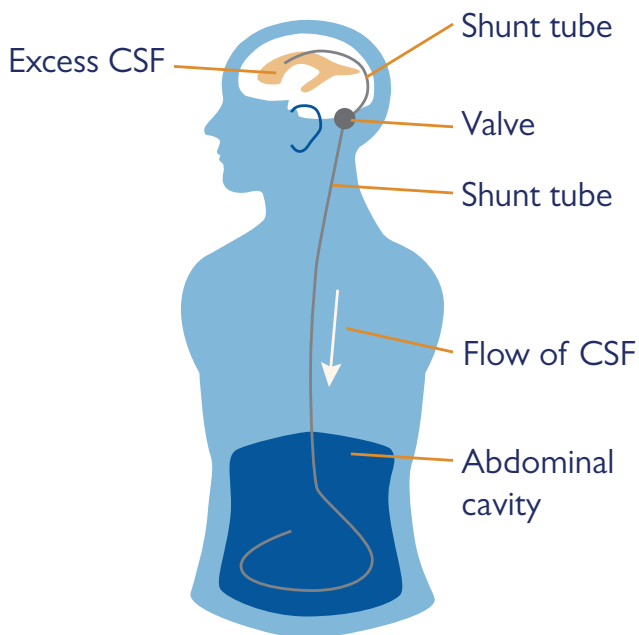
Many people have other conditions which are associated with a Chiari malformation but which do not improve with decompression surgery. It may be necessary to have further surgery to treat these problems.

## Surgery for hydrocephalus

Hydrocephalus is a build-up of fluid in the brain. There are a couple of types of surgery that can treat this condition. Your neurosurgeon can discuss with you which may be your best option.

**Shunts:** Fluid in the brain can also be drained by making a small hole in the skull and passing a drainage tube (catheter) from the brain into the abdomen or the chest cavity. This can sometimes be a primary treatment for a Chiari malformation, depending on the type of malformation and your surgeon.

### Diagram of a shunt



**Endoscopic third ventriculostomy (ETV):** A small hole is made in the wall of one of the brain ventricles (spaces within the brain that produce CSF) to allow any fluid trapped there to escape to the surface of the brain.

### Surgery for syringomyelia

Sometimes, decompression surgery helps to reduce or remove a syrinx. However, some people will require further treatment.

**Syringo subarachnoid shunt:** A drainage tube (catheter) can be placed into the syrinx to drain the fluid out of the spinal cord and into the cerebrospinal fluid space around the spinal cord.

### Surgery for tethered spinal cord

**Untethering:** This is an operation to free the spinal cord from the point where it is being held down at the lower end of the spine.

# Recovery after surgery

## Follow-up appointments

You will be asked to return to hospital for a follow-up appointment in the weeks after your surgery. This is to check on how well you are recovering.

You may have a follow-up MRI scan approximately three to four months after surgery. The scan is to see how successful the surgery has been. If you had a syrxinx before surgery, the scan will show whether or not the syrxinx has become smaller or gone away. If it is still there you may need another operation (see page 27).

Rarely, there may be a leak of cerebrospinal fluid after surgery. If this happens, the fluid may leak from the wound or it may collect under the skin around the wound (forming a bulge). You should contact the hospital if you notice either of these problems.

Always follow the advice given to you on your discharge from the hospital. This includes taking any medications, such as antibiotics, as instructed. Never stop taking any medication without speaking to your doctor.

## Physiotherapy

Depending on your symptoms after surgery, you may benefit from physiotherapy. A physiotherapist can help with a range of different physical problems like muscle weakness and difficulties with balance, movement and co-ordination.

## Strength and movement exercises after surgery

If your neck or shoulders are feeling stiff after surgery, the exercises below may help to loosen up the muscles. It is important to get your neck moving and to keep it mobile again, because stiff muscles can add to pain.

The first four exercises should only be done whilst sitting down, where there is no danger of you falling.

These exercises are recommended for people **after surgery**, and should not be performed if they make your symptoms worse. You should always consult a medical professional before starting any new exercises, to make sure it is safe for you to do so.

1. Tilt your head forwards until you feel a stretch down the back of your neck, and hold for 10 seconds.
2. Tilt your head backwards, and hold for 10 seconds.
3. Turn your head to the side until you feel a stretch, and hold for 10 seconds (repeat for both sides).
4. Tilt your head to your shoulder until you feel a stretch, and hold for 10 seconds (repeat for both sides).
5. Roll the shoulders forwards and backwards.
6. Raise your arm straight out in front of you, thumb first.
7. Raise your arm straight out to your side, thumb first.

It is best to build up gradually with these exercises, repeating each one up to 10 times. Only do each movement as far as is comfortable.



## Balance and co-ordination

It is not uncommon to feel dizzy or unbalanced after surgery. Balance problems usually improve quicker the sooner you get back up and walking after the operation.

Physiotherapists can suggest special exercises to help if you continue to have problems with dizziness, balance or co-ordination.

Exercises will vary depending on the individual. Not all of the exercises will require special equipment. You may be able to do many of them by yourself in your own home.

## Posture

Good posture (the way you hold your body upright) is very important for anyone with Chiari. It can reduce unnecessary pressure from being put on the joints and ligaments in the spine.

A physiotherapist can show you exercises and good habits to improve the way you sit and stand. When sitting you should try to keep your back and neck straight and avoid slouching forwards. When standing and walking, try to keep your head upright but your shoulders relaxed.

## Fatigue

It is not unusual to feel extremely tired following major surgery; your body has gone through a lot and so fatigue is to be expected.

It will take time for your body to heal and it is important that you don't push yourself too hard. Although you will want to return to your usual activities as soon as possible, it's important that you listen to your body and rest when you feel that you need to.

You may find that prioritising and pacing your daily activities helps you to avoid becoming exhausted. Setting yourself realistic goals everyday can also give you a sense of achievement and help you to build your confidence.

## Returning to activities after surgery

### Driving after surgery

The DVLA also has rules about driving after certain types of surgery. There is no fixed length of time after decompression surgery when you can't drive. However, you should speak with your doctor before returning to driving and do not drive until you feel you have recovered enough from the operation.

### Air travel after surgery

If you have had decompression surgery you should not fly until your wound is well-healed and your specialist has said it is okay for you to travel.

You will also need to make sure that your travel insurance covers you after surgery.

### Returning to work after surgery

Returning to work after surgery will depend on a number of things, including the speed of your recovery, your general health and the type of work that you do. Decompression surgery is major brain surgery, so you are unlikely to be able to return to work for at least a few months afterwards. It is best to speak with your doctor or consultant for individual advice.

You may wish to talk to your employer about what arrangements or adjustments could help you get back to work. For example, many people find it easier to return to work on a part-time basis to begin with. If your job involves operating machinery you should always check that it is safe for you to do so in combination with any medication you are taking.

## Returning to sports and exercises after surgery

Anyone who has had surgery should wait until their wound has completely healed before going swimming.

After surgery, you should build up your activity level gradually. Gentle walking and everyday tasks (going to the supermarket, doing the laundry) are good things to start with.

You should avoid any strenuous exercise, such as weightlifting or contact sports (e.g. rugby, football), for at least three months after your surgery. This is to give your body time to heal.

It is best to speak with your neurologist or neurosurgeon about returning to sports should this be something you wish to do following your recovery after surgery.

## Washing and dyeing your hair after surgery

You may be advised to wait a short while after any clips or stitches have been removed before washing your hair. When you do, try to avoid rubbing the wound whilst it is still healing.

You can dye your hair as soon as your wound has fully healed. This is usually several weeks after the surgery.

# Health professionals

**Clinical nurse specialist (CNS):** a nurse who specialises in a particular condition, or conditions.

**Neurologist:** a doctor who specialises in the diagnosis and treatment of people with neurological conditions, for example epilepsy.

**Neurophysiotherapist:** a physiotherapist who specialises in treating people with neurological conditions. A neurophysiotherapist assesses symptoms, plans treatment and treats people with physical problems.

**Neuropsychologist:** a psychologist specialising in the functions of the brain, particularly memory, concentration and problem solving.

**Neurosurgeon:** a specialist doctor who performs brain and spine operations.

**Occupational therapist:** a specialist health professional who offers practical support and advice on everyday skills and activities like washing, cooking and using equipment at home.

**Radiologist:** a specialist doctor who performs, reads and reports on scans such as angiograms, CT scans, MRI scans and X-rays.

# Useful contacts

## **Brain & Spine Foundation**

Office LG01, Lincoln House

Kennington Park

1-3 Brixton Road

London

SW9 6DE

Helpline: 0808 808 1000

[helpline@brainandspine.org.uk](mailto:helpline@brainandspine.org.uk)

[www.brainandspine.org.uk](http://www.brainandspine.org.uk)

Led by neuroscience nurses and staffed by trained experts, the Brain & Spine Helpline provides support and information on all aspects of neurological conditions for patients, their families and carers, and health professionals. Further information on a range of neurological problems is available online.

**Ann Conroy Trust**

3 Cheyne Garth

Hornsea

East Yorkshire

HU18 1BF

Tel: 0300 111 0004

[info@annconroytrust.org](mailto:info@annconroytrust.org)

[www.annconroytrust.org](http://www.annconroytrust.org)

Support, education and research for patients living with Chiari malformation, syringomyelia and associated conditions.

**Syringomyelia Self Help Group (Ireland)**

Kelystown

Slane

Co. Meath

Ireland

Tel: 087 7070160

<http://www.syringomyelia.ie>

Website and support group for people with syringomyelia in the Republic of Ireland.

## **The Brain Charity**

Norton Street

Liverpool

L3 8LR

Helpline: 0800 008 6417

[info@thebraincharity.org.uk](mailto:info@thebraincharity.org.uk)

<http://www.thebraincharity.org.uk>

The Brain Charity offers emotional support, practical help and social activities to anyone with a neurological condition and to their family friends and carers.

## **Brain and Spinal Injury Charity (BASIC)**

554 Eccles New Road

Salford

M5 5AP

Tel: 0161 707 6441

[enquiries@basiccharity.org.uk](mailto:enquiries@basiccharity.org.uk)

<https://www.basiccharity.org.uk/>

The Brain and Spinal Injury Charity offers support to people recovering from acquired brain injury and spinal injury and their families.

## General advice

### NHS Choices

[www.nhs.uk](http://www.nhs.uk)

NHS non-emergency line: 111

Medical advice and information on NHS services



## Online support groups

Online communities are a great way for people to interact, share their stories and experiences and provide mutual support. They are also a great way for people to alleviate stress and health anxiety as people can realise they are not alone.

The Brain & Spine Foundation have set up a Facebook group for people affected by Chiari malformations. Search within Facebook for: **'Chiari Malformations Group - A Space For You'**.

We also have an online group on HealthUnlocked for people with any neurological condition to share their experiences in an anonymous and safe space. Find us at:

<https://healthunlocked.com/brain-spine-foundation>

## Further reading

The Brain & Spine Foundation produces a number of fact sheets that give more information on topics mentioned in this booklet: Brain and spine scans, and Hydrocephalus and shunts.

These publications are all freely available on our website:  
[www.brainandspine.org.uk](http://www.brainandspine.org.uk)

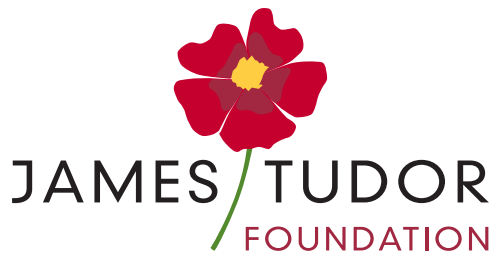
Booklets are also available in print, on request. Requests can be made through the website or the Brain & Spine Helpline: 0808 808 1000.

## References

Details of references used for this booklet can be requested by sending an email to [references@brainandspine.org.uk](mailto:references@brainandspine.org.uk)

## Thank you

We would like to thank everyone who contributed to this booklet, especially Andrew Brodbelt (Consultant Neurosurgeon), Simon Thompson (Consultant Nurse), Manjunath Prasad (Consultant Neurosurgeon), and our service users who provided feedback. We would also like to thank the James Tudor Foundation who supported the development of this booklet.



# Brain & Spine Foundation

Our mission is to improve the quality of life of people affected by neurological problems by providing expert information, support and education. We rely on donations to provide our services to anyone who needs us.

## How to donate

- Online: [www.brainandspine.org.uk/donate](http://www.brainandspine.org.uk/donate)
- By phone: 020 7793 5900
- By post: send a cheque to the address below

## Contact us

Brain & Spine Foundation

LG01 Lincoln House, Kennington Park, 1-3 Brixton Road,  
London SW9 6DE

Telephone (switchboard): 020 7793 5900

[info@brainandspine.org.uk](mailto:info@brainandspine.org.uk)

Helpline: 0808 808 1000

[helpline@brainandspine.org.uk](mailto:helpline@brainandspine.org.uk)

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