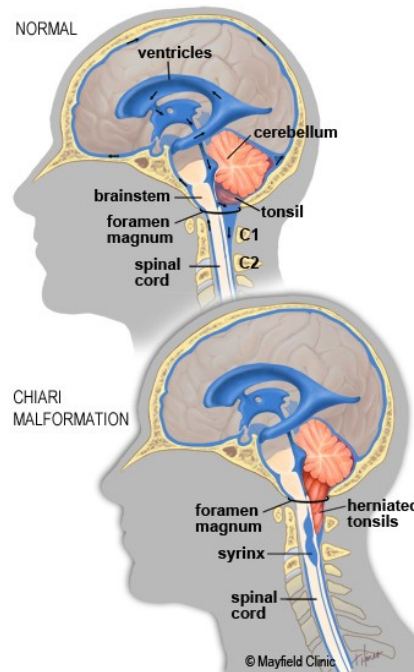


Understanding Arnold–Chiari Malformation

Arnold–Chiari malformation — information for patients

Your clinician has told you that you have, or may have, a condition called Arnold–Chiari malformation (often simply called a Chiari malformation). This leaflet explains what it is, what to expect, how it is treated, and what you can do to help yourself. Please bring it with you to your follow-up appointment.

What is Arnold–Chiari malformation?



In Arnold–Chiari malformation the lower part of the cerebellum (the tonsils) slips down through the opening at the base of the skull.

Source: Mayfield Clinic.

Arnold–Chiari malformation is a structural difference at the base of the skull. The space that holds the lower part of the brain — the cerebellum, which helps control balance — is a little small or crowded, so the lowest part of the cerebellum (the 'tonsils') slips down through the natural opening at the base of the skull. This can gently press on the brainstem and slow the normal flow of the fluid (cerebrospinal fluid, or CSF) that cushions the brain and spinal cord.

The most common type is called Chiari I. It is usually mild, and many people have it without any symptoms at all — it is often found by chance on a scan done for another reason. It is something you were almost always born with, and it tends to change very slowly, if at all.

Key idea: Arnold–Chiari malformation is a structural difference — it is not a tumour, a stroke, or a sign of anything sinister. Many people with a mild Chiari never need surgery, and those who do usually do very well.

What are the symptoms?

- **Headache** — at the back of the head, often brought on by coughing, sneezing, straining or laughing.
- **Dizziness** — unsteadiness, or a spinning feeling (vertigo), sometimes with blurred or jumpy vision.
- **Neck** — or shoulder pain.
- **Other** — less commonly, tingling, numbness or weakness in the arms or hands, or changes in swallowing or voice.

Many people with a mild Chiari have few or no symptoms. When symptoms do occur, they can come and go, and they are not always related to how much movement is seen on the scan.

How is it diagnosed?

Arnold–Chiari malformation is diagnosed with an MRI scan, which clearly shows the position of the cerebellum and the base of the skull. If a Chiari is confirmed, your clinician will usually arrange an MRI of the spine as well, to check for a fluid-filled space in the spinal cord called a syrinx. Sometimes a special 'flow' scan is done to see how the cushioning fluid is moving. There is no blood test for Chiari — the diagnosis is made from the scan together with your symptoms.

How is it treated?

Treatment is built up step by step, and most people need only the first one or two steps.

- **Step 1 — Watch and wait:** many people with mild symptoms need no treatment. Your clinician keeps an eye on things with check-ups and occasional scans, and suggests avoiding heavy straining that brings on headaches.
- **Step 2 — Symptom relief:** pain-relieving and nerve-pain medicines help headache and neck pain, and balance (vestibular) rehabilitation exercises with a physiotherapist help dizziness and unsteadiness.
- **Step 3 — Surgery:** if symptoms are severe or getting worse, or if a syrinx is found, an operation called posterior fossa decompression makes more room at the base of the skull and restores the normal fluid flow. Most people improve well afterwards.

Please contact us if: you develop new or worsening weakness, numbness or clumsiness in the arms or hands; difficulty swallowing or a change in your voice; problems with bladder or bowel control; a severe new headache; or fainting. These features are not typical of a mild Chiari and need prompt review.

Managing day to day

Where you can, avoid sudden heavy straining — support your head when you cough or sneeze, and avoid breath-holding when lifting. Gentle, regular activity is good for you. If you have been given balance exercises, do them regularly, as they make a real difference. Tell your clinician about any new symptoms between appointments.

What happens over the long term?

Most people with Chiari I do very well. Mild cases often stay stable for many years. When surgery is needed, it usually relieves the cough headache and stops a syrinx from getting worse, although some balance symptoms can take longer to settle — rehabilitation helps with these. Women with Chiari can usually have children safely; just let your maternity team know about your diagnosis so they can plan with you.

Reducing the impact of Chiari on your life

- Keep your follow-up appointments and scans so any change is picked up early.
- Support your head when you cough or sneeze, and avoid heavy straining and breath-holding.
- Do your balance and vestibular exercises if you have been given them.
- Tell family and close contacts about the warning symptoms listed above.
- If you also get migraines, ask your clinician about migraine treatment — it often helps the headaches too.

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