



**Down's Syndrome  
Association**

A Registered Charity No. 1061474

## Health Series



# Neck instability in people who have Down's syndrome



The  
Down Syndrome  
Medical Interest  
Group

A Down's Syndrome Association publication

---

## Our resources and Information Team are here to help

Please see our website for up-to-date information: [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)

If you would like to talk about the activities or where to start, then please get in touch with our helpline by calling 0333 1212 300 or by emailing us on [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk).

**Helpline Monday - Friday 10am-4pm | Telephone: 0333 1212 300**

---

### Information to help parents, professionals and people who have Down's syndrome:

- To make informed judgements about the risk of neck instability becoming a problem
- To recognise new, early warning signs that need further medical assessment
- To accompany DSA Easy Read 'Knowing about Neck Problems'

### Summary

Underlying neck instability is more common in people who have Down's syndrome than in the general population. This causes concern because although significant damage caused by neck instability is rare and most people have mild early warning signs, it can be devastating and result in paralysis and in extreme cases death.

Parents, carers and practitioners should be constantly aware of the warning signs (symptoms) which might indicate that a person who has Down's syndrome is at risk of neck instability.

If parents, carers or people who have Down's syndrome suspect any of the signs or symptoms listed below, (a), (b), the person may have a problem with neck instability and should be seen by a Doctor.

#### a) Warning symptoms

- Pain anywhere along the neck
- A stiff neck which doesn't get better quickly
- Unusual head posture ('wry neck' or torticollis)
- Alteration in the way a person walks so they may appear unsteady
- Deterioration in a person's ability to manipulate things with his/her hands

#### b) Poor neck control

Difficulty holding the head up, holding the head at an unusual angle, difficulty nodding or looking up and down and/or difficulty turning the head in certain directions.

Anyone with the above signs could have underlying neck instability and be at increased risk of neck dislocation. Minor impact involving the person with the symptoms may cause spinal damage (e.g. tripping up or a jolt).

Any parent, carer or sports coach with concerns about a person's neck control or any emerging warning signs before, during or after sport sessions, must refer the person for medical assessment.

Neck instability is a highly specialised area of medical practice. The Doctor may refer the person to a specialist centre.

For people who have Down's syndrome who have no symptoms (the majority), there are no reliable tests that can identify those at increased risk of neck instability.

Safe sporting practices, such as appropriate supervision, are essential.

For people who do not have symptoms of neck instability, there should be no additional anxiety about them taking part in non-contact, low impact sporting activities.

Some sports such as trampolining, diving, contact sports and high jump have higher risk for neck injury in all participants (people who do not have Down's syndrome as well as people who do).

Ask the sports provider or National Governing Body of the sport about their safe sporting practices and eligibility criteria.

Based on current information, it is sensible advice for adults who have Down's syndrome to travel in cars with headrests and for children to travel in car seats with neck support.

People who have Down's syndrome who are unconscious are potentially at risk for neck damage. Ambulance personnel and healthcare professionals, including anaesthetists, know how to take special care of the neck in these circumstances.

### Any signs, symptoms, or loss of skills?

#### No signs or symptoms

- Take part in exercise and sports.
- Follow safe practices in exercise and sports activities.
- Look out for warning signs.

#### Symptoms

- See a doctor.
- Do not take part in sports.
- Even a minor impact, such as tripping up, may cause damage.

## Neck instability

Neck instability refers to excessive movement of the vertebra in the neck such that they may slip from their usual position potentially leading to dislocation and a high risk of spinal damage. This can happen in the general population, and although it is more common in people who have Down's syndrome, dislocation is still rare with only around 1% of people who have Down's syndrome requiring surgical treatment for this condition.

Damage to the spinal cord in the neck can happen to anyone and can cause a range of problems from mild pain or a stiff neck to paralysis. This can occur suddenly as a result

of a sudden shift in neck joints caused by trauma, such as whiplash injury from a car accident, for example, or more gradually if there is regular pressure from unusual movement of neck vertebrae.

Fortunately, most people who have significant underlying problems with their neck develop mild warning symptoms singling them out as having increased risk before long term spinal damage occurs. Symptoms can appear gradually and changes in the person may be quite subtle. Therefore, it is vital there is a high level of awareness amongst parents, supporters and professionals about the symptoms and what to do if they are present in a person who has Down's syndrome.

Problems with neck instability can occur at any stage of life and there are no reliable screening tests which can identify those at increased risk, before symptoms occur. This is why it is really important to know what to look out for. If there is any evidence that a person who has Down's syndrome has new problems with neck control and/or has developed any of the symptoms [detailed in part the first part of this resource](#), you need to take the person to see a doctor.

If symptoms come on suddenly, an urgent appointment is needed.

Where symptoms are present and there is no obvious alternative explanation for them, they may be related to neck instability causing nerve damage and the Doctor should make a referral for an urgent neurological or specialist examination. If there is any doubt on the part of the doctor about the presence of symptoms, they should err on the side of caution and still make an urgent referral for specialist examination.

If, after further assessment, there is still no obvious alternative explanation for these symptoms an X-ray, along with specialist referral to either an expert orthopaedic surgeon or a spinal neuro-surgeon, may need to be arranged.

Some people with symptoms will need corrective spinal surgery. Case reviews show that most people requiring this surgery have had symptoms of neck instability, warning of problems, often weeks before. As with most conditions, the earlier the treatment the better the outcome.

### **Where there are no symptoms**

People who have Down's syndrome who do not have any of the warning signs/symptoms (they are asymptomatic) should be encouraged to take part in recreational exercise and sporting activities for the same benefits as anyone else in the population.

**If a person does not have any symptoms of neck instability, it does not mean there is no risk. It means they are not at increased risk when compared to other people who have Down's syndrome and they could develop problems in the future.**

## Questions and answers

### What is Neck Instability?

In people who have Down's syndrome the ligaments which stabilise the joints tend to be particularly lax and this, combined with low muscle tone, results in an unusually wide range of movement at some joints. As well as affecting limb joints, for instance hips and ankles, laxity can also affect the complex set of joints between the head and upper neck vertebrae. One of the functions of the vertebrae in the spine is to protect the spinal cord, a thick bundle of nerves, which runs inside the spine from the base of the brain to the pelvis. The main concern about neck instability is that this increases the risk of spinal cord damage, especially if vertebrae get misaligned.

The greatest potential for excess movement of one vertebra on its neighbour and possible misalignment is right at the top of the spinal column, at the atlanto-axial joint. The atlanto-axial joint lies between the top first vertebra (atlas or C1) which supports the base of the skull, and the second vertebra (axis or C2), or, less often, at the atlanto-occipital joint between the atlas vertebra and the base of the skull (see diagram) Fig 1. There is movement at these joints whenever you nod or shake your head.

The axis vertebra (C2) has a central bony spur known as the odontoid peg which passes upwards from the body of the axis into the front of the spinal canal (carrying the spinal cord) in the atlas or C1. If the atlas moves too much on the axis, the odontoid peg is well-placed to damage the spinal cord. (see diagram)

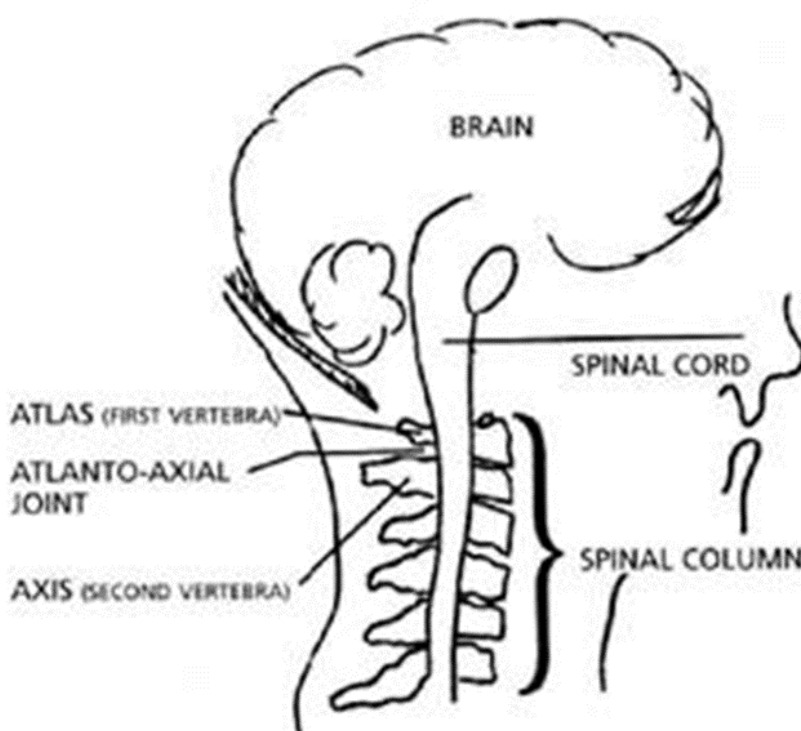
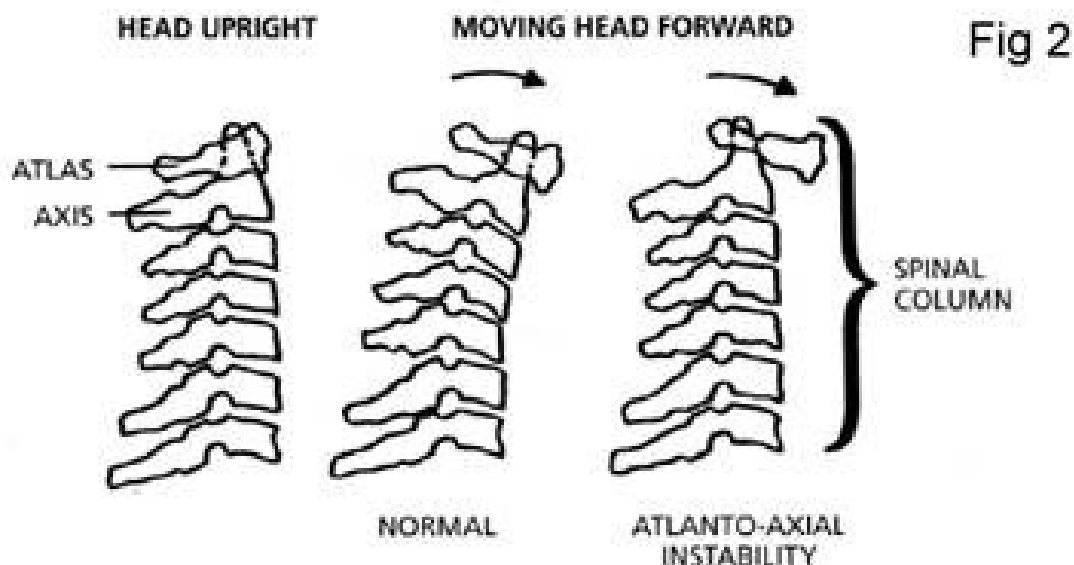


Fig 1

Fig 2 shows, in the middle picture, that when the atlas and axis are firmly bound to each other, both move together when the neck bends forward. The diagram on the right shows the situation when the ligaments binding the joint are slack. Here the atlas moves forward but fails to carry the axis with it thus narrowing the spinal canal through which the spinal cord is passing. This is sometimes referred to as atlantoaxial instability or AAI. Instability and movement can also occur between the skull and first cervical vertebra so the terms neck instability, craniovertebral instability (CVI) or cervical spine instability (CSI) are now more commonly used.



### Can routine neck X-rays help predict risk in people with no symptoms?

Routine neck X-rays of people who have Down's syndrome to try to predict who is at risk of neck instability are not helpful. Neck X-rays from the same person who has Down's syndrome at different times can score differently; very few of the people with X-rays suggestive of neck instability ever develop any symptoms of spinal cord damage, and a normal X-ray does not mean problems due to spinal cord damage could not develop. Neck X-ray before taking part in vigorous activity has been recommended in the past (and still is in parts of the world and by Special Olympics for some sports). This advice was changed in UK in 1995 when research concluded that neck X-rays did not reliably predict risk to the spinal cord.

### What problems can be caused by neck instability?

Damage to the spinal cord in the neck can happen to anyone (people who have Down's syndrome and people who don't) and can cause a range of problems from mild pain or a stiff neck to paralysis in extreme cases. This can either happen suddenly as a result of a sudden shift within the joint (for example whiplash causing dislocation), or more gradually because of day-to-day pressure on the spinal cord as the neck moves. Gradual onset of symptoms can be due to long-term neck instability, bony abnormalities or, in adults, degenerative arthritic changes (which are more common in adults who have Down's syndrome).



## What treatment is available?

If significant instability or dislocation is confirmed, and is thought to be causing problems, an operation can be done to stabilise the upper part of the spinal column and decompress any trapped nerves. The operation is delicate and is not without risk, particularly in younger children. Surgery should be performed at a specialist centre by an experienced specialist in this field. In experienced hands, increasingly good outcomes are being reported. Successful surgery is achieved in up to 90% of cases.

Some children with neck instability require a period of traction to realign the joints and reduce pressure on the spinal cord before proceeding to surgical fusion. Keeping the bones immobilized after surgery whilst they heal can be difficult in children and so surgeons may use a 'halo-body jacket' to provide external support for the neck for a few weeks after surgery.

## Should people who have Down's syndrome be restricted from taking part in some sports?

The vast majority of people who have Down's syndrome do not have symptoms of neck instability. There is no evidence that jumping on a mini-trampoline, early stages of horse riding or forward rolls carry more risk for a child who has Down's syndrome (who does not have symptoms) than for any of their peers.

The very few neck injuries which have been recorded in people who have Down's syndrome whilst taking part in sporting activities would have been just as likely to occur in the general population as a result of a similar accident or fall on to their head.

Participating in exercise and sport can arguably increase muscle strength in the neck and have a protective element. On the other hand, people who have Down's syndrome may be more at risk in some activities because they tend to be less well coordinated. These factors may well balance each other out. Generally, there should be no justification for additional anxiety when people who have Down's syndrome are taking part in non-contact, low impact sporting activities.

Some sports such as trampolining, diving, contact sports (such as rugby) and high jump are known to have a higher risk for neck injury in all participants. Currently there is no established evidence that people who have Down's syndrome have had more neck injuries during their participation in such sports than any other group of people.

However, it is sensible to be especially vigilant about ensuring that there is no concern about neck control or any emerging warning signs before, during or after sport sessions. Parents, carers and coaches need to be attentive about noting any concerning signs and referring on for medical assessment if there is any doubt, at any time. As with all organised sporting activities, safe sporting practices such as appropriate supervision are essential.

Before entering any sporting competition or session it would be advisable to check with the provider or National Governing Body of the sport to find out what their eligibility criteria is. Some sports and competitions, such as British Gymnastics and Special Olympics, require medical clearance before participation.

## **What about participation in recreational activities that are not regulated by sporting bodies?**

Parents and carers should be aware that standards of supervision and safety may not be comparable with those of regulated sports providers. We are aware of sensible, safe adjustments having been made in individual circumstances, in discussion with parents. It would be worth checking with the provider what their standards of supervision and safety are before participating in the recreational activity.

## **What about other activities that have increased risk of neck injury?**

Because of their tendency to neck instability, people who have Down's syndrome may have an increased risk of whiplash injury following road traffic accidents. We are not sure about this, but at present, it is sensible to recommend that properly positioned headrests are always in place when a person who has Down's syndrome is travelling. Children who have Down's syndrome should use properly fitted car seats with good neck supports when travelling.

After a road traffic accident it is important to alert anyone involved at the scene to the fact that a person who has Down's syndrome may be more likely to have sustained a neck injury than another person.

Doctors need to take special care about positioning the neck during surgery requiring a general anaesthetic. If the anaesthetist and recovery room staff are alerted beforehand to the fact that the person has Down's syndrome, they are trained to manage this and the risk of undergoing an anaesthetic is minimal.

Further information can be found at the website of the Down Syndrome Medical Interest Group UK & Ireland:

<https://www.dsmiq.org.uk/wp-content/uploads/2015/09/CSI-revision-final-2012.pdf>

## **Life for everyone is not without risk**

It is for the individual to decide what risks are acceptable for their children or for themselves. There must be a balance between encouraging people who have Down's syndrome to take part in and enjoy exercise whilst identifying those few individuals who may be at increased risk for dislocation so that timely investigation and if necessary, surgical intervention, can be considered.




# DSA Easy read 'Knowing about neck problems'

This information is available as a separate resource, [full size, from the DSA website](#).

Down's Syndrome Association  
A Registered Charity No. 1051191

Health Series



## Knowing about neck problems

Easy Read

A Down's Syndrome Association publication

Easy Read Health Series www.downs-syndrome.org.uk

### About this leaflet

Down's Syndrome Association This leaflet is made by the Down's Syndrome Association

Info It is in **Easy Read**.

**Easy Read** means easy words with pictures to help everyone understand.

We ask **Having a Voice groups** to help us make Easy Read Information

**Having a Voice groups** are groups of people with Down's syndrome. They help people have their say.

Info Having a Voice groups make sure the Easy Read information is easy to understand.

You can find out more about **Having a Voice** on the Down's Syndrome Association website.

A Down's Syndrome Association publication 2

Easy Read Health Series www.downs-syndrome.org.uk

### What are neck problems?



Neck

Neck problems happen because of a health condition called **neck instability**.



It is **important** to know about neck instability.

Neck instability can be **serious**.



Neck

**Some people** with Down's syndrome have neck instability.




Remember - **Not everyone** with Down's syndrome has neck instability.

Only **some people** will have neck instability.


A Down's Syndrome Association publication 3

Easy Read Health Series www.downs-syndrome.org.uk

### What are the signs/symptoms of neck instability?



If you have neck instability, **you may have pain in your neck**.




If you have neck instability, **you may have a stiff neck**.


A Down's Syndrome Association publication 4

Easy Read Health Series www.downs-syndrome.org.uk


**What are the signs/symptoms of neck instability?**




If you have neck instability, **you may have problems holding your head up straight.**



If you have neck instability, **you may have problems nodding your head.**



If you have neck instability, **you may have problems walking.**



If you have neck instability, **you may have problems using your hands.**

---

A Down's Syndrome Association publication 5

Easy Read Health Series www.downs-syndrome.org.uk

**What to do if you have these signs/symptoms instability?**



Go and **see a doctor** as soon as possible. You can **ask someone** you trust to **help** with this.



**Tell the doctor** about your neck problems.



The doctor will **ask you** some **questions**.



Tell the doctor that **some people with Down's syndrome** have problems with **their neck**.


**This is called neck instability.**

---

A Down's Syndrome Association publication 7

Easy Read Health Series www.downs-syndrome.org.uk


**How will the doctor check your neck?**




The doctor will ask you to **hold your head up and look in front.**



The doctor will ask you to **look up.**



The doctor will ask you to **look down.**




The doctor will ask you to **look from side to side.**

---

A Down's Syndrome Association publication 8


Easy Read Health Series www.downs-syndrome.org.uk

**What will happen next?**




If the doctor thinks you are **ok**, they will **tell you to go home**.


**You do not need to do anything.**



If the doctor **thinks you have neck instability**, they will send you to **see a doctor who knows about neck problems**.



You **may** need to have an **X-Ray** at the hospital.







You **may** need to have an **operation** on your neck.

---

A Down's Syndrome Association publication 9

Easy Read Health Series www.downs-syndrome.org.uk

### What will happen next?

If the doctor thinks you are **ok**, they will **tell you to go home**.

**You do not need to do anything.**

If the doctor **thinks you have neck instability**, they will send you to **see a doctor who knows about neck problems**.


You **may** need to have an **X-Ray** at the hospital.



You **may** need to have an **operation** on your neck.

A Down's Syndrome Association publication 9

Easy Read Health Series www.downs-syndrome.org.uk

### What will happen next?



You **may** need to stay in **hospital** for a while until you **get better**.

After the operation your neck **should be ok**.

If after reading this easy read guide **you think you have neck problems**, **tell someone you trust straight away**.

A Down's Syndrome Association publication 10

Easy Read Health Series www.downs-syndrome.org.uk

### How we can help

The Down's Syndrome Association has a helpline.





You can call us on **0333 1212 300**.

We are happy to answer your questions.

The helpline is open Monday to Friday from 10am until 4pm.

You can also email us at **info@downs-syndrome.org.uk**

You can write to us too.

Our address is:

Langdon Down Centre  
2a Langdon Park  
Teddington  
Middlesex  
TW11 9PS

A Down's Syndrome Association publication 11

Easy Read Health Series www.downs-syndrome.org.uk

The Down's Syndrome Association provides information and support on all aspects of living with Down's syndrome. We also work to champion the rights of people with Down's syndrome, by campaigning for change and challenging discrimination. A wide range of Down's Syndrome Association publications can be downloaded free of charge from our website.

#### Contact us

**Down's Syndrome Association**  
Langdon Down Centre  
2a Langdon Park  
Teddington  
Middlesex  
TW11 9PS

t. 0333 1212 300  
e. info@downs-syndrome.org.uk  
w. www.downs-syndrome.org.uk

Wales  
e. wales@downs-syndrome.org.uk

Northern Ireland  
e. enquiriesni@downs-syndrome.org.uk



  
A Registered Charity No. 1057054

WorkFit® is a registered trade mark of the Down's Syndrome Association. Photographs courtesy of DSA members and supporters, kikazani on [www.kikabay.com](http://www.kikabay.com) and SeeAbility






© Down's Syndrome Association 2017

A Down's Syndrome Association publication 12

The Down's Syndrome Association provides information and support on all aspects of living with Down's syndrome.

We also work to champion the rights of people with Down's syndrome, by campaigning for change and challenging discrimination.

A wide range of Down's Syndrome Association publications can be downloaded free of charge from our website.

## Contact us

### Down's Syndrome Association

#### National Office

Langdon Down Centre,  
2a Langdon Park, Teddington,  
Middlesex, TW11 9PS

t. 0333 1212 300

f. 020 8614 5127

e. [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk)

w. [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)

#### Wales

t. 0333 1212 300

e. [wales@downs-syndrome.org.uk](mailto:wales@downs-syndrome.org.uk)

#### Northern Ireland

Unit 2, Marlborough House,  
348 Lisburn Road,  
Belfast BT9 6GH

t. 02890 665260

f. 02890 667674

e. [enquiriesni@downs-syndrome.org.uk](mailto:enquiriesni@downs-syndrome.org.uk)



WorkFit® is a registered trade mark of the Down's Syndrome Association. Photographs courtesy of DSA members and supporters.



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



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



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



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



© Down's Syndrome Association 2020