

Down's Syndrome and Neck Instability

We acknowledge that every person with Down's syndrome is unique.

Neck instability, specifically Atlanto-Axial Instability (AAI) is more common in people with Down's syndrome than in the general population. Although serious injury is rare and early warning signs are usually mild, the consequences can be severe, including paralysis or, in extreme cases, death.

Individuals with Down's syndrome, parents, guardians and carers should remain alert to any warning signs that may indicate a risk.

Risk factors:

If individuals with Down's syndrome, parents, guardians or carers suspect any of the signs or symptoms listed below, the individual may have a problem with neck instability and should be seen by a medical practitioner.

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 their hands
- Loss of sensation
- Pins and needles

Poor neck control signs:

- Difficulty holding the head up
- Holding the head at an unusual angle
- Difficulty nodding or looking up and down
- Difficulty turning the head in certain directions

Why this matters at this facility:

Seeking advice:

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

If individuals with Down's syndrome, parents, guardians, or carers have concerns about neck control or any emerging warning signs or symptoms before, during or after activity sessions, medical assessment must be sought.

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).

We would therefore like to understand your specific needs, whether you have received any form of screening and how we can best support you to enjoy using our facilities.

Please note neck instability is a highly specialised area of medical practice. Our staff are not experts and therefore will recommend you seek advice from a general practitioner, orthopaedic or paediatric consultant, school medical officer/doctor, or chartered physiotherapist to ensure you have a safe and enjoyable time at our facilities in the future.

British Gymnastics – screening information

<https://www.british-gymnastics.org/technical-pages/disability-gymnastics-technical-resources>

Down's Syndrome Association – General information on neck instability

<https://www.downs-syndrome.org.uk/about-downs-syndrome/health-and-wellbeing/bones-and-muscles/>

