

Health Issues in Prader-Willi Syndrome

Muscle tone

Poor muscle tone (known as hypotonia) means that babies appear floppy after birth. Muscle tone generally improves with age, however there are therapies available which aim to improve strength and increase lean body mass.

Eating Behaviour & Health

Some individuals with Prader-Willi syndrome may **experience feeding problems** during infancy due to reduced ability to suck. Special nipples and enteral tubes can be used to improve feeding so that the infant can receive the necessary nutrition.

Hyperphagia (excessive eating) starts between the ages of one and four. If this is not managed, it can **lead to obesity**. Regular exercise, close supervision and a calorie-controlled diet with advice from a dietician can be implemented to prevent obesity.

Hyperphagia poses some health risks;

- As individuals with Prader-Willi syndrome are less sensitive to pain and can consume larger amounts of food before they vomit it back, they are more likely to eat inedible objects. This therefore results in a higher likelihood of food poisoning and choking.
- Gastric ruptures can be a consequence of eating a large amount of food in a short amount of time. This is where the stomach splits open, allowing bacteria to spread through the body causing a life-threatening infection. Thus, it is important to be aware of and monitor eating habits.
- Individuals with Prader-Willi syndrome may experience leg ulcers and oedema (fluid retention) as a result of excess weight.
- Obesity may put some individuals at higher risk of developing diabetes.

Growth & Sexual Development

Due to low levels of human growth hormone (HGH), children with Prader-Willi syndrome are likely to be shorter than peers of the same age. Artificial growth hormone can be prescribed in order to replace the lack of HGH and promote growth. This has the added benefits of improving body composition and promoting activity.

Hypogonadism is where the sexual reproductive systems are underactive (testes in males and ovaries in females). This means that children with Prader-Willi syndrome will undergo puberty later than usual and

may not reach full sexual development. Artificial sex hormones can be prescribed in order to promote sexual development at puberty.

Hypoplasia is where the sexual reproductive systems are not fully developed. In boys, the penis may be smaller and in some cases one or both of their testes may still be in their stomach. This may be resolved with time, however hormonal and surgical options are available.

Scoliosis

Scoliosis is where the spine curves abnormally and is present in 40-80% of individuals with Prader-Willi syndrome. The age of onset and severity of the curvature varies greatly; therefore it is important that it is regularly monitored in children and adults.

Skin Picking

[Skin picking](#) is common in individuals and found in around four out of five children. It can range from scratching, pulling at the skin or using tools such as tweezers to pierce it. This can result in sores, infection and scars. There are some medications that can be used to decrease the amount that an individual engages in skin picking.

Dental Problems

The risk of tooth decay is higher in individuals with Prader-Willi syndrome as there is a reduced production of saliva.

Joint Problems

Hip dysplasia (deformation or misalignment of the hip joint) is present amongst around 10-20% of individuals with Prader-Willi syndrome.

Mental Health

Mental health problems are fairly common over the lifespan of people with Prader-Willi syndrome; major depression is more common in individuals with a [deletion genotype](#) and psychosis, especially bipolar disorder, is more common in individuals with the uniparental disomy subtype. These conditions can be controlled by medication. Help should be sought if low mood persists for a prolonged period or if a person reports hallucinations or delusions.

Links:

For information on how to detect pain in children who have a severe intellectual disability and/or communication difficulties, please [click here](#).

For more information about healthcare in Prader-Willi syndrome, visit the [Prader-Willi Syndrome Association](#) page.

For more information on growth hormone therapy, [click here](#).

For support and advice on weight management for individuals with Prader-Willi syndrome, [click here](#).