

Health Issues in Lowe Syndrome

Parents and carers have told us that being presented with a long list of health difficulties can be daunting. However, they also reported that having this list available can be reassuring and can help them to watch out for early warning signs. The key message here is that children with Lowe syndrome may be prone to some health difficulties; however, with appropriate support and regular health checks with an informed professional, a lot can be done to reduce the impact on an individual's well-being.

There are a number of theories suggesting that the deficits in executive function in intellectual disabilities are contributing causes of particular behavioural characteristics associated with Lowe syndrome; however, it is important to remember that it is likely that executive function is not the sole cause of these behaviours. For example, repetitive behaviours may also occur due to a need for sensory stimulation or the experience of anxiety; challenging behaviours may occur due to pain, the person's learning history, communication impairments, anxiety or frustration, amongst other things. It is important to take into consideration a number of factors when considering the causes of any behaviour.

Information on the health difficulties associated with Lowe syndrome are presented in the following sections:

- [Eyes](#)
- [Kidneys](#)
- [Bones, Joints and Muscles](#)
- [Epilepsy](#)
- [Growth and Sexual Development](#)
- [Other](#)

If you care for an individual with Lowe syndrome, you are likely to be in need of contacting a number of professionals to help with any health difficulties that may arise. These include: a GP, a physiotherapist, an ophthalmologist (eye specialist), a kidney specialist, an educational psychologist, an occupational therapist and a speech and language therapist, amongst others.

Most males with Lowe syndrome do not live past age 40 years of age; however, some individuals who are in their 50's have taken part in research studies. In older individuals, death has been related to progressive renal failure or scoliosis. Death from dehydration, pneumonia, and infections occurs at all ages. However, this is only the predicted lifespan according to the current level of medical knowledge and forms of interventions- hopefully, as knowledge increases, the predicted lifespan of individuals with Lowe syndrome will also increase.

If you are concerned that any of the health issues associated with Lowe syndrome are affecting the individual with Lowe syndrome that you know, please contact a medical professional for advice.

It is always important to ensure that any behaviours that challenge observed are not underpinned by pain.

You can find more information on the health issues associated with Lowe syndrome in the [Lowe Syndrome Trust handbook](#).