

Muscle weakness

- Slowly progressive weakness in the arms and legs may develop near the shoulders, and later in the hips. This may develop many years after initial symptoms. Weakness is usually mild but it can worsen and affect mobility, making activities like climbing stairs and slopes difficult.
- Staying as active as possible is important. Physiotherapists can assess mobility and prescribe exercises to maintain muscle strength, improve range of motion (ROM), posture, and core stability. These can help with reducing muscle stiffness and managing pain. A physiotherapist can help with gait re-education and prescribe a walking aid if necessary.
- For wheelchair users, a physiotherapist can prescribe chair-based exercises and assist in transitioning to a standing

position using gym equipment such as a tilt table. This helps support weight-bearing on the feet and maintain ankle ROM.

- As respiratory infection can be common, a physiotherapist can teach breathing exercises to maintain lung function.

Anaesthetic precautions

- The surgical team and anaesthetist should be made aware of an OPMD diagnosis to allow appropriate pre-operative assessment and post-operative monitoring. Individuals may be more sensitive to anaesthetic and can take longer to wake up from surgery.
- Local anaesthetics and nitrous oxide are safe for minor dental procedures.



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**MUSCULAR
DYSTROPHY
UK**

Alert card
**Oculopharyngeal
muscular dystrophy (OPMD)**

Name..... Date of birth.....

NHS/CHI/H&C number

If presenting at A&E, contact the specialist team at:
.....

as soon as possible on:

For information and support, contact us on our helpline
0800 652 6352 or email info@musculardystrophyuk.org

Oculopharyngeal muscular dystrophy (OPMD)

OPMD is a genetic condition that causes progressive muscle weakness, primarily affecting the muscles of the eyelids and throat. Over time, the condition may also cause weakness in other muscles. Symptoms typically begin after the age of 40.

Initial symptoms are either ptosis (drooping eyelids) and/or dysphagia (swallowing difficulties). These symptoms usually worsen but can sometimes be improved through management and surgical procedures, though the benefits are often temporary and may need to be repeated.

Ptosis

- As the eyelids droop, the eyelid may begin to cover the eyes and reduce vision. Drooping is caused by weakening in the muscle of the upper eyelid. Reduced vision could cause problems with balance.
- People with OPMD will often tilt their head backwards slightly or overuse their forehead muscles to see clearly. Some people could also experience double vision.
- Different surgical approaches are available and should be discussed with an ophthalmologist or oculoplastic surgeon. The Lundie loop, a device fitted to glasses, is sometimes offered as an alternative for people that do not want to have a surgical procedure.

Dysphagia

- Swallowing difficulties are common and progress slowly. Initial signs may include coughing and choking while eating or drinking and feeling that food is sticking in the throat. The ability to drink liquids and swallow saliva can be affected.
- Referral to a speech and language therapist and a dietitian are essential. Strategies to avoid complications include taking time with meals and avoiding talking while eating. Modification of diet, textures, and use of nutritional supplements may also be necessary.
- As swallowing difficulties progress, the likelihood of food and drink travelling into the lungs increases, leading to aspiration pneumonia. This will require assessment and antibiotic treatment.

- Minor surgery may be considered to ease dysphagia and involves stretching the top of the oesophagus. More intrusive but potentially longer lasting treatment is botulinum toxin injections and/or a surgical incision in the muscle just above the oesophagus. These procedures carry risks and are not helpful for everyone. Careful consideration with the treating doctor and speech and language therapist is required.
- If swallowing difficulties cannot be managed, alternative methods of feeding can be considered such as a feeding tube. This allows food and liquid to be received directly into the stomach. The individual can continue to eat and drink by mouth as well.
- OPMD can also affect clarity and volume of speech. A speech and language therapist can provide strategies to help keep speech as clear as possible.