

- Swallowing difficulties can cause unplanned weight loss, malnutrition, and dehydration. Regular choking episodes can be very dangerous. In severe cases, nutritional supplements or a feeding tube (gastrostomy) may be prescribed.
- Speech and ability to chew is usually not affected.

Respiratory

- Some weakness in the respiratory muscles is likely and should be monitored, but this usually does not require medical intervention.
- A weakened cough is likely, increasing the risk of chest infections and blocked airways. Techniques such as chest physiotherapy and breath stacking can help clear airway secretions.

Medication and anaesthetic precautions

- It is essential that the anaesthetist is aware of the diagnosis of IBM to allow appropriate pre-operative assessment and post-operative monitoring. Individuals may take longer to wake up after surgery.
- Local anaesthetics and nitrous oxide are safe e.g. for minor dental procedures.
- Statins are usually well tolerated but caution is needed at high doses due to potential muscle-related side effects that can progress existing muscle weakness.
- Immunosuppression does not help most individuals living with IBM.

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**MUSCULAR
DYSTROPHY
UK**

Alert card

Inclusion body myositis (IBM)

Name Date of birth

NHS/CHI/H&C number

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

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as soon as possible on:

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

Inclusion body myositis (IBM)

IBM is a progressive condition causing muscle weakness, wasting, and inflammation. Most people living with IBM experience slow weakening of the thigh muscles and forearm muscles first. Less frequent initial symptoms may include swallowing difficulties or weakness below the knee.

IBM typically starts in individuals aged over 50 and is considered sporadic, meaning it is not inherited from family.

IBM does not affect the heart, bladder, bowel, or brain.

Muscle weakness

- Muscle weakness can impact walking and make using stairs difficult. It also leads to difficulty rising out of a low chair or standing up from any low surface. Weakness below the knee can lead to difficulty lifting the feet up, known as footdrop.
- Muscle weakness tends to be asymmetrical, so one side of the body will be weaker. All affected muscles will appear thinner, and this is most noticeable at the front of the thighs.
- Hand weakness affects dexterity and tasks like writing clearly, using cutlery, fastening buttons, or picking up small objects will become difficult over time.

Mobility and falls

- Staying active is important and specialist clinics can provide advice on healthy activities and formal exercises. Regular activity and exercise can help maintain stronger muscles. Walking aids can be helpful, and physiotherapists can advise on the most suitable aid at each stage of the condition.
- Falls are common, especially on rough ground, stairs, or when turning, as the knee can give way. It may be difficult or impossible to get up independently, and assistance may be needed. Check for injuries and ask before helping them up. Minimisation of fall risks in all environments is necessary.
- When managing a fracture, consider the individual's muscle wasting condition and mobility.

Swallowing difficulties

- Many individuals with IBM experience swallowing difficulties (dysphagia) usually affecting the throat muscles. Signs include coughing and choking while eating or drinking and a feeling of food sticking in the throat. On rare occasions, the first sign of dysphagia might be a chest infection or aspiration pneumonia, which is caused by food or saliva entering the lungs.
- Strategies to avoid complications include eating slowly and avoiding talking while eating. Modification of diet and textures may be necessary – individuals may avoid very solid, dry, or crumbly foods and foods, such as bread, that can become very sticky when chewed. It can be difficult to swallow pills, so alternative forms of medication may be needed.