

INCLUSION BODY MYOSITIS

Inclusion Body Myositis (IBM) is a non-hereditary inflammatory and degenerative muscle disease which does not tend to respond to conventional immune treatment.

PREVALENCE: 50 per million in those over the age of 50

AGE OF DIAGNOSIS: over 45 years of age

LIFE EXPECTANCY: average life expectancy

The cause of **Inclusion Body Myositis (IBM)** remains unclear. There is ongoing debate as to whether the muscle weakness is caused primarily by the body's own immune attack on the muscles, or from a degenerative process of the muscles.

IBM causes slowly progressive muscle weakness. Specific muscle groups are affected, including the deep finger flexors (affecting hand grip) and the quadriceps (weakening stability of the knees), as well as the muscles involved with lifting the ankles (causing foot drop). Swallowing can also become affected.

The ability to walk is often maintained with walking aids on flat ground, but people tend to lose the ability to walk over 10-15 years.

People with IBM often fall over easily because of weakness in the knee extensors, with the knees easily buckling, curbs and stairs will become difficult to negotiate. They also find rising from chairs increasingly difficult. They often require assistance to get back up if they fall over. Getting dressed, showering and even eating can become increasingly difficult with the progressive weakness.

A minority of people with IBM also have significant muscle pain and fatigue.

Currently there is no proven disease-modifying treatment for people with IBM. However, intravenous

immunoglobulin is sometimes used for those with swallowing difficulty, and immune treatments are sometimes trialled at the early stages of the disease.

Regular exercises are encouraged, and need to be tailored to the changing level of the person's ability. There is suggestion that exercise may delay the progression of weakness.

People with IBM should also be monitored for sleep-disordered breathing, common in this group, and a sleep study may be warranted for further investigation.

Planning ahead for services & equipment is very important, to help maintain a person's independence & quality of life

A speech pathologist review is warranted for those with swallowing difficulty.

Ongoing research is trying to further understand the cause of IBM, and ways to delay or reverse the muscle wasting.

Psychological issues need to be addressed as they grapple with the loss of independence and increased reliance on others such as family, friends or paid carers.

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Families and individuals affected by chronic conditions, including those that may involve numerous visits to hospitals for treatment, benefit most when empowered to have control over their life choices. Through seeking information about what is available, people will be empowered to make the right decisions to meet their goals. Despite the challenges a person with IBM faces, there are many opportunities available to support people to live fulfilled and productive lives. Goal setting and positive attitudes contribute to achieving success in many facets of life.

It is important that service provision is centered around quality of life outcomes & meets the needs of the individual

CONSIDERATIONS FOR PLANNING SHOULD INCLUDE BUT ARE NOT LIMITED TO THE FOLLOWING:

- A consistent General Practitioner (GP)
- Specialists for monitoring and medical care planning eg. neurologist, rheumatologist, respiratory physicians
- Support coordination for complex care needs
- Physiotherapy to tailor a suitable exercise regimen for home exercise eg. hydrotherapy
- Occupational therapy eg. to increase independence, equipment assessment
- Assistive technology eg. scooter, manual wheelchair
- Orthotics eg. leg splints for night time and ankle-foot orthoses (AFO's)
- Speech pathologist review for swallowing problems and recommendation on food intake
- Nutrition support eg. dietician, supplements
- Opportunities to socialise and be away from home eg. support groups, involvement with a myositis association, accessible travel
- Vehicle modifications/transport eg. taxis to and from work and the community, occupational driver's assessment
- Comfort/sleeping eg. air pressure relieving mattress
- Adapted utensils and recreation equipment
- Professional psychological support eg. counsellor, clinical psychologist
- Future goal planning eg. independent living, study, work choices
- Financial entitlements eg. Centrelink, Medicare, Companion Card

USEFUL RESOURCES

MDNSW www.mdnsw.org.au

MDNSW NDIS Toolkit www.mdnsw.org.au/our-services/support-coordination-your-choice/ndis-faqs

The Loop - Your Neuromuscular Resource Hub www.theloopcommunity.org