Inclusion Body Myositis (IBM)

Including 2 related types:

- IBM sub 1
- IBM sub 2

Processing a new diagnosis

A diagnosis of IBM can be a huge shock for yourself, family members and friends. It is normal to feel an overwhelming mix of grief, confusion, anxiety, loneliness and helplessness as your life has been forever changed. Everyone will have different ways of getting through this time but it's important to know that help and support are available for you and your loved ones. Hear advice on processing your diagnosis from a community member with shared experience.

The video is available at **https://youtu.be/A9XM71knDVw.**

Getting help processing a new diagnosis

There are a number of ways you can seek support as you process a new diagnosis:

- A **psychologist** is a university-qualified health professional who can help you talk about your thoughts and feelings to understand and cope with the challenges you and your family are facing.
- A **counsellor** is a trained professional who can help you talk about and work through problems.
- A **social worker** can provide information and support to people experiencing a range of issues including family problems, anxiety, depression, crisis and trauma.
- A **genetic counsellor** can help you understand how DM is inherited and whether there are any implications for other members of your family. Your specialist will be able to advise whether a genetic counsellor is required.
- Your **state or territory neuromuscular organisation** can provide support, advice and information about living with IBM.
- Your GP can talk to you about a **mental health plan** and how you can use this to help you access the support and services you need.
- Other people and families living with IBM have also experienced the emotional rollercoaster that comes with a diagnosis of IBM and are able to understand exactly how you're feeling. You are not alone. Connect with other people and families living with IBM in **The Loop Community**.

How to talk to others about your diagnosis

Having a conversation with a loved one about a diagnosis of IBM is not easy. In fact, it will probably be one of the hardest conversations you will have. But, like all difficult conversations, it is important and necessary.

There are many reasons why people may not want to have this conversation, mostly centred on wanting to protect their loved ones and themselves.

But avoiding the topic is not helpful. People may have noticed differences and changes that have occurred and/or heard the condition being discussed.

So it is crucial that you have a role in your loved one learning about your diagnosis. This will enable you to support them as they process the information and to be on hand to answer any questions they may have. If you are the person with IBM it will provide you with support and someone to talk to. Together, you can learn about the journey ahead.

It will also allow you to:

- Provide answers to questions.
- Correct any misinformation they may have heard or read.
- Show them that you have faith in their ability to handle difficult conversations.

There is no right time to start this conversation. Research suggests the earlier you talk to your loved ones about your/their condition, the more natural the conversation will become. The important part is to pick a time and commit to it.

Some important dos and don'ts:

- Do be positive but also realistic.
- Do tell them you will do many wonderful things in your life – you may just do them differently.
- Do tell the truth. Answer all their questions.
- Do consider your language. Try to avoid negative or emotive words, such as 'suffering from a condition'.
- Do use daily living examples that they can relate to.
- Don't avoid answering questions and don't shut the conversation down.

If you are having difficulty starting the conversation, try asking a couple of questions such as 'Do you know why I have been having difficulty with my muscles?' or 'Do you know why I have been tripping lately?'

Remember, it's okay to be upset during the conversation but try to avoid breaking down as this will only cause greater distress. And if speaking with a child, remember children are resilient and they generally handle information of this nature far better than adults.

Understanding IBM and how it's diagnosed

What causes IBM?

The exact cause of IBM is unclear. For unknown reasons, the body's immune system turns against its own muscles which damages the muscle tissues.

In IBM muscle damage is caused by:

1. Inflammation – inflammatory cells invade the muscles and gather between the muscle fibres.
2. Degeneration – muscle cells breakdown.

It is unclear what causes the inflammation and muscle degeneration, and how these two processes interact with each other.

People with IBM are more likely to also have other medical conditions such as lupus, Sjögren's syndrome, scleroderma, sarcoidosis, thyroid dysfunction, high blood pressure and diabetes.

How is IBM diagnosed?

IBM is a rare condition and is thought to be underdiagnosed or often misdiagnosed. Getting the correct diagnosis can be a long and frustrating process. Tests can help diagnosis, including:

- Blood tests – to measure creatine kinase (CK) levels in the blood. Creatine kinase often leaks from damaged muscle cells into the blood. High levels of CK in the blood can suggest a muscle problem but does not specifically diagnose IBM.
- Electromyography (EMG) – this test measures the electrical activity of the muscles and the nerves controlling the muscles. In IBM, abnormal electrical impulses may be detected. This can show that a muscle wasting condition is likely but doesn't specifically diagnose IBM.
- Muscle biopsy – this is the most definitive test for IBM. A muscle biopsy involves taking a small sample of muscle and examining it under a microscope. IBM is diagnosed if muscle cells contain inclusion bodies (abnormal clumps of proteins seen in damaged muscle cells). Biopsy results may initially give an inconclusive result and sometimes a second muscle biopsy is required.

The genetics of IBM

IBM is not a genetically inherited condition, meaning it is not passed down from parents to their children. There is a rare form of IBM, called inclusion body myopathy, which can be inherited. Inflammation is not common in this rare type of IBM and you can find out more about how it is inherited from the **Muscular Dystrophy Association** (US) website.

Long-term outlook

IBM is a slowly progressive muscle-wasting condition.

Most people will still be able to walk although may require some sort of mobility device at times. After having the condition for more than 10 to 15 years, many people will find they need assistance with daily tasks and some people may use a wheelchair most of the time.

IBM does not seem to affect a person's life span. People who have difficulty swallowing are at risk of serious complications, such as aspirational pneumonia (lung infection caused by inhaling food into the lungs).

- **Living Life**
- **Counselling**
- **Social work**
- **Psychology**

Understanding and planning for changes

What are the main symptoms of IBM?

IBM belongs to a group of conditions known as idiopathic inflammatory myopathies. These conditions cause inflammation (the body's response to injury) of the skeletal muscle (muscle connected to the skeleton). IBM impacts about 50 people per million in the over 50 years population.

The first muscles usually affected by IBM are:

- Forearm muscles that flex the fingers and wrists – weakening a person's hand grip.
- Quadriceps muscles at the front of the thighs – weakens the strength and stability of the knee. This can increase the risk of falls as knees can buckle or give way, particularly when going up and down hills or stairs. Rising from chairs will also become difficult.
- Muscles involved in lifting the ankle and foot – weakness of these muscles cause "foot drop", where a person struggles to hold their foot and toes in a horizontal position when lifted. People experiencing foot drop often trip or catch their toes on the floor when walking.
- The muscles involved in swallowing may also be affected in some people – this can cause symptoms such as frequent chest infections or choking when eating and/or drinking.

IBM can affect muscles in your body asymmetrically e.g. the left hand and the right leg may be weaker than the opposite side.

IBM does not usually affect other body systems such as the heart, lungs, gut, bladder and brain.

How does IBM progress?

IBM is a condition that causes muscle weakness that worsens slowly over time. As the muscle weakness worsens over time, people will have increasing difficulty walking, getting dressed and doing their daily activities, usually after 10 – 15 years of living with the condition. The loss of strength tends to be faster the older you are when symptoms first appear.

Community Advice

Hear from a community member who has walked the path before you.

The video is available at **https://youtu.be/I7labxjWv9w.**

Life stuff

To find out more about living life with a neuromuscular condition and to access stories and peer-advice from the community, visit our **Living Life** section.

Where to find more information about living with IBM

- **Inclusion Body Myositis fact sheet** from Muscular Dystrophy New South Wales, 2017. This fact sheet includes considerations for future planning**.**
- **Inclusion Body Myositis information page** from Muscular Dystrophy Australia.
- **Myositis Association Australia** This Australian organisation is dedicated to providing a network of support for myositis patients and their families and assisting myositis patients to manage their condition. Newsletters, meetings and events are held where people can access information and share experiences. The Association also supports research to help find a cure for myositis or improve the quality of life of myositis patients. Promoting awareness for myositis to the health profession and the general public is also a function of the Association.

International organisations

- **Muscular Dystrophy Association**

This US-based website has excellent information regarding IBM. You can find a full list of neuromuscular conditions, symptoms, causes and care options, as well as use the clinical trial finder tool.

- **Muscular Dystrophy UK**

A UK based site that has useful information regarding IBM

Treatment and management

At the moment there is no cure for IBM but there is a lot you can do to improve your quality of life. Being a rare disease, it is often not well understood by the general medical community and you may find you need to work in partnership with and help educate your healthcare team.

Current treatment focuses on the management of symptoms and reducing the risk of medical complications. Treatment options include:

- **Physiotherapy** – can help to maximise the strength and function of the unaffected muscles. They can also provide advice on the use of mobility aids and teach people how to transfer between chairs, beds and wheelchairs.
- **Occupational therapy** – can provide advice and equipment in overcoming difficulties in daily living activities, work, recreation and participating in your community.
- **Speech pathology** – can help with the management of swallowing difficulties.
- Regular exercise – helpful to improve your general wellbeing and may even improve strength. Care must be taken to avoid falls and injuries and therefore exercise should be closely monitored by a health professional. No specific exercise prescription exists but combining both aerobic and resistance exercise is generally recommended. **Hydrotherapy** is a good exercise option for people with IBM.
- Keeping an ideal weight - weakened muscles may struggle to carry excess weight.
- Sleep study – breathing problems during sleep are common in people with IBM.

Source: **Muscular Dystrophy Australia**

Other helpful support services

The video is available at **https://youtu.be/BDaCNsd9R_s.**

- Your **state or territory neuromuscular organisation** can provide information and advice on what support they can offer such as local support groups, camps, programs, services in the local area, access to cough assist machines, advocacy or assistance in times of crisis. They can also provide an ear to listen if you need someone to talk to or guide you to get the assistance you are needing.
- Seeing a psychologist, counsellor or social worker can be incredibly helpful if you, your child or other members of the family are having a tough time or struggling with negative thoughts and feelings. Learn more about what services are available and how to access them in our information about **Counselling**, **Social Work** and **Wellbeing**.
- Living with IBM may mean that you or your child may need some assistance for everyday activities. Find out more about how a **disability support worker** could help and how to engage this type of support.
- Other people and families living with IBM have also experienced the emotional rollercoaster that comes with a diagnosis of IBM and are able to understand exactly how you're feeling. You are not alone. Connect with other people and families living with IBM in **The Loop Community**.

How to have better conversations when communicating your needs

To learn how to have better conversations when communicating your needs, visit the following pages:

Employers

Educators

Education

About IBM

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International Organisations

The Myositis Association (US)
The mission of The Myositis Association is to improve the lives of persons affected by myositis, fund innovative research, and increase myositis awareness and advocacy. Our programs and services provide information, support, advocacy, and research for the myositis community.

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