

FURTHER RESOURCES

Castleman Disease Hub

You can access the Castleman Disease Hub through www.castlemandisease.co.uk - this offers you comprehensive information about Castleman disease, including types, symptoms, diagnosis, and treatment options. It also provides resources for patients and caregivers, updates on research, and ways to get involved in advocacy and support communities. Visit the Castleman Disease Hub to learn more about Castleman disease and how to access valuable patient support.



Please scan the QR code or visit:
castlemandisease.co.uk



GUIDING YOU THROUGH

AN INTRODUCTION TO iMCD



COMING TO TERMS WITH YOUR DIAGNOSIS

When you are coming to terms with a life changing illness there is no right or wrong way to feel and it is normal to experience a range of emotions. The road ahead won't be easy, but it can also be a path to discovery. In our experience, patients often find that they are stronger than they think and in that we would encourage you to remain positive as there's a wealth of things that you can do to tackle your condition head on.

This booklet aims to provide you with introductory information and guidance around your diagnosis and what lies ahead. We understand that there will be a lot of unknowns in your world right now.

WHAT IS IDIOPATHIC MULTICENTRIC CASTLEMAN DISEASE?

MCD is a rare disease that affects the lymphatic system, which is a network of organs, vessels and lymph nodes responsible for removing toxins, waste and other unwanted materials from the body. iMCD is a form of Castleman disease that has spread to multiple regions of lymph nodes rather than being isolated to a single location or node which makes it more aggressive in nature.



What causes MCD?

Being "idiopathic" means that the cause of your MCD is not known. In some cases, it can be triggered by a human herpesvirus (the same family that causes cold sores) and is referred to as HHV-8-associated MCD.



Is it cancer?

MCD is not cancer.

It is actually a *lymphoproliferative disorder* which means that there is an abnormal overgrowth of cells in your lymph system. Although not officially a cancer, MCD behaves very much like cancers of the lymph nodes known as lymphomas and is often mistaken as such. However, the treatment options for MCD are different to that of cancer.



iMCD IS RARE, BUT TREATABLE

Treatment of iMCD is challenging, and treatment options and outcomes depend on the severity in each person. There is no standard therapy for iMCD, and no single treatment works for all patients. Generally, doctors will aim to use treatments that reach all parts of the body such as:



Corticosteroids – reduce immune system activity (administered by injection)



Chemotherapy – shrink fast growing cells in your body (administered intravenously)



Immunotherapy – targeted immune suppression (administered by injection)



Anti-viral drugs – e.g. anti-HIV treatments (administered orally)

iMCD is often too widespread for targeted treatments such as surgery and radiation to be effective in isolation, however, these methods may be used on a case-by-case basis for symptomatic relief.

It is important for you to understand that treatment outcomes depend heavily on individual circumstance. In some patients their iMCD improves or even goes away completely (at least for a time) while others may not be helped by drugs at all, however, there are still further options for these patients. You should discuss your individual circumstance with your doctor who will be able to explain and provide detailed information around your treatment plan.

WHAT DOES IT MEAN FOR ME?

? Ongoing symptoms and what to expect

Prior to your diagnosis you may have exhibited a variety of symptoms which could have been mistaken for a variety of other diseases. iMCD varies from person to person and can range from mild to severe with symptoms including:

- **Fever**
- **Enlarged lymph nodes**
- **Night sweats**
- **Loss of appetite and weight loss**
- **Weakness and fatigue**
- **Shortness of breath**
- **Nausea and vomiting**
- **Enlarged liver or spleen**
- **Peripheral neuropathy**
- **Skin problems such as rashes**

? The day to day impact

A diagnosis of iMCD can have a significant impact on you and everyone in your life. Common feelings during this life-changing experience include anxiety, distress, and depression. The physical and emotional impact of the disease may be felt at home, school or work and its treatment can often present a cost burden to families and patients. There are several featured resources at the end of this booklet which may be able to offer some guidance on how to approach and cope with some of the challenges that iMCD can bring.

? The long term impact

The long-term outlook for patients with iMCD is often worse than for people with the localised form of the disease (Unicentric Castleman Disease). It is important to understand that iMCD is a progressive disease which may lead to more severe symptoms if left untreated. If you stop your treatment, the disease may come back. You will be at risk of developing other conditions which may have a significant impact on the prognosis. You should discuss your diagnosis with your doctor to understand what your individual circumstance may bring.

LOOKING FORWARD

Rare disease support

Given the rarity and general lack of awareness of iMCD (even in the medical community) it is normal to feel in the dark about your condition. Many iMCD patients are looking for detailed information about how the condition will affect them in the future.



For more information about your disease, there is a website which can help you, scan the QR code or visit:
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TAKING CARE OF YOUR MENTAL HEALTH

Proactivity around the maintenance of your mental health during your iMCD journey will prove to be vital as you progress through treatment. Even if you don't feel like your mental health is at risk, maintaining practices to ensure its upkeep is strongly advised. You should develop a mental health maintenance strategy with your doctor, which may involve some of the following:



Regular mindfulness practice (such as guided meditation or apps like 'Headspace')



Cognitive behavioural therapy (face-to-face with a therapist or online)



Getting quality sleep



Managing your stress and stress inducing activities (e.g., work or school stress)



Staying active with exercise (discuss with a doctor before commencing new exercise)



Maintaining social connections (spending time with friends and family)

If you have developed feelings that overwhelm or concern you, or that go on for more than 2 weeks, you should talk to your doctor.