

Living with Fabry

A guide for people living with Fabry disease



beMi[®]

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This booklet provides general information and is not a replacement for medical advice. Any questions about medical conditions, including Fabry, should be discussed with a healthcare professional.



Living with Fabry

For many people living with Fabry, knowing that there is a supportive community can be really helpful. Many resources and support networks are available to help manage lifestyle, wellbeing, and health. Seeking support when needed is always encouraged.

This guide offers some helpful tips and outlines the support available for people living with Fabry.

This booklet has lots of tips and tricks for:

- managing symptoms
- maintaining a healthy lifestyle
- coping with work or school
- finding a support network.

Finding out what works

Try ideas from this booklet and see how they work out. Experimenting with other strategies can also be effective - so continue using what works best!

The goal is to find healthy and meaningful ways to assist with everyday life.



**To find out more about Fabry,
see the *What is Fabry?* booklet
on the beMi website.**

Tips for managing symptoms

People living with Fabry can experience many different symptoms. Symptoms may change over time or even from day to day. Some of the most common symptoms are:

- pain or discomfort in the hands and feet
- a spotty, dark red rash
- reduced ability to sweat
- feeling tired or fatigued
- gut issues such as abdominal pain, diarrhoea, constipation, nausea or vomiting.

Read more about Fabry symptoms in the **What is Fabry?** booklet.

Here are some things people can do to try and help with the symptoms of Fabry. Remember, always seek medical advice or direct any questions to a healthcare professional.

For pain

- Try to keep the body temperature steady —avoid extreme temperature changes and adjust clothing layers as needed.
- Drink plenty of fluids after physical activity.
- Find ways to minimise stress or manage it effectively.
- Try to reduce alcohol consumption.
- If feeling tired, be kind to oneself and get plenty of rest.
- Apply cold packs to painful areas.



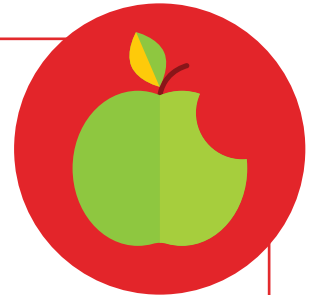
For skin

- Avoid being in the sun for a long time.



For the gut

- Try eating regular smaller meals, rather than fewer bigger meals.
- Consider keeping a food diary to help identify any foods that cause gut symptoms.
- Try to make healthy food choices.
- Enjoying food is important! While there may be concerns about foods that could upset the gut, individuals can still aim to eat regular meals and discover tasty food choices that work for them.



Connecting with the Fabry Community

It can take some trial and error to figure out what works best to help manage symptoms. Connecting with other members of the Fabry community is another great way to share experiences and ideas that may be helpful to manage symptoms.



Lifestyle tips and tricks

We all need to maintain a healthy lifestyle, and people living with Fabry are no exception. Staying healthy may help reduce overall discomfort - even small changes can have a big impact!

Here are few helpful tips and tricks to maintain a healthy lifestyle.

1. Avoid smoking

Stopping smoking can help to prevent future illness and may improve some symptoms.

2. Take part in enjoyable and regular physical activity

While too much physical effort may trigger pain in some people with Fabry, it's important to keep physically active. Try different activities that don't cause discomfort, over-heating or pain.

3. Make healthy food choices

Many people find that maintaining a healthy diet can help reduce gut symptoms. For those already eating a healthy diet, that's great! For those seeking inspiration to get started, these tips may help. Reading food labels on packaged foods can also be beneficial.

- Eat a range of nutritious foods from the five food groups each day. Keep it varied and keep it colourful with:
 - fruits, vegetables, legumes
 - grain-based, high-fibre foods, and wholegrain if possible
 - lean meats (including poultry), fish, eggs, nuts
 - milk, yoghurt, cheese or dairy-free alternatives.
- Be selective about the fats in your diet – not all fats are equal! Olive oil and canola oil are healthier than animal-based fats like butter.
 - Try and minimise fried and highly fatty products.
- Limit added salt and added sugars
 - Try and avoid salty foods and sweetened foods and drinks (energy drinks, cordials, confectionary).

4. Avoid too much alcohol

If drinking alcohol, try to stick to the recommended limits to reduce the risk of harm and poor health. The recommended amount for adults is no more than 10 standard drinks per week, with no more than 4 standard drinks on any given day.

Find more information on standard drink servings in Australia at www.health.gov.au/topics/alcohol/about-alcohol/standard-drinks-guide.

5. Find relaxation techniques that can help to manage stress

Take some time to discover ways to achieve relaxation. Learn special techniques such as meditation and mindfulness exercises or try some calming activities (reading, watching a favourite TV show, etc.) during times of stress. Sometimes going for a walk or doing some kind of physical activity can help with stress levels. Again, it takes trial and error to see what works.

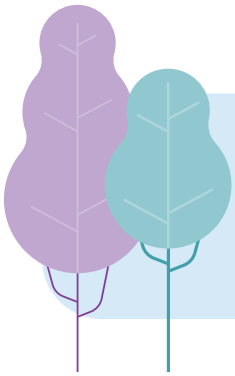
6. Keep up with medical appointments

Keep up-to-date with medical appointments and regular check-ups and contact a doctor if feeling unwell or noticing changes in symptoms.



Going to work

- Some people may be able to continue working without any issues. Even so, it is helpful to have support from an employer and colleagues, and to have ways of managing symptoms at work if needed. There is no requirement to disclose a chronic condition to an employer.
- Depending on the type of work, it can be helpful to build rest periods into the regular workday. It is a good idea to talk to a manager about how to take breaks in a way that best suits individual needs.
- Confiding in a manager or support person about specific needs can help them provide better support. Employers can often make adjustments to reduce strenuous physical activity, organise the workspace for increased comfort, and accommodate time off for illness, medical appointments, or treatment.



Work that involves manual labour, exposure to rapid changes in temperature, physical exertion or stressful situations may trigger pain symptoms for some people with Fabry.

Going to school

- It is important that children with Fabry feel comfortable and included in school. This usually involves balancing their needs with feeling part of school activities along with their peers.
- Parents and guardians can inform the school and teachers about a child's needs, and how that can impact life at school.
- Consider informing the school so that they may be able to offer support, such as taking medications at school and being absent due to sickness or medical appointments.



Building a support network

Family, friends, and a reassuring healthcare team can form a valuable support network.

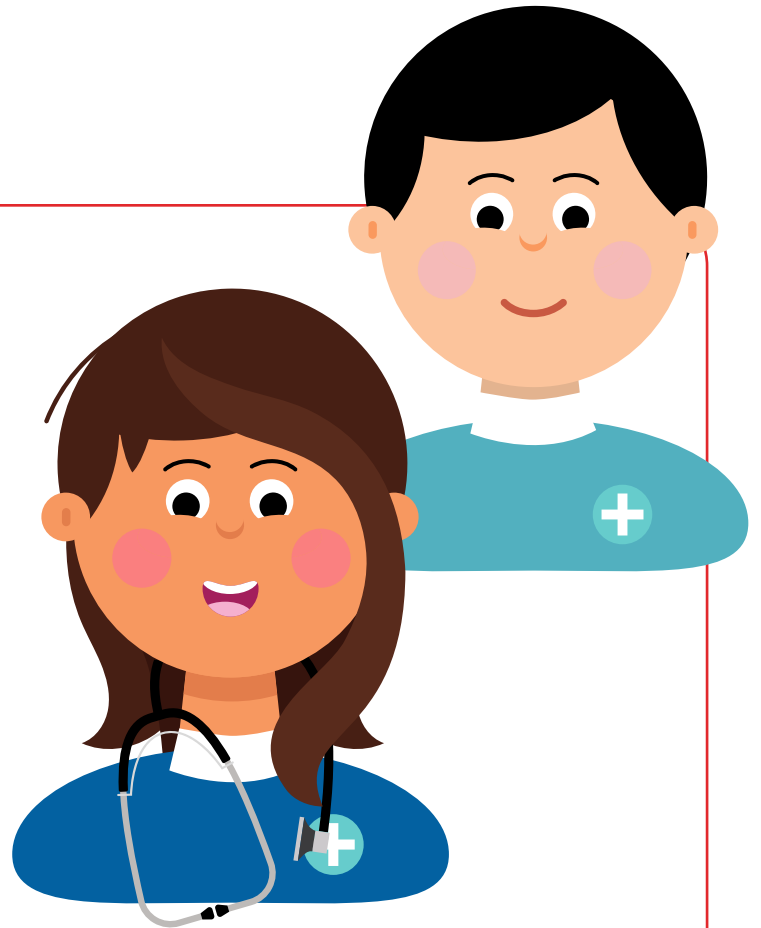
Family and friends

- Consider discussing with family and friends how they can provide support. Sharing information about Fabry and its impact might help them offer appropriate support tailored to individual needs. This support could include assistance with appointments, day-to-day tasks, or simply being available to listen and provide backup when necessary
- Learning about a genetic condition can be concerning for close family members. While they will likely be worried about the individual, they might also be concerned about the possibility of having Fabry themselves. Screening for family members typically involves a blood test.
- The **Guide for Family and Friends** offers additional information on supporting people living with Fabry.



The healthcare team

When receiving a diagnosis of Fabry, individuals can work with their healthcare team to identify the most suitable management options and treatment. This healthcare team will likely be made up of professionals with various skills and expertise, typically including specialist doctors and nurses.



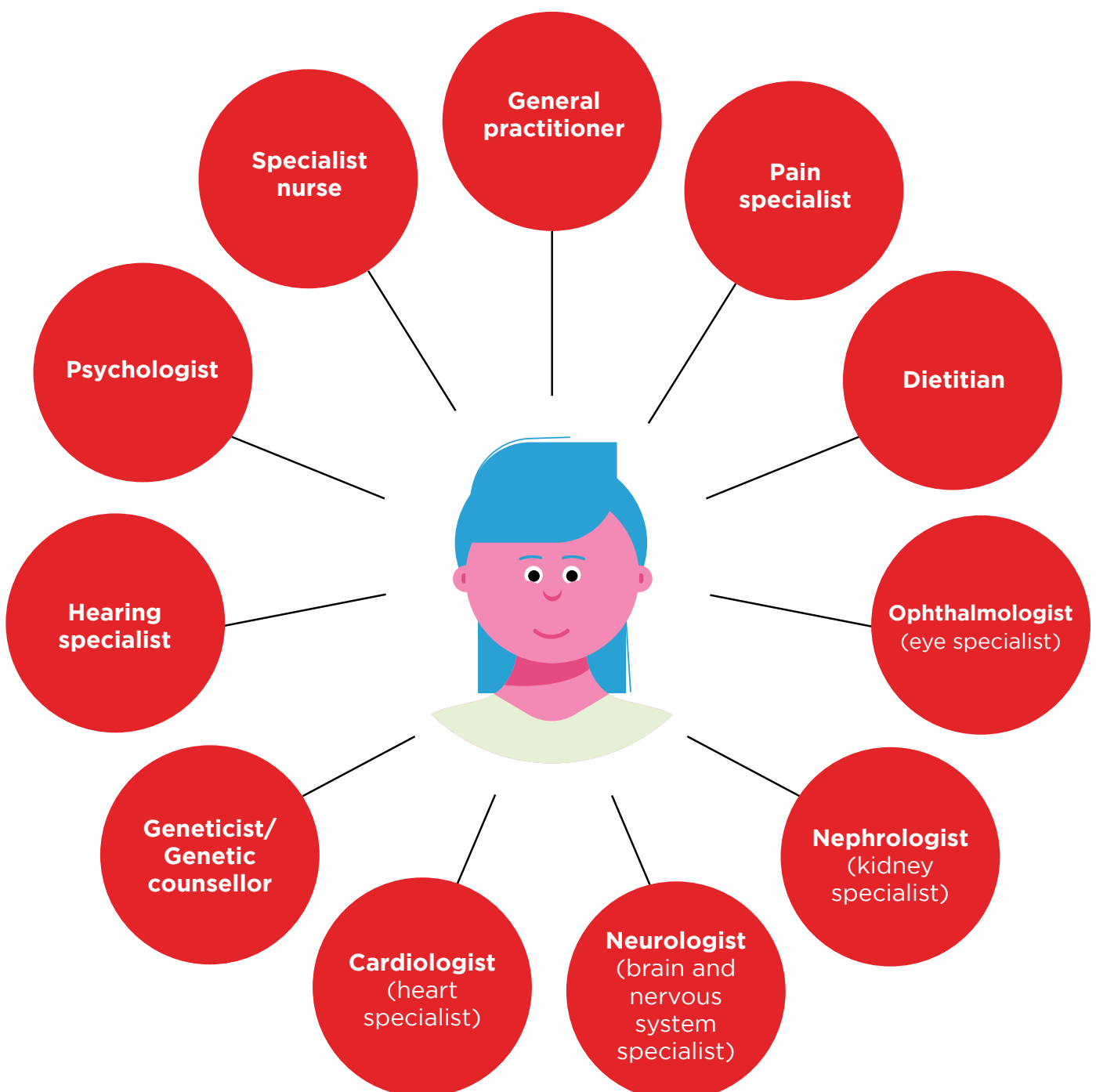
The specialist healthcare team may bring other healthcare professionals into the team to assist with ongoing care.



Depending on the differing care needs experienced when living with Fabry, individuals might see one, a few, or all of the following healthcare professionals.

Talking with the healthcare team

It's important for individuals to discuss what matters most in their care to ensure they and their healthcare team are working towards the same goals. Try to communicate openly, share information, and ask questions. The healthcare team is there to address any concerns and provide reassurance.



Find out more

Support is out there

Connecting with others online is a great way to find support. There are plenty of online forums and social media groups dedicated to providing support and information about Fabry.

Always remember that independent websites control their own content, and it is important to critically assess any information available online. Always speak to a qualified healthcare professional for medical advice.

There are also several Australian organisations that support people with Fabry. These organisations offer a range of resources for those living with Fabry and their families.

To find out more about Fabry, visit the following independent Australian organisations. They can provide valuable resources and assist in finding the support needed.

Fabry Australia

www.fabry.com.au
admin@fabry.com.au

Rare Voices Australia

www.rarevoices.org.au
info@rarevoices.org.au
RARE Helpline:
www.rareportal.org.au/rare-helpline/



Other booklets and animations are also available on the beMi website at **bemi.health**

In the spirit of reconciliation, Takeda acknowledges the Traditional Custodians of Country throughout Australia, and their connections to the land, sea and community. We pay our respects to their Elders past, present and emerging, and extend that respect to all First Nations peoples.

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