

## Pain in Fabry

Thousands of people around the world live with Fabry disease, but no two people experience it in exactly the same way. In addition, some of the symptoms of Fabry may seem 'invisible' and difficult to measure through medical tests. This can be frustrating, and you may feel that healthcare professionals do not fully understand.

Pain is one of the most common symptoms of Fabry, affecting almost 75% of those living with the disease. It is also usually one of the earliest symptoms of the disease, often starting in childhood. Up to 90% of children with Fabry have pain.

Even though most people with Fabry have some kind of pain, their experiences can be very different. This fact sheet explains how and where people with Fabry might experience pain, and might help with having productive discussions about pain with healthcare professionals.



If you want to learn more about Fabry and its effects, contact your local patient organisation or talk to your healthcare professional.

### Information in this guide came from the following sources.

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## What does Fabry pain feel like?

**Burning**  
**Stabbing**  
**Tingling**  
**Agonizing**

These are the most common words people with Fabry use to describe their pain. Some people also describe it as pressing, prickling, squeezing, electrifying or sore.

As well as there being many descriptions of pain, there are also different ways that people experience pain, and in different parts of the body, as shown on the next page. Researchers have described four main types of pain associated with Fabry.

### Pain attacks

This is sudden intense pain that does not last very long.

Pain attacks are experienced by almost 47% of people who have pain with Fabry.

### Evoked pain

This is pain caused by something that would normally cause no pain or only slight pain, like a light touch or hot water.

Evoked pain is experienced by 66% of people who have pain with Fabry.

### Pain crisis

This is intense pain that can last for hours or even days.

Pain crisis is experienced by more than 17% of people who have pain with Fabry.

### Chronic pain

This is pain that is always present.

Chronic pain is experienced by more than 17% of people who have pain with Fabry.

Many people don't have just one type of pain, but have different types at different times, or at the same time. How often people experience pain can also vary. Most people have pain up to four times a month, but some people have pain every day, every week, about once a month or only a few times a year. This can change over time. For many people, pain becomes less severe with age (possibly because the longer someone has Fabry, the more damage there is to their nerves, which may make them less able to feel pain), but it does not get better for everyone.

## What makes pain happen?

Pain attacks, evoked pain and pain crises can be set off (triggered) by a number of things in everyday life. These include the following.



Illness, such as flu or other viral illness



Emotional stress



High or low temperature or a rapid temperature change



Exercise



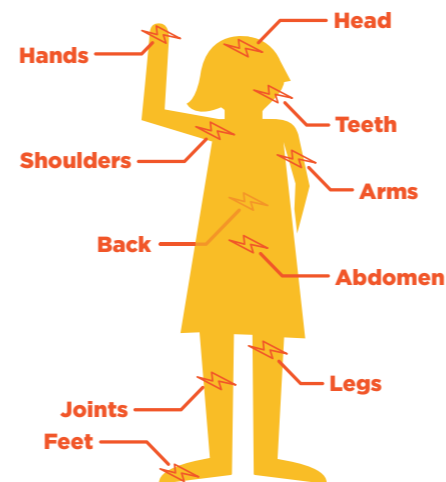
Fatigue



Certain foods, such as coffee and alcohol

## Where do people with Fabry feel pain?

Where pain is felt is another thing that can change from person to person. Pain is most commonly felt in the hands and feet (experienced by more than 65% of people who have pain with Fabry). Severe pain in the hands, feet, fingers and toes is called 'acroparaesthesia' (pronounced ack-roe-pare-us-THREE-zee-ah). People report pain in many areas besides their hands and feet - some in their whole body.



## Effects of pain



Pain can have a big effect on daily life. People experiencing significant pain might need to avoid physical activities, or limit daily activities such as working, socialising, or even going to school. Because of these effects, overall quality of life can be lower for people with Fabry who experience pain. And sometimes pain can be so bad, and so constant, that it affects mood and state of mind.

## What can be done about pain?



If you know what triggers your pain, you can try to avoid those things. For example, you might want to avoid extreme temperatures, physical exertion or caffeine. Some people use prescription medication to manage pain. Healthcare professionals can help you choose the right medication and suggest ways of managing pain.

One of the most important things you can do is let your GP and other healthcare professionals know exactly how, when and where you are experiencing pain. Researchers have developed a specific questionnaire about pain in Fabry. You can read about this questionnaire in the article 'Self-administered version of the Fabry-associated pain questionnaire for adult patients' that was published in the Orphanet Journal of Rare Diseases in 2015. This questionnaire could help you explain your pain, and help healthcare professionals understand it so they can help you to manage pain and the other effects of Fabry. Never be afraid to speak up about what you are going through!