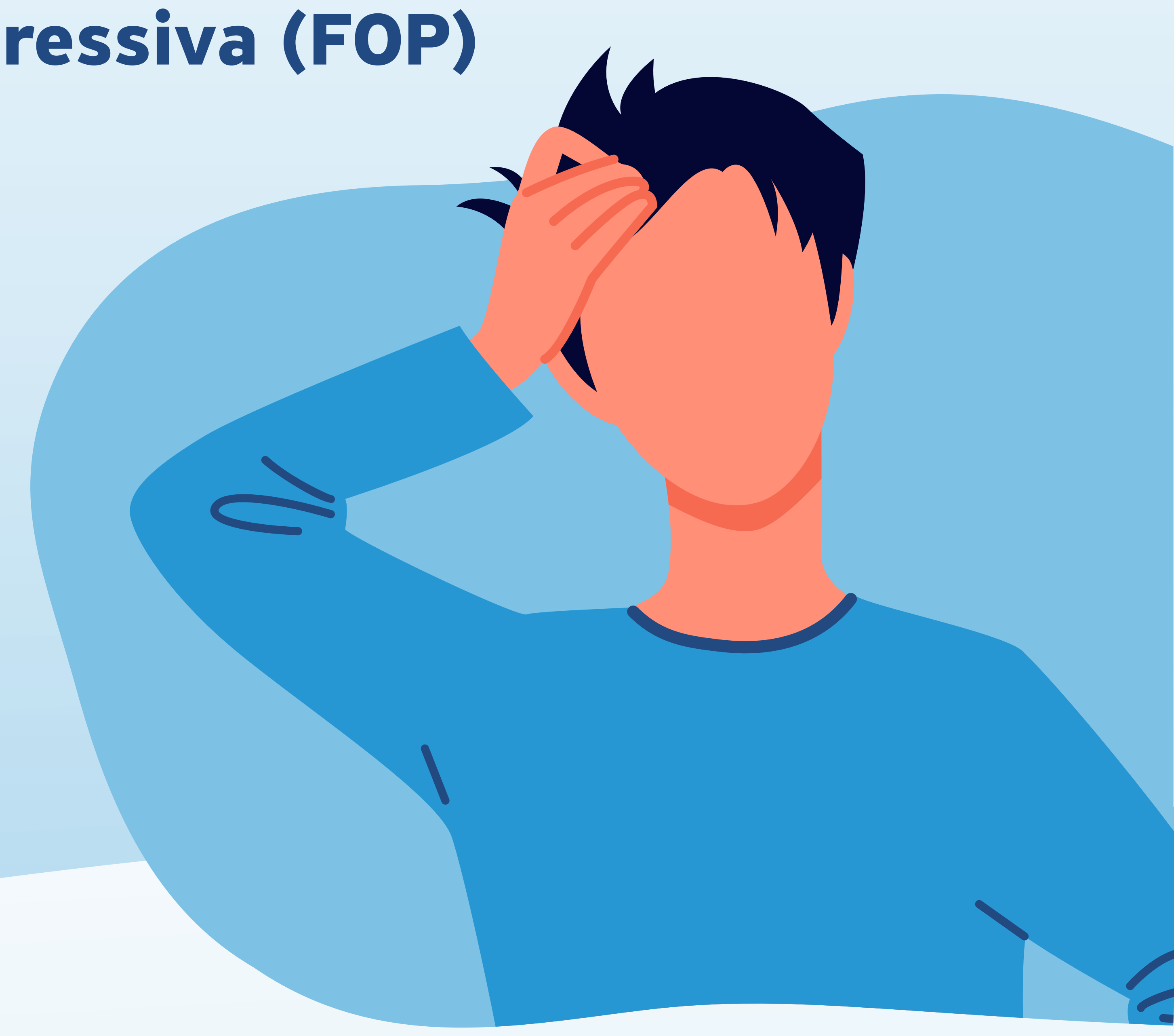
Talking FOP:
Making conversations easier

Simple advice to help you navigate some of the common conversations you might have about fibrodysplasia ossificans progressiva (FOP)



Talking about FOP can be difficult

FOP is a genetic condition where the soft tissues of your body (muscles, ligaments, and tendons) gradually turn into bone through a process called heterotopic ossification (HO).[1] Over time, this can make it more difficult to move.[1] FOP is ultra-rare, affecting just one in 1 million people.[2]

Living with an ultra-rare condition may sometimes feel isolating. Most people you meet probably won't have heard of FOP, and it might feel like those around you don't understand the condition. Based on insights from people living with FOP, we know there are some situations where you may need to explain or talk about FOP with others, but it can be hard to know where to start.

About this guide

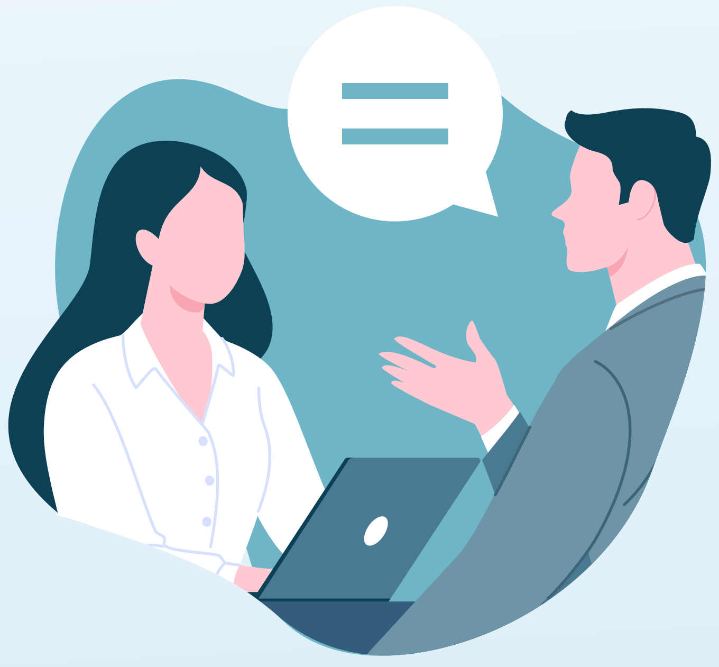
This guide has been developed to help you navigate some of the common conversations you might have about your condition, to help make talking about FOP easier.

It has been written with input from people living with FOP and FOP experts, and includes tips for communicating about your condition with different people, from friends to employers, and even healthcare professionals.

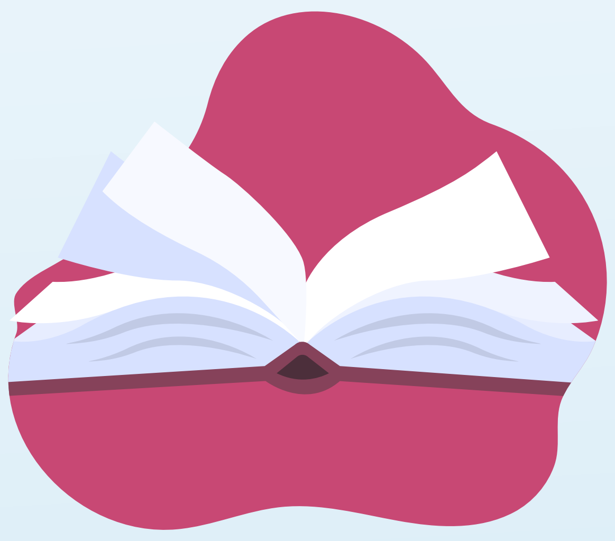
Each page of the guide is designed to support you in a different scenario, with a list of useful definitions and resources at the end:

A guide to communicating with friends and family

A guide to communicating with non-specialist doctors and nurses



A guide to letting schools and employers know about your needs



FOP dictionary and useful resources

Family and caregivers

If you take care of someone who is living with FOP, you might also need support with communicating about the condition.

Look out for this symbol, where you will find tips and advice that are also useful for family and caregivers.

> *"As an adult sufferer of FOP, I have experienced occasions where I have struggled to communicate about FOP. When I was younger, I was very anxious discussing my condition, especially when asked about it by a new person or new friend at school. As I have gotten older, I have felt more at ease communicating about FOP as I find it easier to explain what it is and how it affects me. FOP can be difficult to explain because it is so rare. This guide will be an excellent tool in helping people to explain FOP and communicate how it affects them, their carers and family."*
>
> **Luciana Wulkan, living with FOP**

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If you find the information in this guide useful, please consider sharing it with someone else it might help. This could include other people living with FOP, or your family and friends.

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A guide to communicating with friends and family

Telling friends and family about FOP

FOP can be complicated to explain. It may be useful to practice a short ‘explainer’ sentence to describe it in simple terms. Try the below example, or write one of your own:

> **“*I’m living with a very rare genetic condition called FOP. It means the soft tissues (muscles, ligaments, and tendons) in my body are gradually being replaced by bone over time, which can restrict my movement.*”**

Talking about the future

Friends may ask what your future with FOP looks like. To help them understand, try to be clear and factual, for example:

> **“*FOP is a progressive condition, which means that over time more of my soft tissues (muscles, ligaments, and tendons) will turn into bone. I can’t predict how quickly this will happen because this varies from person to person.*”**

Tips to help you navigate these conversations:

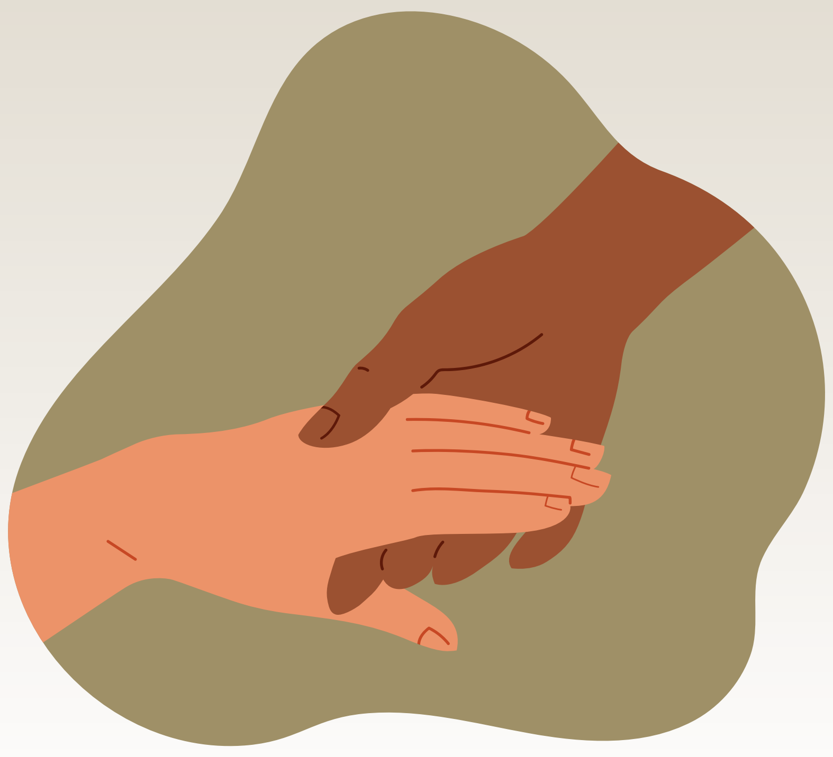
- **Be clear and factual** – share information in bitesize chunks, so it’s easier to understand
- **Choose the time and location wisely** – try to make sure you are in a relaxed, private setting
- **Go easy on yourself** – talking about FOP can be emotionally tiring
  - Consider asking someone you trust to tell people about the diagnosis on your behalf
  - Point friends and family in the direction of the **FOP Friends’** website to find out more
  - It is normal to feel anxious about the future, and there is no right or wrong time to talk about it. It can be helpful to talk to your loved ones about how you feel

As the first signs and symptoms of FOP often appear by age ten,[3] the above advice may also be useful for you when explaining your child’s diagnosis.

Setting boundaries

It’s important to let your friends and family know how they can support you, including setting boundaries. For example, when experiencing a flare-up, you may be less keen to socialise or more in need of support.

- **Use direct language**, e.g., “I’m sorry, I can’t make it” instead of “I’m sorry, I’m not sure if I can make it”
- **Let friends and family know when you’re having a difficult day** – it’s ok not to feel 100%
- **Don’t be afraid to ask for or accept support** when you need it
- **Consider what you want to share and with who** – it’s up to you what you feel comfortable with



Take cues from the person living with FOP and respect their boundaries. Offer support proactively as they may be reluctant to ask for it.

Sharing your story

You may want to share your experience beyond your immediate circle– e.g., on social media. Try to ensure anything you share is factually accurate and avoid potentially stigmatising language like ‘stoneman syndrome’ or ‘second skeleton’. You could use the example sentences above as a starting point when talking about your condition publicly.

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A guide to communicating with non-FOP specialist doctors and nurses

Because FOP is so rare, you may sometimes need to explain the condition to doctors, nurses, and other healthcare professionals who are not familiar with it e.g., if you've moved GP, or you are being treated in A&E. It's important to let them know about your condition, so they can make the right decisions about your care.

The below guidance may help to make these conversations easier:

- Clearly state that you're living with a rare condition – *see the example 'explainer' sentence on page 2*
- Tell them when you were diagnosed, and about any major flare-ups you have had including how many and how often they occur
- Explain that you need to try and avoid anything which causes physical injuries (known as 'trauma'), including surgery or injections which go into your muscles, which could trigger an FOP flare-up
- If you're experiencing a flare-up, tell them where on your body it is, and report any pain, stiffness, or restrictions to your movement it is causing. If you think you know what has caused the flare-up, share this too
- It may be helpful to ask an FOP specialist, or a doctor who you have been seeing for a long time, to write a letter explaining FOP and your needs which you can share with new doctors or nurses
- Consider completing a Care Passport, like the one on the FOP Friends' website, and carrying a copy with you in your wallet or purse
- To help healthcare professionals to understand more about your condition you could:
  - Print off reliable information about FOP and bring it with you to appointments. *See page 6 for an overview of useful resources*
  - Direct your healthcare professionals to **The International Clinical Council (ICC) on FOP Medical Guidelines**
- For specialist advice, contact an FOP expert or share their name with your doctor, for example **Professor Richard Keen: rno-tr.metabolicsecretary@nhs.net**

If the person living with FOP that you're taking care of is in too much pain or is unable to communicate clearly about their condition, then this responsibility may fall on you. Try to remain calm and follow the steps above, as appropriate. Ask doctors for advice on how you can support the person you are caring for, ensure you know where to direct healthcare professionals to find accurate guidance quickly and consider undertaking first-aid training to improve your confidence.

Differences between individual cases of FOP may have an impact on care considerations. Decisions about appropriate care for a person living with FOP must ultimately sit with the individual patient, their doctor, and their caregivers.

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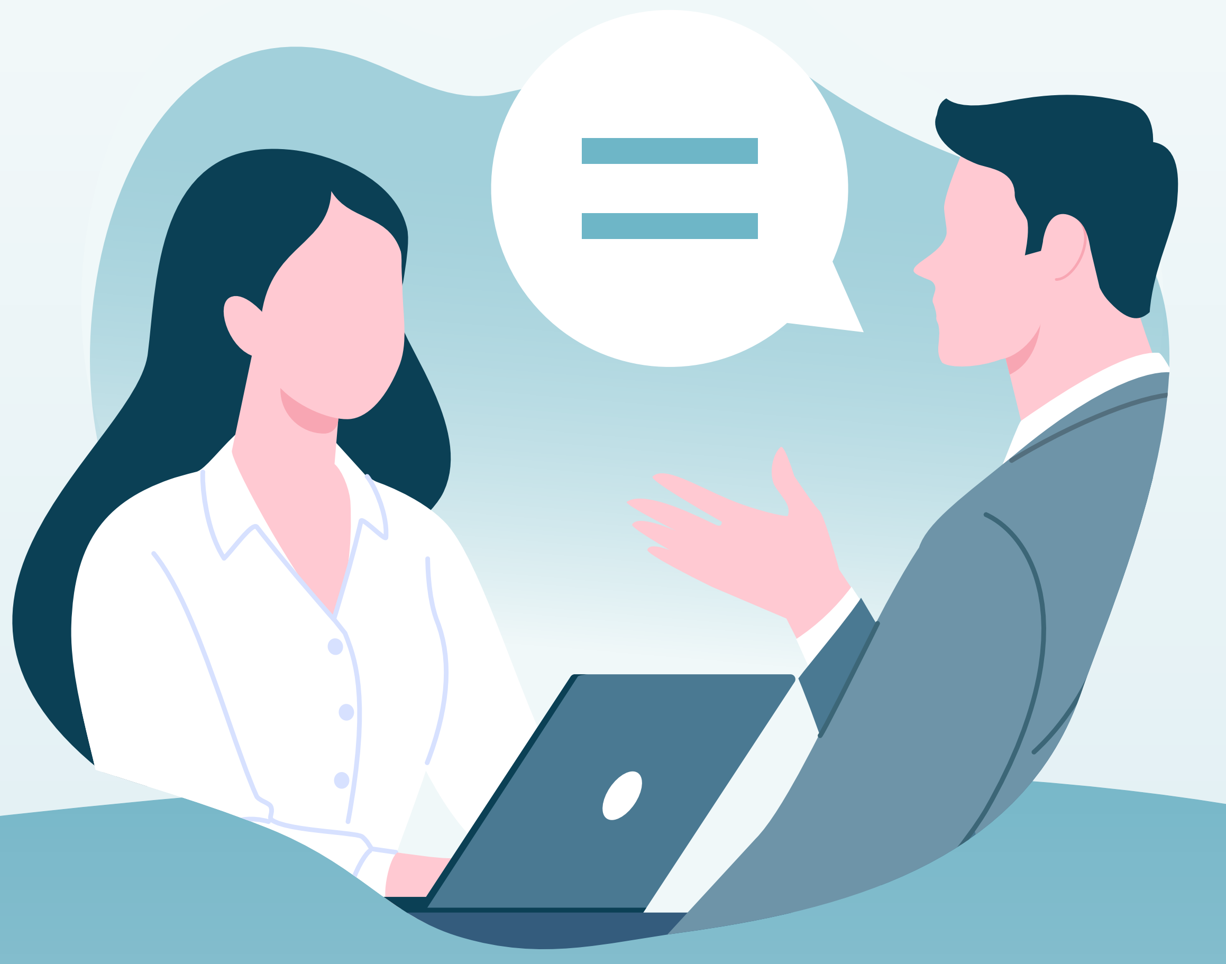

Speaking to schools or universities about FOP

If you are caring for a child or young person who is living with FOP, speaking to their teachers or professors about their condition will help you to ensure they get the support they need.

- Consider arranging a meeting with the school's special education needs and/or disabilities coordinator (SENDCO or SENDCo). You can then apply for an Education, Health, and Care Plan (EHCP), outlining your child or young person's educational, health, and social needs, and additional support to meet those needs
- Have an open conversation with the SENDCO about the level of support you feel is needed. For example, parents of children living with FOP may request to get an additional member of staff to help support their child with day-to-day activities, help make learning environments safer and monitor risk
- If you are caring for a young person of university age, consider arranging a meeting with the university to clearly explain the condition and discuss any additional support they might need. See the **UCAS** website for more guidance for students with disabilities
- See the **FOP Friends' handbook on supporting a child with FOP through school** for detailed, practical guidance on supporting your child through school and the steps you should take

Speaking to employers about FOP

At times, FOP may impact your ability to do your job and you may need to take time off when experiencing flare-ups. It is up to you how much information to disclose – but being open and honest about your condition and how it impacts you may allow your employer to be more supportive of your needs.

- Only share the information you are comfortable with sharing
- It may be best to let your employer know about your condition during the interview process, so they can put steps in place to support you from the start
- Ask a healthcare professional to draft a letter or an email to share with your employer, explaining FOP and your needs. Share this with your Human Resources (HR) department and direct supervisor, and have a conversation with them about how FOP might impact your work
- Be clear about what you can and can't do – particularly if your job requires physical activity
- Ask for time off when you need it, and ask your doctor to provide a note to support these requests
- Don't be afraid to accept support from your employer if it will make your job role more accessible
- See the **GOV.UK Disability Rights** webpage for more information about your employment rights, or visit the **SCOPE employment services** webpage for employment support for people living with disabilities

When it comes to both education and employment, always follow your doctors' advice, and do what feels right for you. Decisions about appropriate care for a person living with FOP must ultimately sit with the individual patient, their doctor, and their caregivers.

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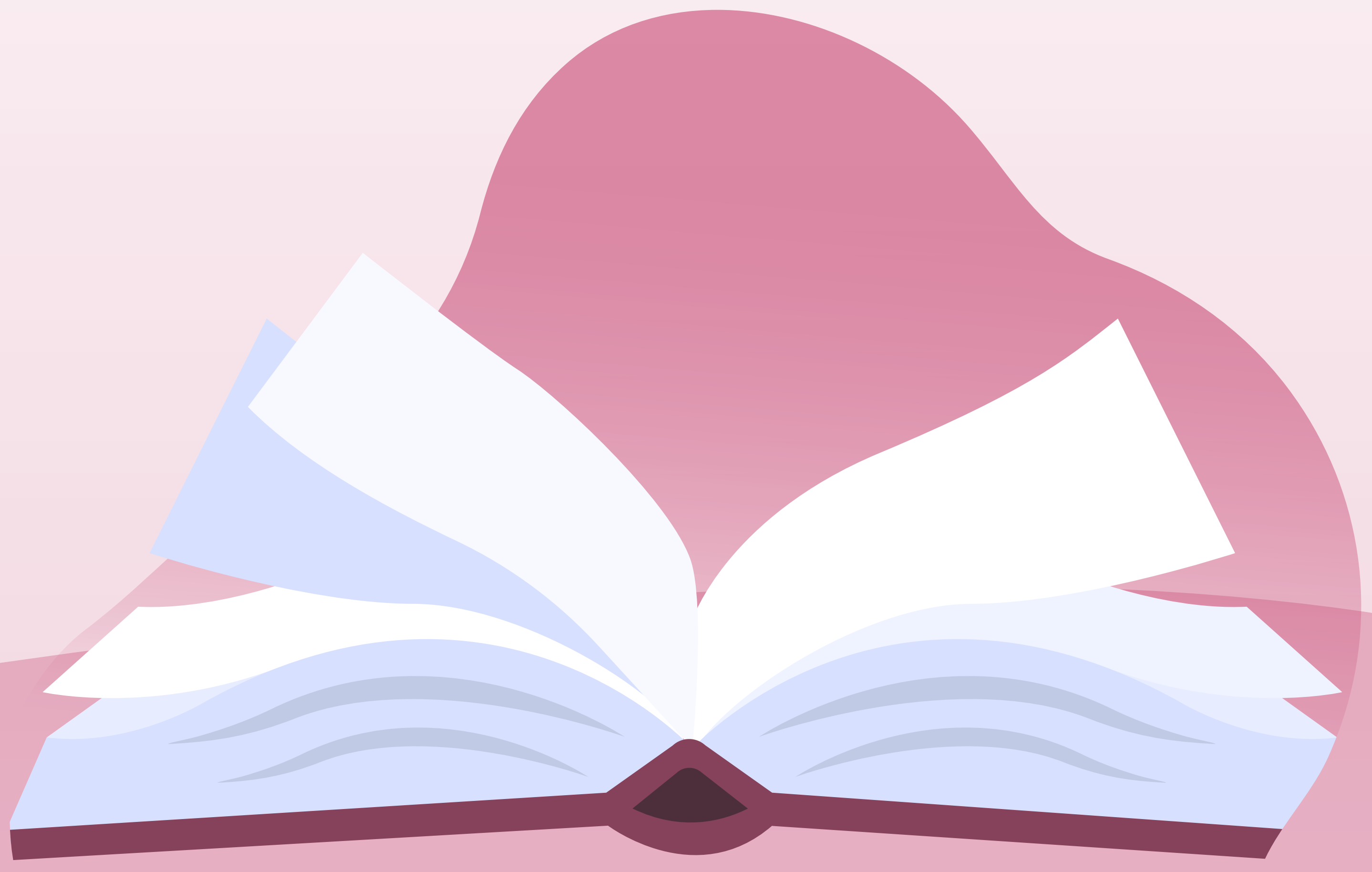
Words matter: FOP dictionary

Talking about FOP might sometimes feel like you are speaking a different language. See below for a dictionary of FOP key words with definitions that are easy to understand. You might want to share this with your family and friends so they can familiarise themselves with the terms too.



Fibrodysplasia Ossificans Progressiva (FOP) – FOP, sometimes referred to as 'Münchmeyer disease', is a genetic condition, where the soft tissues of your body (muscles, ligaments, and tendons) gradually turn into bone.[1] It is one of the rarest diseases known to medicine,[4] impacting just one in 1 million people.[2] Signs of FOP include shortened big toes, big toes pointing inwards and swellings across the body called flare-ups.[3,5]

Genetic mutation – A 'fault' or change in one or multiple genes. These changes can sometimes prevent the gene from carrying out its usual function in the body, which can lead to health problems.[6]

Genetic condition – A genetic condition is a disease caused by changes or mutations in one or more genes.[7]

Genetic testing – Genetic testing, also known as genomic testing, is often used to diagnose rare conditions which are known to be caused or linked to specific genetic mutations that lead to health problems.[8] If a doctor suspects that an individual might have FOP, they will likely recommend them for a genetic test. Diagnosis for FOP is confirmed through genetic testing.[3]

ACVR1 gene – All individuals with FOP have mutations in the ACVR1 gene.[9]

Flare/flare-up – An FOP flare-up is a painful swelling on the body which can be warm to the touch, and may last for days, weeks, or months.[4] Flare-ups can occur spontaneously or following physical trauma or illnesses.[10] When a flare-up settles down, often new bone has grown.[4]

Heterotopic ossification (HO) – The development of bone in areas of the body where bone is not normally present.[1] The word 'heterotopic' comes from the Greek words 'hetero', meaning 'other', and 'topos' meaning 'place'.[11]

Heterotopic bone – Bone formed as a result of heterotopic ossification. Also known as 'extraskeletal bone' (i.e., bone that is not part of the skeleton).[11]

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Useful resources and references

Useful resources

- IFOPA: What is FOP - A Guidebook for Families
- My Care Passport
- ICC FOP: The Medical Management of Fibrodysplasia Ossificans Progressiva: Current Treatment Considerations
- The FOP Friends' guide to supporting a child with FOP through school
- FOP Patient Experience map available on the FOP Friends' website
- GOV.UK Disability Rights

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