The below insights have been collated based on interviews with three people living with FOP and one caregiver. They do not necessarily represent the views or experiences of all people living with FOP, but instead provide a general overview of the themes and insights gathered during these interviews.



Worsening of symptoms and day-to-day management

Looking to the future with FOP

"I knew something wasn't right"

Initial symptoms

and journey to diagnosis

"You feel lost the whole way through, no one knows what it is"

**Diagnosis** 

"You're losing a part of your body, you're grieving. It's out of your control and it's all overwhelming"

Symptom progression

"A lot of doctors, because it is so rare, don't want to know. They don't know how to deal with it"

"We live everyday as it comes, we don't think too far into the future because a lot of things are going to change"

Patients and their families may

avoid spending time planning

for the future, but are aware

that additional care will need

to be arranged as flare-ups and

mobility worsen

Initial features and symptoms tend to appear in childhood and can include unexplained lumps and toes shortened or curved inward

It can take years to receive an accurate diagnosis. Most will receive misdiagnoses ranging from bunions to tumours. May undergo unnecessary treatments such as chemotherapy, or operations that can accelerate the progression of FOP

Patients will be passed between HCPs, ranging from oncologists to paediatricians, who have never come across FOP

RATIONAL EXPERIENCE

**PATIEN** 

**EMOTIONAL EXPERIENCE:** 

**EMOTIONAL EXPERIENCE: CAREGIVER** 

ENVIRONMENT

PATIENT NEEDS

It may take a series of X-rays, body scans and a genetic test before a diagnosis is confirmed. Patients might choose to book a private appointment to speed up the process

Diagnosis is likely to come from an HCP who doesn't specialise in the condition. After diagnosis, patients are often put in touch with FOP specialists and patient associations e.g., **FOP Friends for tailored** education and advice

**Patients likely to experience** several painful flare ups throughout childhood and adolescence triggered by accidents or injuries. This can lead to new bone growth and a loss of mobility in different parts of the body

Can be difficult to navigate leisure time - parents may try to protect children with extra padding on clothing or in the home

Whilst still mobile, patients will go to school (but may need one-to-one support), and may work in early adulthood

Patients treated in paediatric hospitals throughout childhood and adolescence, check-ups approximately once a year as little can be done in between flare-ups

Patients and their families will reach out directly to FOP specialists for advice when experiencing a painful flare up

Flare ups are sporadic and triggered by injury or illness but can also occur for no known reason. With mobility lessened over time, patients tend to rely on crutches or a wheelchair in adulthood

stiff, and slow. As patients lose mobility, they are unlikely to work and can need full-time care at home

Patients report feeling sore,

Patients may go to local A&E departments for medical advice when experiencing a troublesome flare up

Some may go years without experiencing a flare up and HCP checks ups are infrequent

Whilst patients stay in contact with FOP specialists for ad-hoc advice, check-ups may be with HCPs who specialize in other areas and need to upskill themselves on FOP e.g., local GPs. This has, on occasion, resulted in patients receiving unnecessary treatments e.g., physiotherapy or injections which can further accelerate

disease progression

Patients may be prescribed steroids and pain medication when flare-ups are suspected or particularly severe

> Afraid to talk about long term care as the future feels scary and daunting. Tries not to focus on the future too much and take each day as it comes

Memories from childhood may include tests, treatments and hospital wards

May remember feeling different and not a 'normal' child

Most diagnosed in childhood so have little memory of it, instead thinking of FOP as something they have always lived with and part of their identity

As initial flare-ups occur, patients can be left with feelings of loss for a part of their body they will no longer use

Report feeling out of control and overwhelmed as flare-ups worsen

May experience a desire to have a 'normal' childhood and not be 'wrapped up in cotton wool'. May try to retain independence by learning to drive, or going out regularly with friends. People with FOP are fiercely independent. They often use a range of tools and devices which help them to maintain their independence

simple acts of self-care like going to the bathroom unassisted or washing hair Frustrated at having to be the

Some miss being able to carry out

Feel frustrated when things are not done the way they want them to be done by carers, want others to understand what they're going through

expert and tell doctors about FOP

Feel supported by friends, family, patient associations e.g., FOP Friends and patient community

Generally, feel able to manage own emotions but additional support can be helpful when things get hard

**Emotional impact of waiting** weeks between appointments can leave caregivers feeling lost and hopeless

feel it isn't explained properly, some don't understand the full implications of the condition but feel afraid of the unknown and the fact it is progressive

Have never heard of FOP and

Carry out own research to find out more and rely on patient associations e.g., FOP Friends for advice

or offering helpful advice

Every situation becomes damage limitation to avoid injury which can be stressful, constant fears over trying to keep patients safe

Can feel like you have the whole world on your shoulders, misses the days when little things were all you had to worry about

Professional advice can be helpful to manage emotions, some emotional support offered for caregivers but not enough

Thoughts about the future cause anxiety, try not to concentrate on what won't be possible

**Caregivers and patients are** hopeful for advances in medicine

Friends and family offer support. This might include helping with childcare, researching into FOP

Friends and family understand the condition to an extent

Friends try to treat them as if they are 'normal' and like everybody else

Local MPs, schools and wider community may be supportive in helping to raise awareness of FOP or make adaptations

for the patient

Patients who are able to work are grateful for the opportunity

Those around them don't understand the scope of what they can and can't do, or how long it takes to complete simple tasks

People are not always patient or understanding

Greater awareness of the signs and symptoms of FOP amongst paediatricians, orthopaedists and podiatrists

Signposting to resources to help patients and their families to better understand FOP, including testimonials and support from others living with / caring for someone living with the condition

Support for patients and caregivers to help deal with the physical and emotional changes that come with a progressive condition

Greater awareness of FOP amongst GPs, emergency doctors, nurses

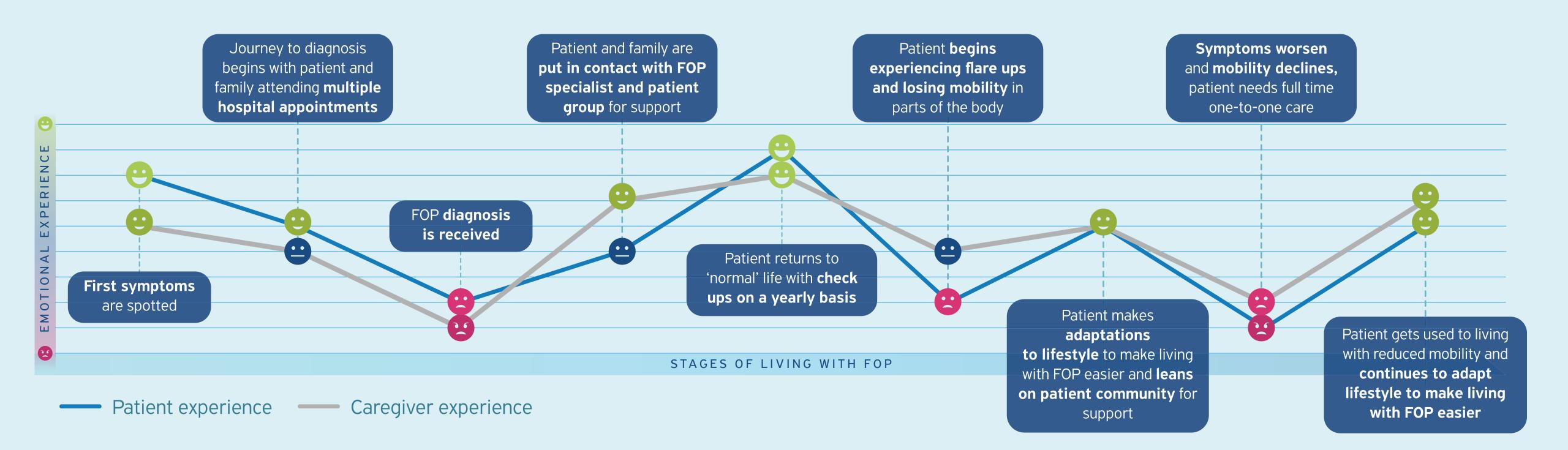
**Greater awareness of FOP** amongst the public

Emotional support and resources to help patients communicate about their condition with those around them

**Emotional support and practical** advice to help patients manage short and medium-term care, one step at a time

Patient X - FOP journey





Note: This is an example patient journey, based on consolidated insights from interviews with three people living with FOP, and one caregiver. This does not represent one patient's experience, nor the experience of all patients living with FOP. It is a representation of the patient pathway and emotional experience that a patient living with FOP could experience.