

Supporting a child with FOP:

*a practical guide to
their learning journey*



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Spectrum Community Arts

Inclusive dance

Featured Individuals

Please see Appendix 6:

Gallery of Friends

But our biggest thanks go to the amazing individuals who are living with FOP and continue to be an inspiration to us all.

For our little warrior.

HBG

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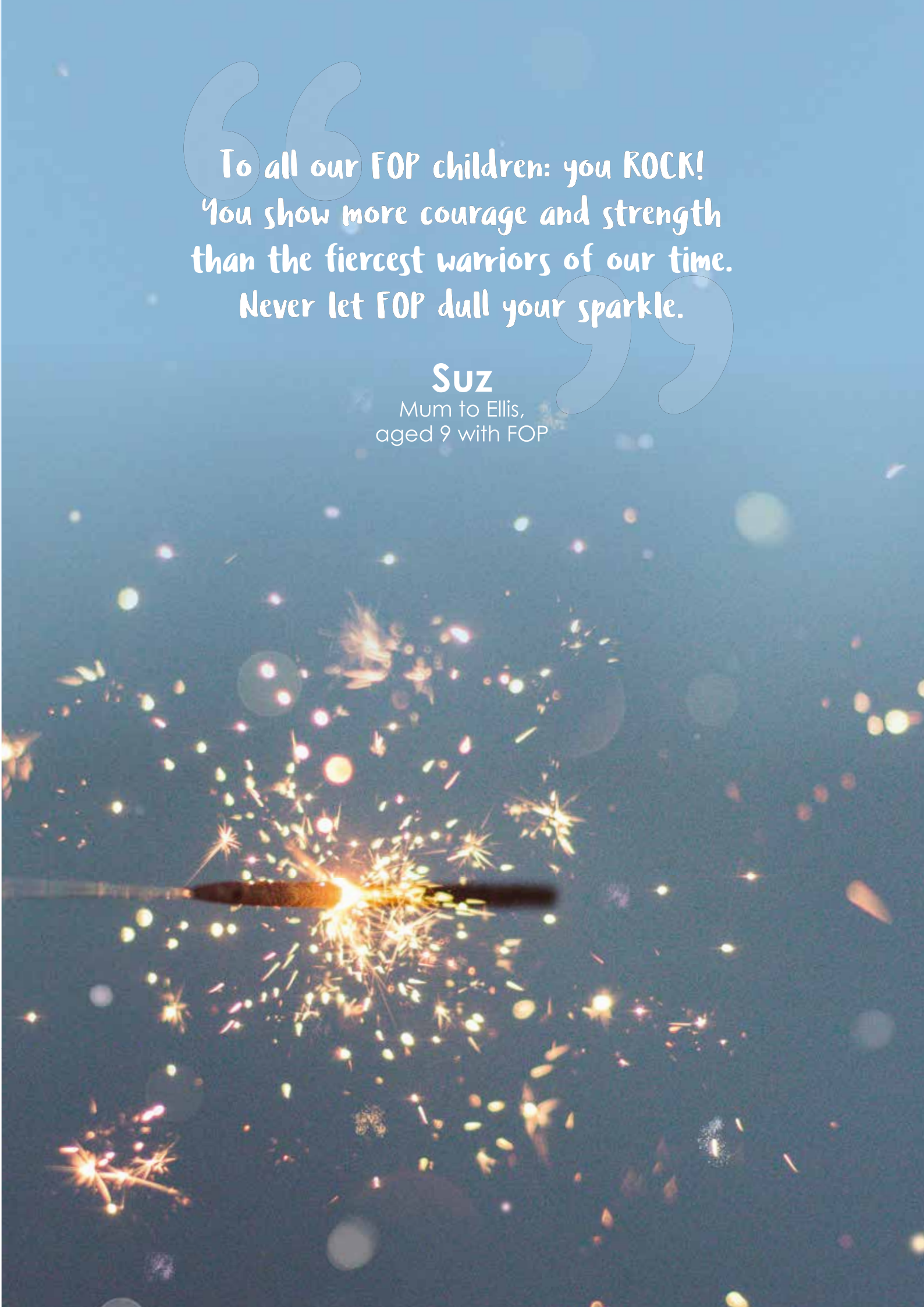
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“
To all our FOP children: you ROCK!
You show more courage and strength
than the fiercest warriors of our time.
Never let FOP dull your sparkle.”

SUZ

Mum to Ellis,
aged 9 with FOP





There is nothing more inspiring than a young person with FOP making the most of life.

We are all dealt different cards and it's how we play them that matters. People with FOP who enjoy life and light up the lives of others are grand masters of the game.

This book outlines opportunities and precautions to enable children with FOP to thrive at school. It is a collaborative project by educational and medical professionals and people affected by FOP. There is practical advice alongside heartfelt personal reflections.

There is a wealth of support available, from people who truly understand the emotional rollercoaster that is living with FOP, including a wonderful network of families, to the professional services provided by local and health authorities. **This book is just one example of the many ways that a small community can make a real difference.**

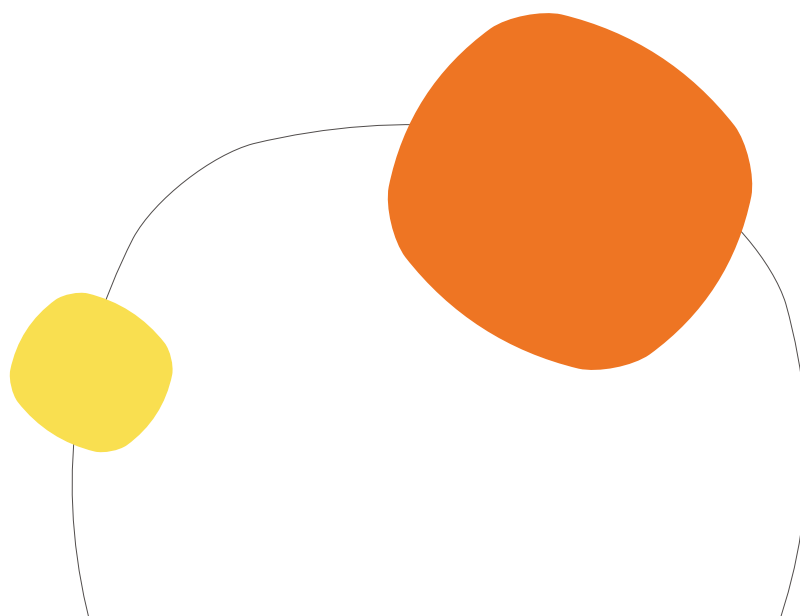


Stephen Fry



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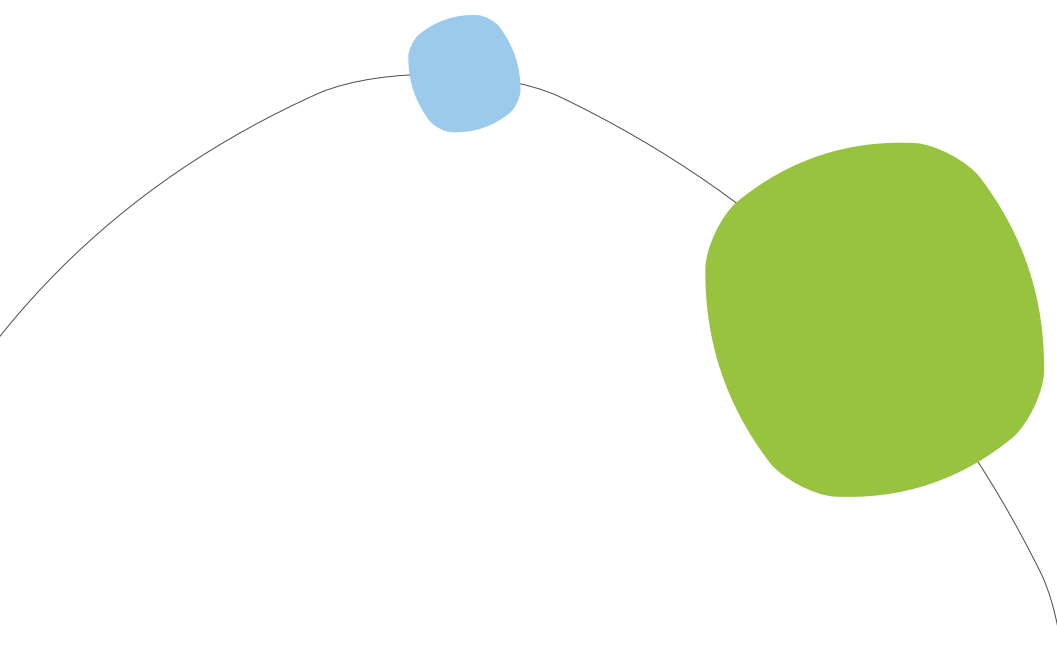
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Introduction

Have you ever been told you're "one in a million"?

Well, people with FOP are actually rarer... they're around 1 in 1.5 million!

Living with an ultra-rare condition such as FOP brings challenges most people can never imagine. But it also brings with it a different set of achievements and successes to be celebrated. They say your school days are the greatest days of your life: we hope that this book will help FOP children get the most out of their school days, with the best possible outcomes and happy memories to treasure too.

A note to readers:

The aim of this book is to provide a detailed, practical guide to ensure the necessary opportunities are available for pupils with FOP to achieve their potential. We hope this will support everyone involved with navigating the situations and challenges that educating a child with FOP can present. Whilst the initial brief was 'just for schools', we soon realised that much of the information in it would also apply to those who were running out-of-school groups such as orchestras, Scout and Guide groups, sports clubs and so on.

To say the scope of the book is wide is clearly an understatement: new teachers, experienced teachers, teaching assistants, parents new to FOP, Early Years settings, primary schools, secondary schools, parents whose child is moving-on to secondary school and beyond, coaches, group leaders, the list goes on... so there may be information in here that you already know, or that is not relevant to you.

We decided against producing multiple publications, "For Parents", "For Practitioners" and so on, as we felt there was a significant overlap for all audiences. Therefore, we hope you will be able to dip in and out of this book as and when you need it.

We know there are many, many amazing educational practitioners and other people who work with, and cheerlead for, the children. We believe we have some of the best teachers in the world! They have worked with children with needs ranging from high to low, 'gifted and talented' to those with a number of barriers to their learning. We are honoured to say we have had the privilege to work with a great number of these individuals. We hope that where teachers feel we have 'stated the obvious' they will read it with the view that it is offering guidance and support to those less experienced than themselves.

There are several Parents' Guides already in circulation regarding the statutory guidelines and processes for including pupils with additional needs in a mainstream school. It is not the intention of this guide to repeat this information; rather our goal is to give an overview of considerations specific to FOP. For further reading and advice, please read the Library section at the back of this book.

This handbook was not written by a medical professional, although FOP medical experts have been consulted on the content. Medical information included is presented where relevant to a child's schooling and the setting's provision and care for a child with FOP. For specific and up-to-date medical guidance, including diagnosis, please consult an FOP specialist, or read the medical guidelines "The Medical Management of Fibrodysplasia Ossificans Progressiva: Current Treatment Guidelines" published by the International Clinical Council on FOP, as referenced in Appendix 2.

The IFOPA's "What is FOP? A guidebook for Families" has formed the basis for much of the medical information in this book. We have also sought the advice and contributions of the experienced FOP specialists credited at the front of this guide, who serve and care for the FOP community on a daily basis, and have done so with tireless dedication for many years.

Effective communication between the child with FOP, their family, and the educational setting or group, is essential to enable the child to achieve both academic and personal success. What works for one child and their family may not work for another: one family living with FOP may be more comfortable taking a 'considered risk' approach than the next. Other families may be, understandably, more cautious. There is no right or wrong way to parent any child, and this is never truer than for a child with FOP.

Disabled children are children first. They are people with their own lives to lead and ambitions to achieve.

Using this book

We hope that this book will follow the child throughout (most) of their schooling. The book can be annotated and highlighted with reference to the child's specific needs. We have included space at the back of the book for parents and teachers to make notes. The book can then be handed on to the next educational professional, creating a personalised learning record of the child's specific needs.



All information on this book is given in good faith and is based on sources believed to be reliable and accurate at the time of publication. Parents and educational practitioners should use the guidance in this book as a starting point from which to make informed decisions based on the child's specific needs at that time.

Parents and schools should seek expert medical guidance from a qualified medical professional before making any decisions that will affect the child.

We do not accept legal liability or responsibility for the content of the advice or information contained in this guide, or any consequences arising from its use. Where parents need resolution advice with regards to their child's SEND provision, they should seek the appropriate legal advice.

FOP Friends cannot be responsible for any advice or information from external websites referenced in this book.

We recommend that you verify the accuracy and suitability of the information for your needs.

What is FOP?

Fibrodysplasia ossificans progressiva, or FOP, is a rare genetic disease that affects around 1 in 1.5 million people, making it an ultra-rare genetic condition. However, this figure is just an estimate and is currently under review. Research teams are attempting to refine this incidence with further studies in different worldwide locales. It is one of the most disabling conditions known to medicine. FOP causes the soft connective tissue of the body to turn into new bone. When that occurs over or near joints, it restricts the sufferer's movements. This new bone, or ossification, within a muscle, tendon, or ligament, can mean that the sufferer is unable to move a joint. Over time, the FOP sufferer will progressively lose movement throughout their body, eventually imprisoning them in a second skeleton. It is painful, debilitating, and distressing. At present there is no known treatment or cure. However, clinical trials are underway with hope for a treatment in the future.

FOP is a progressive and variable condition which means that it affects each person in different ways and at different stages of their life. It is due to a fault in the ACVR1 gene and is usually caused by a mutation in the gene at conception. There is no way of knowing how or when 'the beast' that is FOP will rear its ugly head. Some children are impacted from the first few years of their lives, whilst other people with FOP may not even realise they have the condition until their early teens or even later. This is just part of the cruelty of FOP.

At birth, most people with FOP look 'normal', except for the tell-tale malformed big toes. The big toes are short, missing a joint and curved inward. Sometimes, they may also have shortened or turned-in thumbs or may have other skeletal changes. During the first or second decade of life, a person with FOP may endure painful swellings across their bodies that can look like tumours. They often appear over the neck, shoulders and back first. As the swellings mature, they can leave new bone growth behind, thus restricting the person's movements. A child with FOP may endure a series of FOP flares, almost in succession - a flare cycle, which can have a serious impact on their education and their ability to access school. Other children with FOP may not have the same challenges.

The variable nature of FOP means the health of a child with FOP can cruelly change overnight with no reason or warning. Swellings can spontaneously occur and ultimately cause irreparable change. The resulting bone growth cannot be removed with surgery as that in itself causes the body trauma, thus potentially triggering further flare-ups.

If a person with FOP suffers a knock, bump or fall, or impact into the muscle, tendon or ligament, it can trigger an FOP flare-up or swelling. Even immunisations into the muscle can trigger a flare response. These swellings are often excruciatingly painful and can last a few days, weeks or even longer. There is very little a child with FOP or their parent can do to prevent any fall-out except wait and hope. Over time, as the flare subsides, new bone may have grown and where this occurs over a joint or within a muscle, they will lose some or more of their mobility.

It is because of the potential for these irreversible consequences resulting from an accident or incident, that precautions and accommodations need to be put in place for the child with FOP in their educational setting.



Sharing your child's diagnosis

When you receive the diagnosis that your child has FOP, your world falls apart. You have no idea what you are going to do, how you will cope, why it is even happening to you and your child. Over time, you and your family will have come to terms with part or all of the diagnosis. You will have had good days and bad, but you will be making small steps on your new journey with your child and your family. You are getting there.

Then you have the next milestone which is breaking the news to close family and friends. Telling the same story over and over again. Explaining "No, you won't have heard about it" ... "No, there's no treatment" ... "No, they won't get better in the near future" ... is simply heart-breaking. It does get easier, but it's never a conversation you ever want to have. Again, those days and weeks will pass, and your life will return to its new normal.

And then comes school. You now need to decide if and how you tell the parents and other children in the class that your child has a medical condition and will need to be treated differently, however desperately you want it not to be true.

Every parent and every family deals with this situation in a different way: there is no right or wrong, only what is best for your family at that point in time.

Where FOP has started to impact your child physically, it may be that people approach you and start up a conversation, which you may find easier to deal with. If your child isn't impacted at all, you may not be ready to tell a number of strangers personal things about your baby.

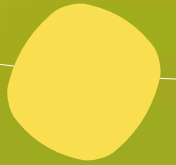
In the experience of most families living with FOP, the responses that they have received when telling people about their child's diagnosis have been overwhelmingly positive. As for you and your child, you may decide to tell people as the situation arises. Some parents choose to send a letter home to all families, so they don't need to keep explaining things over and over; other parents like to go into school and talk to their child's class and give a small presentation about FOP; and some children like the opportunity to talk openly and honestly to their classmates about FOP and how it impacts their life.

Whatever decision you make must be right for you and your family. Reaching out to other families living with FOP who have been through the same situation may help. The FOP community is a close-knit group of people and should you choose it, there will always be someone there to listen and offer you the friendship and guidance you need.





Getting Started



What does 'special educational needs' mean?

In any classroom, in any country, there are children all learning at different rates, in different ways. Their class teacher will be ably adapting their teaching styles to meet the needs of those children.

However, it is likely that there will be at least one child, usually more, who have a special educational need or disability, or SEND as it is currently referred to in England. This also includes complex medical conditions, and FOP comes under this umbrella. This may mean that they have one or more barriers to their learning and to accessing a broad, balanced and dynamic curriculum that their peers are able to access.

The Department of Education (DfE) for England states:

A child of compulsory school age or a young person has a learning difficulty or disability if he or she:

- Has a significantly greater difficulty in learning than the majority of others of the same age, or
- Has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions

A child under compulsory school age can also have SEND if they fall within the definitions above or would do so if educational provision was not made for them.

This means that a child with FOP is entitled to additional support within their setting to ensure they are able to enjoy the same quality of education and experiences as their peers.

The Department for Education's SEND Code of Practice can be found online at:

bit.ly/SEND_CodeofPractice_2015

The school system is only as good as the information, time and support you put in.

Remember how scared you were as a parent when your little one was diagnosed? You were probably overwhelmed lived in a constant state of worry and panic...should they do this? can they do that? That's what it must feel like to your child's school and class teacher. They too can easily become overwhelmed which can then give rise to the tendency to overcompensate and allow your child to do nothing!

You have to have an honest, two-way conversation with the setting and reassure them. You are in this together.



Support for pupils with SEND across the United Kingdom and beyond

The governments of England, Scotland, Wales and Northern Ireland all have different statutory requirements for supporting children with additional needs. Where references are made in this book to the legal duty of educational settings, it is referencing the English Code of Practice 2014. An overview of the requirements in Northern Ireland, Scotland and Wales is provided below.

However, the primary focus of this book is to provide FOP-specific information, support and guidance for children and their teachers. This will enable them to receive the highest standard of education and opportunities, within a safe and supportive learning environment with the best outcomes possible.

We hope the guidance specific to FOP will be relevant, useful, and transferable throughout the UK, USA, Australia and beyond...

Northern Ireland

The SEND process is currently under review in Northern Ireland with a new framework being developed. The Special Educational Needs and Disability Act (Northern Ireland) 2016 (SEND Act) received Royal Assent in March 2016. The Act places new duties on the Education Authority (EA) and health and social services Trusts, and Boards of Governors of schools. It provides new rights for parents and children over compulsory school age. Work to finalise the draft SEN regulations is ongoing. At the time of publication, the proposed implementation date for the SEND Act (NI) is September 2019. However, due to there being no sitting government, this date is more likely to be 2020 although even that date is provisional.

For further, up to date information regarding the SEND process in Northern Ireland, to read the current Code of Practice, and to see the new proposed Framework, visit:

bit.ly/NI_code_of_practice

For further support and information regarding the SEND process in Northern Ireland, contact the Special Educational Needs Advice Centre (SENAC).

[SENAC.co.uk](https://www.senac.co.uk)

or read:

bit.ly/senac_guide_2017



Scotland

Schools and educational settings in Scotland must comply with the Education (Additional Support for Learning) (Scotland) Act 2004 (as amended), often referred to as the ASL Act. It puts a duty on local authorities to identify children who are failing to benefit from school education, for whatever reason, and to provide them with “adequate and efficient” additional support for learning to help them achieve their fullest potential. Under the ASL Act, local authorities must also keep additional support for learning under review. Local authorities in Scotland use a variety of different approaches to do this, so learning plans are called different things in different areas. Children with more significant additional support needs may need a more structured plan which is sometimes called an Individualised Education Programme or IEP, but they may also be called Additional Support Plans, Child’s Plans, Wellbeing Plans, etc.

The only statutory plan in Scotland is called a Co-ordinated Support Plan (CSP). Children are eligible for a CSP if they:

- need support due to complex or multiple factors that adversely and significantly affect their school education
- have needs that are likely to last for more than a year, and
- need significant additional support from the education department of the local authority and other agencies, such as the NHS and social work.

In Scotland it is presumed that children will attend mainstream school unless exceptional circumstances apply. These are:

- where a mainstream school would not suit the child’s ability or aptitude
- where providing education in a mainstream school would negatively affect the learning of other children in the school
- where placing the child in a mainstream school would cost an unreasonable amount

To read the Code of practice for Scotland visit:

bit.ly/scotland_additional_support_for_learning_2017

For further information visit:

education.gov.scot/parentzone/additional-support

Or:

enquire.org.uk

Wales

The provision for pupils with additional needs is currently under review. The title of Additional Learning Provision (ALP) will replace Special Educational Provision. A single category of Additional Learning Needs (the equivalent to Special Educational Needs in England) is being introduced. This will replace Statements, School Action, and School Action Plus. All children under ALN will have an Individual Development Plan (IDP) which is equivalent to an Educational Health and Care Plan in England. The IDP will be reviewed annually and will include health and social care needs and provisions, as well as a person’s educational needs.

To read the Code of Practice for Wales visit:

bit.ly/wales_sen_code_of_practice

For information regarding supporting learners with healthcare needs in Wales, visit:

bit.ly/learning-wales

For additional information and support visit:

snapcymru.org



How to access additional support in England

The process to gain the additional support and funding a child with FOP requires, and is entitled to, is complex and can be overwhelming. SEND is also an area of education which is over-subscribed and underfunded. For families, it can feel like there is a never-ending pile of forms to read and complete, and the process can feel like it is taking forever. It is important that parents fill in and return forms promptly, and if they feel like things are taking too long, the parents must chase up the appropriate people in the relevant administrative departments. It is very easy for a child to 'slip through the net', so it is essential that the parents, or a family friend, act as an advocate for the child so they can get the support they require and to which they are entitled. Parents should not be afraid to push for what is in the best interest of their child.

Irrespective of which country the child with FOP lives in, it is imperative that the process to get additional support be started as soon as possible. The process is time-consuming and emotionally demanding, and getting the right provision for the child will take longer than the parents realise.

In order to begin the SEND process in England, the parents need to contact their local council to speak with the SEND Local Offer team. Parents can contact the department as soon as they have the diagnosis. There is no need to wait until the child is of school age. The sooner parents make the child known to the council, the sooner they can begin accessing the services their child needs. If the child already has a social worker or family worker, they may be able to help the parents begin the process and support them along the way.

Parents can search for the council's Local Offer online and find the page relevant to their location. There are pages offering advice and guidance to parents and carers. There is advice on how to apply for an EHCP as well as examples of completed forms and guidance on how to complete their own forms. This is part of a government initiative to transform the landscape of SEND and every area in England has a Local Offer. Parents and young people will also be able to find details of their local Parent Partnership Services.

If a child is already in an educational setting, an appointment can be arranged to meet with the SENDCo (Special Educational Needs and Disabilities Coordinator) to discuss the child's needs, and to make arrangements to begin the SEND process for the child.

For further guidance and support relating to the SEND process, there is a charity called Contact which helps families with disabled children. They offer excellent support and advice for families and are experienced in dealing with the SEND process. They also provide a number of useful and easy-to-read factsheets.

Throughout the process, chat with other families who have knowledge and experience of the process and can offer you both practical and emotional support. They will be more than happy to 'hold your hand' and help you if you ever feel like things are getting too much.



Education, Health and Care Plans (EHCP)

The process of getting an Education, Health and Care Plan for your child is the same as for any child with any form of additional need: learning, medical, physical, emotional, psychological. This chapter is meant to be a brief overview of the process.

The advice in this chapter is for pupils of legal school age in England, rather than pre-school (0–4 years). For advice and guidance for your pre-school child with FOP, please see the chapter on the Early Years Learning Environment.

Every educational setting has a member of staff in the role as the SENDCo, or Special Educational Needs and Disabilities Coordinator. The SENDCo plays a critical role in ensuring that pupils with additional needs get the provision they need and to which they are entitled.

Many parents feel that it is helpful for their child with FOP to have an Education, Health and Care Plan (EHCP) to ensure all their needs are recognised and met by the educational setting. An EHCP is a legal document that outlines a child's educational, health and care needs, where they are different to what you would expect for a child at that age.

It explains what additional support is required in order to access a broad and balanced education in school and then, as they move into adulthood, what support they will need to fulfil their own goals and achieve in life. It will be the SENDCo at the setting who will oversee the process.

The EHCP is written by the local education authority, following an Education, Health and Care assessment which is usually carried out by the setting. In the unlikely event that the setting does not think the child needs a plan, parents can contact their local authority directly to request one.

Getting a plan can be an overwhelming process, with a number of forms and reports to be filled in by a range of people who are known to the child, are knowledgeable about the condition, or who know about supporting children with additional needs in an educational setting. Most settings will support the family through the process. However, you may find it useful to ask a close friend or family member who is one-step removed from the situation to assist you with the process and the paperwork. Alternatively, your local authority should be able to provide you with an advocate from their Information, Advice and Support team (IAS), previously known as the Parent Partnership Service.

The local authority must complete the assessment within 16 weeks of the initial referral and, if they decide that your child needs an EHCP, then they must do so within 20 weeks of the original request.



Applying for an EHCP for your child with FOP

One of the trials when applying for an EHCP, is explaining FOP to agencies who will most likely never have heard of the condition. The challenge for your family is to explain the 'worst case scenario' for your child i.e. if they were to have a preventable accident whilst in school that leads to a serious injury and an FOP flare-up. The variable and unpredictable nature of FOP also makes it stressful when writing your case for support: reflecting on everything that could go wrong whilst your child is at school, is terrifying and heart-breaking in equal measure.

Where your child already has a number of restrictions due to ossification, it is easier to illustrate the brutal nature of FOP and explain what processes and safeguards need to be put in place, and why that will require additional funding. However, if your child is relatively unimpacted, or maybe not even at all, it can be difficult to justify to an observer why that child can't join in with the other children at that time without the additional provision.

To strengthen your case for support, you will need solid medical supporting statements from the FOP specialists. FOP Friends can put you in touch with medical professionals who are able to write a letter of support, explaining from a qualified, expert, medical standpoint why your child needs additional support as a precautionary measure.

Every child has the right to the same educational experiences, and it is not acceptable that a child with FOP has to 'sit out' of activities in order to keep them safe, when an additional adult would be able to risk-assess and adapt the activity to enable your child to participate at their own level.

For more detailed but generic advice regarding the EHCP process, please visit the following charities' websites:

Independent Parents Special Education Advice:

 [ipsea.org.uk](https://www.ipsea.org.uk)

Or

Contact (a Family):

 [contact.org.uk](https://www.contact.org.uk)

It is important to note that the child must be at the centre of any EHC plan and their wishes and feelings taken into consideration where practicably and reasonably possible.

For examples of a completed Education, Health and Care Plan, please contact FOP Friends.

The Review Process

The provision for most children with SEND is reviewed annually. However, in the event that the needs of your child change significantly, it may be necessary for you or the school to request a review of the provision before the end of the year.

If you are not successful...

Most children with FOP in England have/had an ECHP, so it is accepted that children with FOP need the additional support and provision. However, in the event of your local authority refusing to grant an EHCP following their assessment, you have the right to appeal their decision through the Special Educational Needs and Disability Tribunal (SENDIST). You will first need to go through mediation.

When the local authority writes to you with their decision, they must tell you the details of the mediation service they have chosen to use. In order to file an appeal, you must contact your mediation service within two months of the date on the decision letter.

Mediation is a less formal way of trying to settle the dispute between the family and the local authority. It will involve a meeting between both parties and an independent mediator who will endeavour to help you all reach an agreement on the point/s of dispute. Other relevant parties may be at the mediation. There is no charge for this service. You do not have to go through this step, you can phone the mediation advisor and explain you do not wish to take part in mediation.

Once you have either completed the mediation or informed the mediation service that you no longer want to go through with the mediation, you will then be issued a Mediation Certificate.

If you are not satisfied with the outcome after mediation, you can file an appeal. You will need to send the Mediation Certificate, along with your appeal document to the SENDIST to start an appeal.

If you feel it appropriate to continue with your appeal, please visit: www.ipsea.org.uk/general-advice-for-all-appeals for detailed advice, guidance and support for how to proceed.

Professionals involved in your child's schooling

Depending on your FOP child's needs and developmental stage, there will be a number of educational and medical professionals involved in the decision-making and planning processes. This can be very overwhelming, especially when you attend a meeting and find a room full of strangers, all discussing your child.

These are some of the professionals you may need to work with during your child's time in school. There may also be some discrepancies in the job title of certain professionals, with different councils giving slightly different job titles.

Audiologist

If your child has hearing difficulties, they may be referred to an audiologist. Even if your child does not have a hearing loss, it may be worth testing their hearing regularly as it can change over time, and with the seasons. Around 50% of people with FOP have hearing problems.

Clinical Psychologist

Your child may be accessing the advice of a psychologist service through the NHS's Children and Adolescents Mental Health Service (CAMHS) or Healthy Young Minds. They can advise the school on your child's emotional needs. They may also offer you sessions for your child to help them work through the emotional challenges of living with a life-limiting condition such as FOP.

Community Paediatrician

Their role is to over-see all the services that a child is receiving as part of their EHCP / the SEND process. They will provide medical advice to schools as part of the EHCP process. It is not likely they will have any first-hand knowledge or experience of FOP. They can refer your child to additional services or for further assessments or diagnosis.



Educational Psychologist

An Educational Psychologist (sometimes referred to as an EP or Ed. Psych) may be involved in your child's plan to assess their needs and pass on detailed information to the school. They work with the child and family to ensure the child reaches their full potential. They can assess any difficulties (learning, behavioural, social and/or emotional) your child may be experiencing. Their assessments and findings will influence and inform the outcomes of the council's SEND process, as well as the provision outlined on the school's EHCP for your child.

FOP Specialist

There are a number of UK based medical experts, mainly based at the Royal National Orthopaedic Hospital (RNOH). They can provide expert medical information about FOP to support EHCP applications. Also, there are international medical experts who are happy to support parents when they are applying for support for their child with FOP. FOP Friends can signpost you to an FOP medical specialist should you require it.

Governors

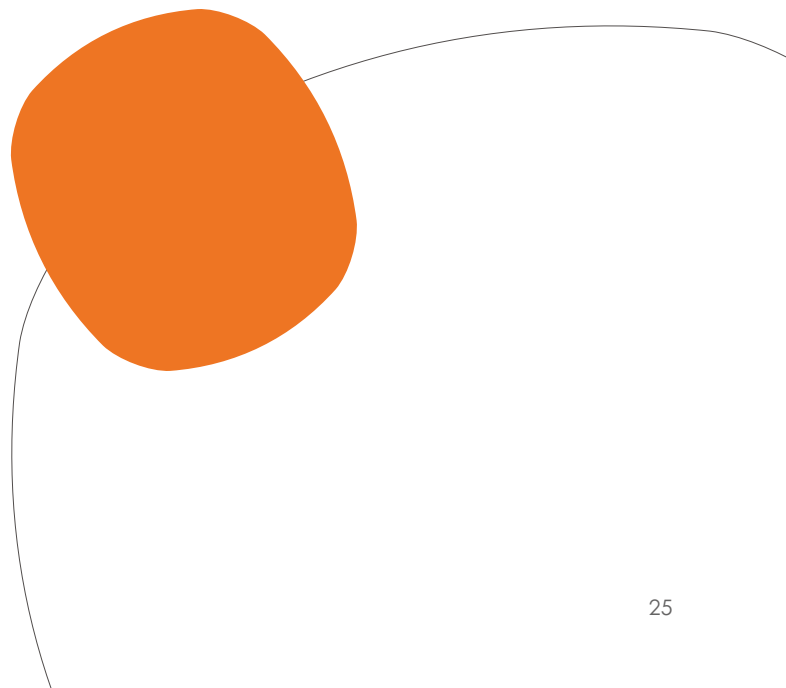
The Governing body of a school is an elected group of people who are there to assist with the decision-making of the school and to ensure that the school is doing the best for all its pupils. The Governors of a school may get involved in your child's support and care if adaptations are required that need the authorisation or financial support of the Governing Body. This may include alterations to the school's organisation (such as changing classroom allocations around to improve accessibility).

Occupational Therapist, often referred to as an OT

An occupational therapist will work with the child, family and school to ensure that the physical environment is adapted to meet the needs of the child. They can also provide information, advice and exercises to help with the health of the child. They can be invited into school at any time to reassess the equipment if the child with FOP's needs change. They can conduct a series of assessments to establish the child's movement abilities and strength, and then suggest adaptive aids that will enable the child to access the curriculum as well as maintain their independence for as long as possible. They can advise schools on lifting and moving techniques for the child. An OT can also advise on the appropriate adaptations and the best design when making building adaptations, such as accessible bathrooms. They can advise on the purchase of equipment that will enable the child to access as much of the curriculum as possible.

Physical and Sensory Support Worker

They can provide expert, practical advice for schools to help teachers provide an appropriate learning environment with positive outcomes for children with physical or sensory impairments.



Physiotherapist/Physical Therapist

A child with FOP may have a physiotherapist to help them to improve their physical capabilities through appropriate activities. A physiotherapist can put in a range of exercises that will aid the child with FOP. These can be completed by the child and their TA, or at home. The exercises can help to maintain the child's level of strength and flexibility, although these exercises need to be performed 'actively' by the child, to prevent putting additional strain on the child's muscles. Any attempt to regain function runs the risk of further injury to the child. Ensure that the physiotherapist understands the nature of the condition, and the need to not exert undue stress on the muscles which can cause fatigue and possibly trigger a flare. Some of these activities and exercises can be done at a time when the rest of the class are doing an activity the child with FOP is unable to join in with. They can also develop a range of exercises that will assist the child with their breathing to promote healthy lung function. Ensure that the physiotherapist has consulted with an FOP specialist doctor prior to commencing any exercise programmes with the child.

Podiatrist

The classic 'turned in' FOP toes may require additional care and maintenance to prevent infections or further problems. If your child's legs or feet have been impacted by FOP, they may need adapted footwear.

Representative from the PYPPS

The Parent and Young People Partnership Service is provided by your council. They can provide you with free, impartial, confidential and accessible advice and support relating to SEND.

Representatives from the Council's Access and Inclusion Team/SEND Case Worker

Your local council will have a SEND team who are responsible for coordinating the EHCP process for all children. You will be allocated a person who will learn about your child's case and ensure that their plan meets their needs.

SEN Consultant Physical/Medical

Your local council may send a SEND consultant who will be able to offer impartial advice to both the setting and the parents as to the best way to support the child on their educational journey, with a focus on as inclusive an education as practicable and possible.

Social Worker/Family Support Worker

After a social care assessment, you may be allocated a social worker or family support worker for your child. They can help you to access a range of additional services for your child. They can liaise between different departments such as health and education. They will also act as an advocate for your child and your family.

Transport

Depending on the needs of the child and their level of mobility, they may be eligible for free home to school transport. It may be that, in order to meet the physical or learning needs of the child, they need to go to a school further away from home. When a council provides transport, it must be both suitable for the child's needs, and free.

Even when transport is necessary, getting the council to agree to provide it can be a challenge and the parents may be faced with a number of excuses as to why it isn't possible, thus creating additional battles and stress for the child and their parents. Again, the charity Contact can provide excellent advice and guidance on this matter.

Details regarding the eligibility of a pupil for transport support and how to apply can be found on the council's Local Offer page.







Caring for the child

Medical considerations

When a child has a complex medical condition, there are several provisions that will need to be made in order to look after the health of that child. Schools should use 'Supporting pupils at school with medical conditions' guidelines from the Department for Education. This provides statutory guidance for the governing bodies of both maintained schools, and academies.

bit.ly/supporting_pupils_with_medical_conditions

Within these guidelines are templates to support the writing of an individual healthcare plan or HIP. The organisation 'Health Conditions in Schools Alliance' can provide additional and expert guidance for educational settings. Any Individual Healthcare Plan should be a working document that is adapted and modified as required, not just at an annual review meeting. As explained, the nature of FOP means that a child with FOP can suffer significant health changes within a short period of time, so their IHP must be updated to reflect the child's current medical needs.

Despite all the best practices and planning in the world, accidents can and will happen with children. It is essential that all members of staff (both teaching and auxiliary) are aware of the child with FOP and that they are aware of procedures that are in place to deal with both simple accidents, an emergency, and potential flare up situations.

At the time of writing, any treatments for FOP based on the treatment guidelines have varying rates of success. Some therapies seem to have higher rates of efficacy than others, but none are perfect. Every parent will have their own way of dealing with injuries to their child with FOP, so it is imperative that the family and educational setting agree on a care plan and an emergency plan that meets the needs of the child, that the family is comfortable with, and that is regularly reviewed to ensure it reflects the impact FOP is having on the child. This will need to be in line with the school's Medical Conditions policy.

Children with FOP are at higher risk of complications from common illnesses. When a school notices that a number of their pupils are becoming ill with the same illness (for example whooping cough, stomach bugs, tonsillitis to name just a few), they should notify the FOP parents. The parents can then seek additional expert medical guidance on what measures, if any, they should take to prevent their child from contracting the illness. Viral illnesses, whilst upsetting, distressing, and usually inconvenient for a healthy child, can in fact precipitate flare-ups in a child with FOP. Parents and schools should be aware of this so appropriate action can be taken if required and deemed necessary.



Individual Healthcare Plans (IHP)

As outlined in the 'Supporting pupils at school with medical conditions' document, the governing body of a school should ensure that the school's policy for supporting children with medical needs addresses the role of individual healthcare plans (IHP) and who is responsible for their development. An IHP should be developed with the child's best interests in mind and ensure that the school assesses and manages risks to the child's education, health and social wellbeing, and minimises disruption to the child's development and learning.

An IHP can:

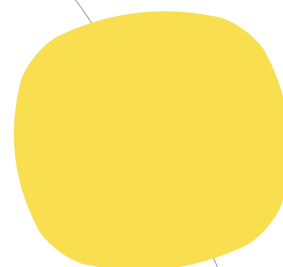
- Help to ensure that schools effectively support pupils with medical conditions
- Provide clarity about what needs to be done to support the child, when, and by whom
- Be particularly helpful when outlining care for a complex condition
- Be essential in cases where conditions fluctuate or change
- Provide detailed information in the event that a high-risk emergency intervention is required

An IHP should be:

- Easily accessible to all who need to refer to it, particularly in the event of an emergency
- Kept as a confidential document
- Useful and not place a burden on the school, but should capture the key information and actions that are required to support the child effectively
- Specific to the needs of that child
- Regularly reviewed, when necessary, to ensure they always reflect the current needs of the child
- Drawn up in partnership with the school, parents, relevant healthcare professionals who can advise on the most appropriate course of care for that child. Pupils should be involved, and their views taken into consideration, whenever possible

Templates for schools to develop their own IHP forms are available on the government's website. For more specific guidance on writing an individual healthcare plan, please refer to the DfE's 'Supporting pupils at school with medical conditions' document.

Where the child has a special educational need identified in an EHCP, the individual healthcare plan should become part of that EHCP.



Administering medication at school

The administration of medication to pupils is a common source of concern for education staff. Whilst they will want to provide the best level of care for a pupil, they may also be apprehensive about giving the correct dosage at the correct time. It should be noted that teachers are not contractually obliged to administer medicine or supervise a pupil taking it. However, it may be that support staff (as in the case of someone with responsibility for a child with FOP) may, in their contract, have specific duties to provide medical assistance to some pupils. As advised by the National Education Union, prime responsibility for a pupil's health rests with the parents who should inform the headteacher of the child's medical needs. In the case of a child with FOP, this then needs to be written into the child's Individual Healthcare Plan which will form part of the EHCP.

The document 'Supporting pupils at school with medical conditions' states that medicines should be administered in school if it would be detrimental to a child's health, or school attendance, not to do so.

Agreement should be reached between the parents and the school as to the school's role in supporting the child's medical needs, in accordance with the school's policy. Staff should then be consulted by the headteacher and asked to volunteer. Individual decisions on involvement must be respected.

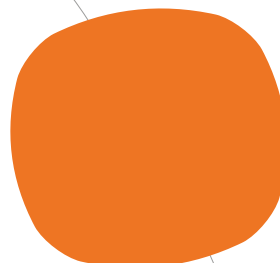
All guidelines need to be written in line with the school's medical policy.

All members of staff who have responsibility for administering medication to a child with FOP, should receive appropriate training from a qualified person/s and feel confident that they understand what to do, and when. This training should be regularly reviewed.

Any member of staff with responsibility for the child with FOP, including auxiliary staff members and office administration staff, should know where the child's medication is stored. Instructions for how to administer the medication should also be stored alongside it. The location of the medication should be stated in the IHP/EHCP.

All medicine should have the child's name and dosage clearly labelled on the packaging. Whilst some GPs no longer routinely prescribe paediatric paracetamol (Calpol) or ibuprofen (Nurofen), they will prescribe it if the parents explain that it is for the purposes of administering at school. Some schools will only administer GP-prescribed medication.

In the case of an ambulance being called, a copy of the Individual Healthcare Plan should be given to the paramedics on arrival. See the section 'What to do in an accident'.



Supporting first aiders

All educational settings have members of staff who are first aid trained to a lesser or higher degree; some settings may also have access to a school nurse or clinical aide. Whilst they will have experience of administering basic first aid, and of treating other children with specific medical conditions, it is highly unlikely they will have had experience of treating a child with FOP.

All school first aiders should consult the IFOPA's FOP medical guidance which is referenced in this book. They should re-read this guidance for refresher purposes on an annual basis, or more frequently where necessary.

Office administrative staff who would be responsible for calling for an ambulance in an emergency situation should also familiarise themselves with the information, reviewing the protocol regularly. They should also know exactly where the Emergency Medical Information is located, and the child's IHP/EHCP, so they can hand it over to paramedics immediately.

In preparation of an EHCP, it may be decided that additional medical training is necessary for first aiders in how to treat a child with FOP, and to help define what constitutes an 'accident' or an 'emergency' and the other situations in between. It may also be helpful for the parents to be in attendance for part or all of this training and to make themselves available to answer any questions or concerns the first aiders may have.

It is always good to reassure first aiders that there are no silly questions they can ask, and that as a parent you would prefer them to ask than to make a guess and get it wrong. It is likely that in the beginning, any member of staff who is responsible for dealing with any medical incidents involving the child with FOP, will feel the need to contact the parents with every minor scrape, just to ensure they are 'doing the right thing'. However, as the relationship between the setting, child and family develops, their need for reassurance is likely to lessen as they follow the agreed plan, get to know the child, and begin to understand the condition. Also, as the child gets older, they are more able to advocate for themselves. Over the years, there will be a natural ebb and flow to the dialogue between home and school. It is always good to regularly review and remind first aiders of the plan to ensure things are still relevant and to ensure a level of complacency doesn't set in.



What to do in an accident or emergency

Minor cuts and scrapes

Children, especially younger ones, tumble over all the time. It's all part of the learning process. However, the implications for children with FOP can potentially extend far beyond a cartoon plaster and a note home.

Children who are already impacted by FOP may also have the added challenge of impaired balance which can lead to an increased likelihood of falling over. Some children with FOP may have protective headwear or a band to wear at certain times of the day or during specific activities. The parents will include details of this in the child's care plan.

For a minor injury:

- A simple cut, like with scissors, poses no additional risk to a child with FOP. Clean wound and apply a plaster.
- For a small bump, apply ice to the area and rest. Some parents may request the child is given ibuprofen. GPs can prescribe ibuprofen for the purpose of administration within schools, with the correct dosage adhered to the medicine.
- A phone call to the parents is advisable to inform them what action has been taken.
- If the child with FOP has a home-school diary, record the incident.

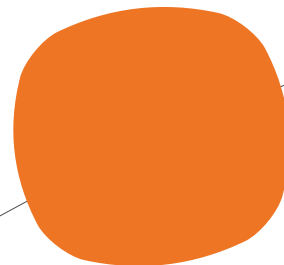
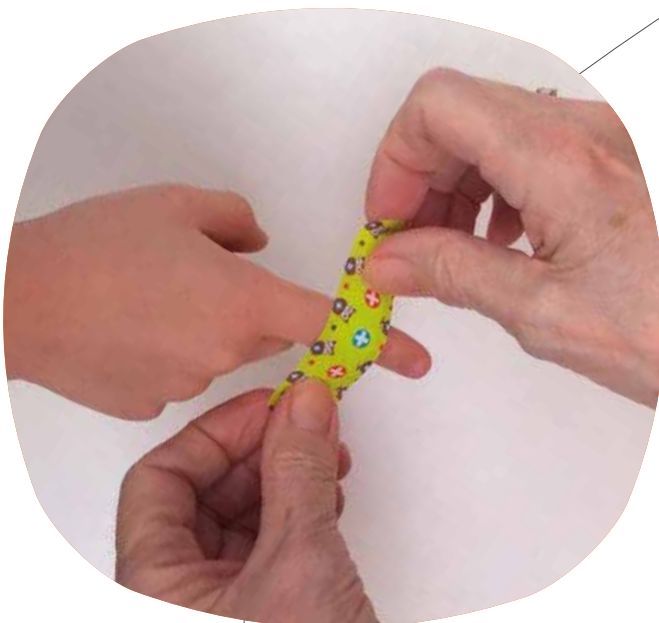
More severe injuries:

Where a child suffers a more significant impact, perhaps where they have been struck by a hard object e.g. a coat peg, falling off a bike or trike, taken a heavy fall on a hard surface, the school needs to have a protocol in place to decide whether to administer prednisolone (see next section). This will be outlined in the child's individual healthcare plan.

Applying a cold ice pack to the area of impact should always be implemented as an intermediary treatment with no negative implications.

Where bruising occurs, or bleeding under the skin, parents should be contacted.

Prednisolone can be administered in the school setting where such practices are agreed by Senior Management and are outlined in the healthcare plan, in line with the school's medical policy.



In case of an ambulance

In the event of a serious emergency where an ambulance is required, it is essential that the child has an advocate who understands FOP and who can pass the required information on to the paramedics if the parents/carers aren't able to attend before the paramedics arrive.

In the UK, it is possible to have a 'marker' or 'flag' put on the child's home and school addresses. This means the local ambulance service will have information relating to FOP and the child on file so that they know the child will require specialist handling and treatment, including what not to do.

Contact your local ambulance service or FOP Friends for details on how to set up this service.

Ensure that the current treatment guidelines for FOP are readily available to pass to any medical professionals. These can be found at:

ifopa.org/for_medical_professionals



A copy of the child's IHP and EHCP, should be ready to pass to a paramedic in an emergency, along with any other specific medical considerations relating to the child's FOP needs. This may include information relating to the child's physical restrictions due to FOP (i.e. unable to move certain parts of their body) and that will impact how the child is moved, lifted or handled. It may also impact how the child is secured in the back of the ambulance in the case of them requiring transport to hospital.

Avoid deep tissue trauma and, unless it is a life-preserving measure, intramuscular (IM) injections should not be administered. Obtaining intravenous (IV) access in the case of emergency is acceptable and can be performed with negligible harm when done by an experienced professional. Avoid central venous access or intra-arterial lines unless medically required.

A poster identifying the child should be clearly displayed in the office with all staff members (teaching and auxiliary) aware of the child's needs. See Appendix 4 for an example.

In the case of an emergency: Protect the child's life as if FOP was not an issue

However, an emergency medical professional will likely have no knowledge or understanding of the implications of FOP. The adult in charge of the child with FOP's care MUST take on role of advocate and expert in the case of an emergency until the parents/carers arrive.

Prednisolone

Whilst at the time of writing there is no treatment or cure for FOP, it is generally accepted that there may be benefits to a child with FOP to take a short course (normally 4 days) of the steroid prednisolone. The decision to use prednisolone will have been made between the parents, the child if they are old enough, and a medical professional who is knowledgeable about FOP.

Prednisolone is a strong anti-inflammatory drug, so it is considered to have some beneficial effects in the treatment of an FOP flare-up. However, there is no evidence that prolonged use of such a drug has any benefits for a child with FOP. What does need consideration is that the long-term use of steroids is associated with Cushing's syndrome and diabetes. It may also lead to weight gain, increased risks of infection, osteoporosis, and anxiety.

For use in a flare-up

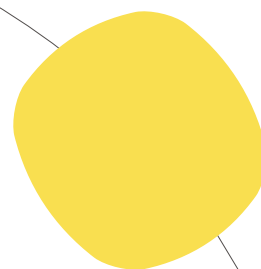
A flare-up can occur without warning and for no apparent reason. Often a flare-up is signified with a swelling, although not every time. They can occur anywhere across a child's body. The lumps or swellings may be very small and almost unnoticeable, or they can be quite large in size. Initially the lumps are soft and can be painful. They may also be warm to the touch. There may also be redness, stiffness or other indicators. If a member of staff thinks they have noticed an unusual swelling on the child, or the child complains about pain or discomfort, then the parents should be consulted.

Where a child with FOP is having a flare-up, or is suspected of having a flare-up, depending on its location it may be decided to start the child on a course of prednisolone. In practice, the use of prednisolone is based on the location of the potential flare-up and its symptoms.

Hopefully, when required, the prednisolone would be given within 24 hours of the onset. This would be given by the parents at home once daily (unless the child is on a residential visit with the school, or the first identification of the flare-up is whilst the child is at the setting).

It is imperative that all medical plans are written clearly, in conjunction with expert medical guidance, and with specific reference to the needs of the child with FOP. They must be regularly updated as and when the medical needs of the child change.

The information here should be taken as general guidance. Qualified medical advice must be sought by the parents before the completion of the plan.



Since prednisolone is only taken once a day, very often parents choose to administer it in the morning. Therefore, it is not usually necessary for the school to administer the medicine whilst the child is on the course. Where an injury requires treatment with prednisolone, it should not be withheld until morning but administered immediately. However, the side effects do have implications for the school setting. If the flare responds to the prednisolone but then returns, the parents may decide to give the child a second course of steroids. It is not always possible to treat all flares with prednisolone as it depends on the location of the flare.

It is not usually used for chest or trunk flares, as these flares tend to be long-running. Prednisolone is not routinely used for flares of the posterior neck or back either. However, for some areas of the body such as the jaw and anterior neck, prompt use of steroids can be beneficial as locking of the jaw and swelling near the throat can cause serious implications for eating and breathing for the child with FOP.

For use after an injury

Prednisolone may also be used to treat a soft tissue injury in order to try to prevent a flare-up and minimise the effects of the injury. It should not be used regularly after minor bumps or falls. Bruising under the skin may be an indicator that it is a proportionate response to give the child prednisolone.

If the child does have a more serious injury or accident at school then the first-aider, after consultation with the parents, may decide to give prednisolone at the setting. This should be administered according to the directions on the child's EHCP.

Once the initial dose has been given by the school, the subsequent daily doses for the course will be given by the parents at home before school.

Side effects

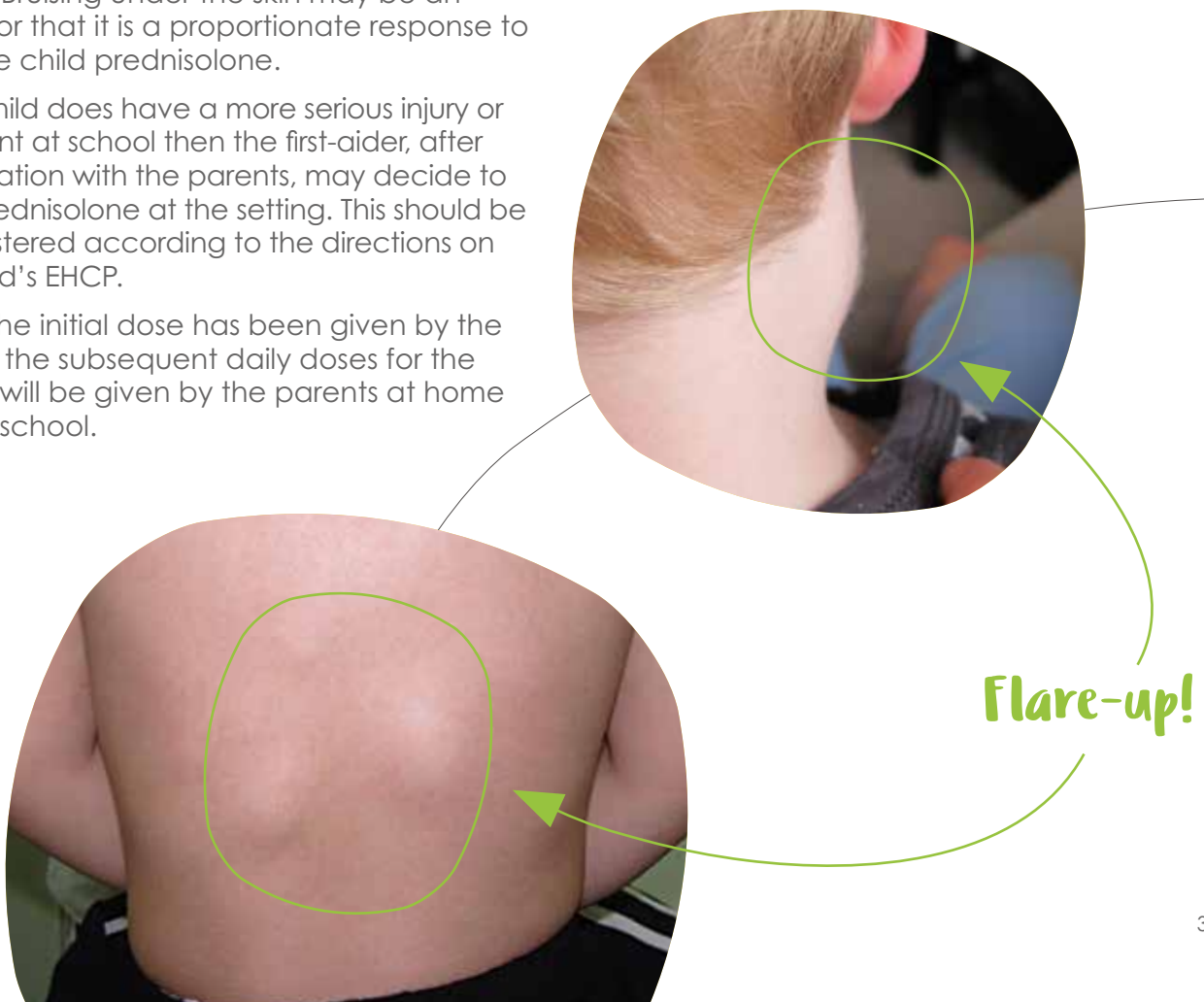
There are commonly noted side-effects to prednisolone. Teachers should familiarise themselves with these if the child with FOP is undergoing a course of steroids. Additional allowances may need to be made for the child during this period. Not all side effects affect every child, and the effects can be different at different times of day.

They may include, but aren't limited to:

- Hyperactivity
- Lethargy or tiredness
- Over-animated brain
- Increased hunger
- Mood swings
- Emotional and clingy behaviour
- Increased impulsiveness
- Being less cautious

This is a list of the short-term side effects from the use of steroids. For a list of long-term side effects, please seek medical advice.

The setting will need to be prepared to be flexible with their expectations of the child, and sensitive to any additional or changing needs, whilst they are on prednisolone, and for the few days after the course.



Flare-up!

Clinical Trials

Despite FOP being an ultra-rare condition, there is much interest in the research and pharmaceutical worlds to find a treatment and a cure for the cruel disease.

At the time of writing, there are two active clinical trials for drugs which have the potential to be an effective treatment for FOP; however only one of these trials is accepting children or young people under the age of 18.

If a child is participating in a clinical trial, then it will inevitably have an impact on their schooling. It is vital that the parents work closely with the school so that everyone understands the process that the child is going through and procedures that may need to be undertaken at school. In order to preserve the integrity of trial data, schools must follow the trial protocol as explained by the parents and instructed by the trial's medical professionals.

If the child is enrolled mid-year onto a clinical trial, the child's IHP should be amended to reflect any changes. Do not wait until the annual review. Similarly, the child's emergency information at the school office should be updated with the trial information so it can be passed onto a paramedic in the case of an emergency.

If at any point the school has concerns about the child's health or wellbeing, they must notify the parents immediately.

The nature of a trial means that the side effects, or their severity, may be unknown. This might prove distracting to the child in a lesson, or more significantly it could lead to discomfort or even pain. Communication about the child's wellbeing must be ongoing between the home and school.

Participation in a clinical trial may also require the child to travel long distances to visit the trial site for monitoring and check-ups. It is essential the school supports the family in this and does its utmost to reduce its impact on a child's schooling. Clearly this will also affect a child's attendance record, so a sympathetic and understanding approach is necessary.

Another consideration is the effect of the clinical trial on a child's siblings. Depending on the age and nature of the child/ren, they may understandably be concerned for the wellbeing of their sibling with FOP, who is going through a difficult time with the trial and its effects. The sibling/s may also be emotional, worried or anxious if their parents have to travel away for a few days, leaving the sibling/s home with family or friends. Clearly, the logistics and emotional impact of the trial on the sibling/s education should also be treated with sensitivity and understanding. Therefore, ensuring that the teachers of any siblings are also kept in the loop regarding a clinical trial, seems like a reasonable and sensible thing to do.



Ongoing medical care

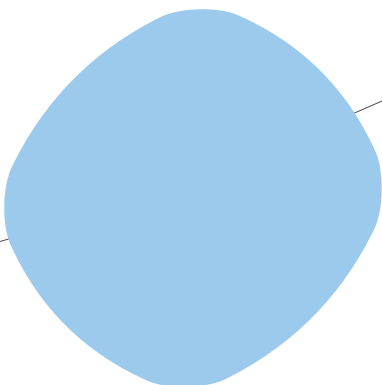
Depending on the impact FOP has had on the child, they may have ongoing medical care needs. All medication must be given in line with the school's Medical Policy. GPs can prescribe over-the-counter medicines in order to assist the school with its administration.

- If the child is in flare, they may need to have ketoprofen gel (a strong, topical anti-inflammatory gel) administered during the day to help reduce the inflammation.
- Unwanted FOP bone can cause problems if it starts to protrude through the skin. The child may need assistance with wound dressings, especially if they become loose during the day.
- A child may need to take pain medication, such as paracetamol or stronger, if they are having a flare-up.
- Although no longer generally prescribed by GPs, paediatric paracetamol (Calpol) and paediatric ibuprofen (Nurofen) can be prescribed to enable educational settings to administer the medication in line with the doctor's directions and the school's medical policy.
- Regularly review the child's IHP to ensure that the care outlined reflects the child's current physical and medical needs.

- As the child gets older, after discussion with the parents, it may be decided that the child is competent enough to start taking responsibility for managing their own medication and care needs where possible. This should be reflected in the individual healthcare plan.

At certain times of the year, bugs and viruses can seem to spread through a school or educational setting within a few days. It is part of ongoing good practice, to remind all children and adults of the need for excellent personal hygiene at all times. Any virus can be harmful to a child with FOP in that it could trigger a flare response.

Children should be regularly reminded of the need for washing hands thoroughly after using the toilet. Tissues should be readily available, and all children should be reminded of the need to use a tissue to cover their nose and mouth to prevent the spread of infection across the classroom. Tissues should be disposed of in a hygienic manner.



FOP and Vaccines

As part of the NHS Vaccination programme, children receive vaccinations at different stages of their life, from immediately after birth, to secondary school, and all the way through to university. Participation in the programme is not compulsory and where a child has additional medical needs, it may not be medically advisable for them to receive all vaccinations. It has been stated that approximately 1/3 of all intramuscular vaccinations result in a flare-up for children with FOP.

It is likely that many of the infant vaccinations will have been administered prior to diagnosis of FOP, meaning that the appropriate and necessary precautions were not taken. However, once a child has been diagnosed with FOP, then expert medical advice should be taken by the parents before any further vaccinations are administered.

As a first response, no further intramuscular vaccinations should be given.

There are safer ways to administer most vaccinations, this is known as sub-cutaneously or sub-q, which means 'under the skin'. This removes the need to perform the immunisation as an intramuscular or IM injection.

For further advice about immunisations and intramuscular injections, please read the section in the IFOPA 'What is FOP Guidebook? A guidebook for Families'.

Parents should not automatically consent to the vaccines when permission letters are routinely sent home from school. The decision of if and how to vaccinate should be taken after expert consultation, possibly at the GP's surgery or hospital to ensure the vaccination is performed as safely as possible.

For a detailed timeline of the NHS Childhood Vaccination programme, please visit:

bit.ly/NHS_Vaccine_Timeline



FOP and Flu

Why is it a concern for a child with FOP?

Flu is a matter of serious concern for a child with FOP. Flu can bring many complications for any person who is at a higher risk of becoming seriously ill and the complications for a child with FOP contracting influenza can be catastrophic. This is for two reasons: if they have already suffered restrictions in their chest area, catching flu could cause them to have further breathing problems which may require drastic treatment; the other reason is that flu has been noted to cause new FOP flare-ups in sufferers. For these reasons, the FOP experts recommend that a child with FOP takes precautionary measures to reduce the risk of catching flu.

Nasal flu programme in schools

The NHS has rolled out a mass vaccination programme in schools, where children receive the flu nasal spray. This is a live attenuated virus and **children with FOP should not receive it**. There is a risk that the live virus may cause a flare-up in a child with FOP. Because a child who has received the spray will be carrying the live virus, it is also recommended that siblings of a child with FOP also do not receive the vaccination in this way. Parents should complete the DECLINE (red) section of the form that is sent home with the child. Unless a child with FOP has been vaccinated against flu, they should also avoid being in contact with any child who has received the nasal spray for a few days. As the nasal spray programme has now been rolled out to most children of primary school age, FOP parents may feel it a proportionate response to keep their child with FOP off school for a few days.

Receiving the flu vaccination

The latest medical advice for a child with FOP is to have the flu vaccination sub-cutaneously, using the thinnest needle possible. After the injection, it is advisable to ice the area immediately to reduce the risk of inflammation. The vaccination should be performed by an experienced and skilled nurse, NOT a student. Paediatric ibuprofen can also be given before and after (following the instructions on the bottle). If a child with FOP is in active flare, they should NOT receive the vaccination. All close family members and carers of a child with FOP should be immunised against the flu virus.

For further medical guidance visit:

ifopa.org/important_update_flu_season

Pneumonia

Taken from 'What is FOP? A Guidebook for Families', IFOPA, 2009

"Pneumonia is one of the most common causes of death in individuals who have FOP. It is part of the reason for the relatively low median life span of 41 years. (The term median simply means that half of people with FOP die below this age, and half live to be older than this. Individuals with FOP who do not develop life-threatening complications can live to be in their 50s, 60s, and even 70s.)

So what is pneumonia and why is it so dangerous to people with FOP? Pneumococcal disease is an infection that can attack different parts of the body. It can infect the lungs, where it causes pneumonia. It can also invade the bloodstream. If it reaches the brain, it can cause meningitis. These are all very serious infections. People with health problems such as FOP are more susceptible to pneumonia and may have more difficulty fighting the infection."

In the UK, babies receive the pneumococcal vaccine (pneumococcal conjugate vaccine, or PCV) as part of the NHS childhood vaccination programme at 8 weeks, 16 weeks and 1 year old. It is likely that a child has received all three of these vaccines before they have received the diagnosis of FOP. For people living with a long-term health condition, they may need a single one-off pneumonia vaccine (pneumococcal polysaccharide vaccine, or PPV) or five-yearly vaccination, depending on their condition. Children at risk of pneumococcal infections can have the PPV vaccine from the age of 2 years onwards.

For further information about pneumonia, visit:

bit.ly/nhs_pneumococcal-vaccination

Contact your GP or FOP specialist for further expert guidance.



Hearing loss and FOP

Hearing loss is a common feature of FOP sufferers, with up to 50% of people with FOP needing to wear a hearing aid of some sort or reporting complete loss. Children with FOP are at a greater risk for hearing loss, with the onset usually in childhood or adolescence. Generally, it is a conductive hearing loss with a slow progression. The loss may be due to the small bones within the middle ear fusing together.

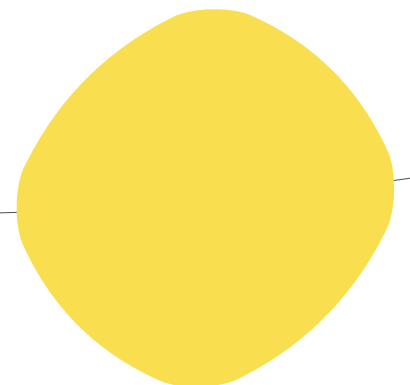
All classroom practitioners need to be aware of this for a child with FOP and be alert to key indicators such as the child not responding to instructions; asking for things to be repeated; continually replying with 'What?' or perhaps continually struggling with new concepts. As with any child, they should notify the parents and/or school nurse if they have concerns that a child with FOP may be developing a hearing impairment so the child can be referred to an audiologist for appropriate tests and monitoring.

Strategies for a child with hearing loss in class

The strategies for supporting a child with FOP with hearing loss in the classroom are much the same as for any child with a hearing difficulty. The child with FOP may wear one or two hearing aids. The hearing loss in a child with FOP may be transient and may 'come and go' with the seasons due to changing weather conditions.

- Where the child has lost movement in their neck and upper body, practitioners need to be aware of, and sensitive to the fact that, the child may have difficulty 'turning to see the speaker'.
- The child with FOP may struggle to hear other children in the group, so ensure background noise is kept to a minimum and that the speaker uses a clear voice.
- It may be possible to get a speaker sound system installed in the child's classroom, with the practitioner using a microphone. This also makes it easier for all children to hear the speaker.
- Consider noise-dampening measures in the classroom, like carpet or soft feet on chairs to reducing scraping noises.
- Think about the allocation of classroom for the child, where possible away from additional background noise such as a main road, music room, hall/dining room etc.

For further advice and specific guidance on how to support a hearing-impaired child within the classroom, please visit the National Deaf Child Society website.



Scoliosis

Scoliosis is a medical condition whereby a person's spine curves and/or twists to one side. The twisting can also pull the ribcage out of position. It can affect people of any age, from babies to adults, although it most often starts in adolescence. There are a number of reasons why a person might develop scoliosis: congenital scoliosis is a type of scoliosis that a person is born with; however, scoliosis can also be caused by a neuromuscular condition. Painkilling tablets may help to relieve the pain that can be associated with scoliosis.

Many people with FOP develop scoliosis over time; this can vary from mild to severe. When a person has scoliosis, the FOP creates additional challenges with regards to treatment options. Surgical intervention is not usually recommended for people because it often does not fully correct the problem and can lead to severe complications such as flare-ups in other areas.

Having scoliosis can have implications for the seating for the child with FOP, and careful consideration will need to be taken to ensure all furniture is designed to accommodate their spine, providing the necessary comfort and support. As scoliosis can be progressive, and as the child gets older, it is essential that all furniture adaptations are checked and reviewed regularly (not just annually) to ensure they are still appropriate for the child and not causing any harm.

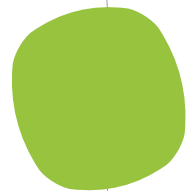


Puberty

Puberty is a difficult time for any child, but when combined with FOP, the challenges (and the potential for embarrassment) can increase exponentially. Any adult honestly reflecting on their own 'years of change' will most likely remember them as awkward and difficult, and that was without the complication of FOP. When embarking on these years with a child with FOP, care, sensitivity and discretion must be foremost in the minds of the adults supporting the child as they move into adulthood.

Although there is no definitive natural history data, clinical observations suggest that some children with FOP seem to experience an increase in disease activity with puberty. There does not seem to be a clear difference between boys and girls. Some people with FOP weather puberty without any problems, while others may see their disease activity increase or decrease. Girls with FOP may be at higher incidence of irregular periods. There are also anecdotal reports that FOP flares can increase with menstrual cycles. In addition, there is evidence that significant changes in joint function can occur around puberty.

The teenage years also bring with them the 'dating' years, when pupils begin to develop feelings for, and become attracted to, other people. Again, this is an awkward time for most, and an emotional rollercoaster for young people and their parents alike. The era of social media only serves to compound the emotional complexities of this phase of 'growing up'. Body image is a huge concern for most young people: am I too fat, am I too skinny, am I muscly enough, does my hair look good, am I wearing the right trainers? But when this is combined with the disfigurement that can come with FOP, the emotional impact on a young person cannot be underestimated. Parents and educational professionals working with the young person should ensure that the young person knows where they can turn to, if they want to talk or need an outlet for their feelings and emotions.



Menstruation

Although starting periods is something most girls go through during puberty, it can be a stressful, uncomfortable and embarrassing experience. It can also be a very painful time with chronic period pain being a recognised illness. This is all before you consider how FOP will affect a young woman's ability to self-care. When girls start their periods, they are irregular and unpredictable, making planning and preparation even more difficult. If some flow starts without warning, it can be extremely embarrassing. This is only exacerbated when a girl is then not able to discreetly take herself to the bathroom to freshen up.

However, there are also some women with FOP who never started their period, which can also be a source of distress for a young girl if they feel it is another instance of them being 'different' to their friends. Whilst no girl enjoys being on their period, there can be a sense of sisterhood: to not be a part of that can have further implications on a young woman's feeling of belonging. It can also raise difficult questions regarding the implications of this if they want to start a family when they are older. The decision for a woman with FOP to become pregnant is complex and emotionally fraught. Whilst it may be possible for a woman with FOP to have children, there is a significant risk to the health of both her and her child through pregnancy and childbirth. For further information regarding pregnancy and FOP, please refer to the IFOPA's Guidebook.

When a young woman reaches the age that her periods may start, it is advisable for the parents to have conversations with their daughter as to how she will cope in school and what support she may need. If the young woman has no physical restrictions, then the start of her periods can be managed in the same way as any other young woman in school. However, where she has restrictions, sensitive conversations will need to be had, both at home and then at school with staff members with whom both the pupil and the family are comfortable.

Once conversations have been had with the young woman about what accommodations they need from the school, a meeting can be arranged with the school to look at the best way to provide suitable facilities for the pupil. See the section on Personal Hygiene for suggestions and adaptations.

The link between menstruation and its effect on FOP are anecdotal. Some women report that there seems to be some correlation between the time surrounding their menstrual cycle and their flare-ups. There is a private Facebook group which is for women and girls with FOP, where girls and their mums can ask questions of a very personal and sensitive nature to other women who are in the same situation and may have more experience. Please contact FOP Friends if you would like to be added to this group.

For young women who have increased FOP activity with their periods, it is advisable to consult with their doctor whether oral contraceptives might be helpful to decrease the number of cycles that occur during the year. There are gynaecological considerations that need to be evaluated on an individual basis such as whether hormone therapies are appropriate with relation to other risks (e.g. age appropriate use, deep vein thromboses, stroke, and cancer risks). These and other options should be discussed with the pupil's GP or specialist.

Details and guidance of how to support the child with FOP with their personal and intimate care could be detailed in their IHP. Never more so than when dealing with such sensitive matters as menstruation, the IHP must be reviewed regularly (not necessarily annually) to reflect the current physical and emotional needs of the young person.



Taking care of emotional health

With more and more famous people and celebrities opening up about their struggles with anxiety and mental health issues, it is becoming more socially acceptable for people to talk about their feelings. Indeed, the Duke and Duchess of Cambridge, along with the Duke and Duchess of Sussex, are vocal advocates of ending the stigma associated with mental health, spearheading their own campaign 'Heads Together'.

However, despite this raised profile, many young people still feel trapped and unable to cope with their everyday life and either live unhappily, or worse, choose to end their lives.

The implications of living with a life-limiting condition such as FOP should never be under-estimated, and whilst the focus for the child's schooling will be on their physical care, consideration must be paid to their mental and emotional well-being. There are many services and charities which offer a range of support services for children, young people and their families who are living with a life-limiting condition such as FOP. Some of these organisations are listed at the back of this guide.

There is useful statutory guidance regarding the provision in schools for children with social, emotional and mental health needs outlined in the government's 'Supporting children with medical needs in school' document.

Anxiety

Living with a life-limiting illness is a challenge most people will never have to deal with, and certainly not at the young age most children with FOP have to come to terms with 'being different'. If you have a rare disease, or are the parent of a child with a rare disease, it is extremely likely that you will experience anxiety, with many people dealing with it on a daily basis.

In the same way FOP physically affects people in different ways, so too is the way patients and families come to terms with the diagnosis. FOP families are living with constant uncertainty and unpredictability, and the rollercoaster of emotions this brings with it.

Most children like routine and structure, and children with FOP are no different. Due to the never-knowing nature of FOP, it is only to be expected that a child with FOP will have periods of anxiety. Whilst the educational setting will, and rightly so, be focussing on the physical situation and implications of having a pupil with FOP, the child's mental and emotional well-being should not be overlooked.

However difficult life may seem, there is always something you can do and succeed at.

Stephen Hawking



What is anxiety?

Anxiety is a normal part of childhood and life. Every child goes through phases where there are 'monsters under the bed' or they 'don't like school', or they are worried about doing well in a test or exam. But these are often phases and will pass. Once the difficult situation is over, the child will feel better and calm down.

However, children who suffer from an anxiety disorder experience fear, nervousness and may even start to avoid certain places and activities. If the situation has passed, but the feeling of fear or panic is still there, then that is when the anxiety becomes a problem.

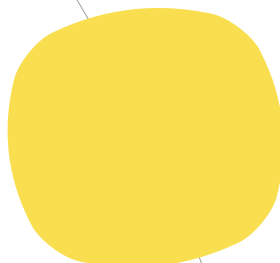
It is thought that as many as 1 in 6 young people experience anxiety.

Symptoms of anxiety in children

Signs to look out for in your child are:

- finding it hard to concentrate/lack of focus
- not sleeping, or waking in the night with bad dreams
- not eating properly
- frequent meltdowns or tantrums
- quickly getting angry or irritable, and being out of control during outbursts
- being verbally aggressive
- constantly worrying or having negative thoughts
- feeling tense and fidgety, or using the toilet often
- frequent crying
- being clingy
- complaining of tummy aches, headaches, muscle aches, and feeling unwell
- feeling lonely or social isolation
- fatigue "I'm just tired..."
- seeking validation, asking the same questions over and over again
- concerned about safety
- refusing to go to school
- negativity
- defiance
- avoidance
- overplanning
- chandeliering – when an apparently calm person suddenly flies off the handle for no reason, because they have suppressed their hurt and anxiety so deep for so long that a seemingly innocent comment or event suddenly sends them through the chandelier

Separation anxiety is common in younger children, whereas older children and teenagers tend to worry more about school or have social anxiety.



How to help your anxious child

If your child is having problems with anxiety, there's plenty you can do to help. Above all, it's important to talk to your child about their anxiety or worries. It's a good idea to seek professional help if your child is constantly anxious and:

- it's not getting better, or is getting worse
- self-help isn't working
- it's affecting their school or family life, or their friendships

Social media

The impact of social media on a child's mental and emotional well-being is much-documented at present. Parents should also consider ways to talk with their child about how 'picture-perfect' images on apps such as Instagram, Snapchat and Facebook can negatively impact them and their wellbeing, and contribute to a person's feelings of inadequacy. It can be very easy for young people to look at photos of other people's lives and feel like their own life is worthless, and for a child with a restrictive condition such as FOP, the negative impact of such images can be exponential.



Where to get help for anxiety

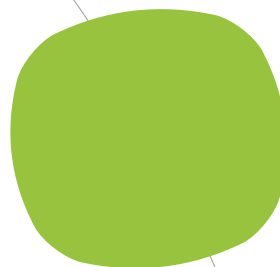
An appointment with your GP is a good place to start. You can talk to the GP on your own or with your child, or your child might be able to have an appointment without you.

If the GP diagnoses your child with an anxiety disorder, they may refer them to the local mental health service. This is now called Healthy Young Minds but used to be known as the child and adolescent mental health service (CAMHS). Practitioners at Healthy Young Minds are trained to help young people with a wide range of problems, including anxiety.

If your child doesn't want to see a doctor, they may be able to get help directly from a local youth counselling service. For more information, visit Youth Access www.youthaccess.org.uk.

As an educational professional, especially once the child reaches the end of Key Stage 2 and moves on to secondary school, it is your duty and responsibility to look out for signs that the child is struggling to cope with the social, physical and/or emotional demands of living with a rare and life-limiting condition such as FOP.

As a parent, it is equally necessary for your child's (and your family's) emotional health and mental well-being that these emotions are validated and aren't simply put under the umbrella of 'It's just FOP'.



Parental Anxiety

'First Day at School' is a milestone in any child's life. Many parents find it an emotional time as it's another reminder that their little one is growing up. Parents spend the days and weeks beforehand, excitedly shopping for the big day. They rush out to buy new shoes, a bag, the correct uniform. New parents can feel completely overwhelmed with the extensive 'You will need...' list that is helpfully provided by the school, worrying that their child won't have the right coloured socks for PE.

However, as the parent of a child with additional needs, those worries are quite simply the tip of the iceberg. You aren't the parent skipping away from the school gates, finally glad to have a few hours peace and quiet; you are the parent who gets into the car and bursts into tears, certain that the phone is going to ring any minute to tell you that your child has fallen over in the playground, so what should the teacher do?



In the same way as many other parents of children with FOP, you have probably been highly selective over who you will entrust your child to. But now you have to send your little one off on their own, to spend the day in a big, scary place called School, seemingly with hundreds of other children.

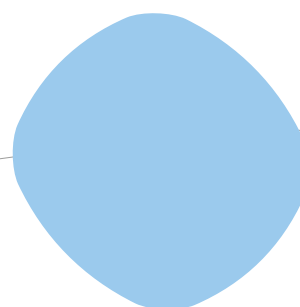
Despite common sense telling you that you've put all the plans in place; that your child is surrounded by professionals who have been educated about FOP; that everything will be ok, and your little one will have a great time making new friends... you just want to take your child back home. Parental anxiety has kicked in.

That's not to say that the concerns and whittlings of parents of 'regular children' aren't valid (after all, life isn't a competition), it's just that the worries and anxieties that you have as a SEND parent are on a whole different level: off the scale. Parents of a SEND child still have all the concerns of others, but with another layer of usually-valid concerns on top. Many parents have poured their time, energy and emotions into learning about the condition in order to provide the highest level of care for their child. Then suddenly, your child goes to school and the house is quiet and calm: an empty nest, only twenty years earlier than you planned. If you don't have younger children at home, you may feel isolated and lonely.

Recognising these feelings of anxiety and isolation are an important step towards finding ways to manage and overcome them. Of course, time does help, and sending your child on their way every morning does become less heart-wrenching. You begin to relax and trust that your child is in the best place and that the planning and preparation is working: your child is enjoying school!

But what if those feelings don't pass, if the feelings of anxiety and isolation continue? Whilst you are rare as a parent of a child with FOP you are not rare in these feelings. There are things you can do, some easier than others.

- **First of all, it's ok.** It's ok to be worried and to feel separation anxiety from your child. You are not alone with these feelings. Many parents find leaving their child at school a big step, and they don't have to deal with the complexities of FOP too.
- **Talk. Talk to someone. Talk to anyone.** This may be your partner, a parent, a best friend or sibling. Once you get your feelings out in the open, it can help to rationalise your fears and help you to feel better about things.
- **Pretending that you aren't anxious and everything's ok is counterproductive and could lead to bigger problems in the future.** You can end up feeling more anxious and stressed by thinking there is something 'wrong' with you for feeling like this.



- **The fears associated with the fall-out from an FOP flare are real.** The impact is real. You are allowed to be scared.
- **Conversely, the fear of 'not knowing what the future will hold' or 'when the worst will happen' is also very real.** Being able to plan for things can be very calming for some people, yet the variable and volatile nature of FOP can mean that simply isn't possible. That lack of control can be extremely anxiety-inducing for many people.
- **Try to stay calm in front of your child.** Model calm behaviour so that your child doesn't become over-anxious either about themselves or you. This is often easier said than done.
- **There are a number of FOP support groups where you can meet other parents who have been in the same situation as you so truly understand what you are going through.** They will have gone through all the emotions you are going through right now. You may find it easier to express your feelings through messaging rather than face to face. Contact FOP Friends to be added to these groups.
- **However, taking a break from social media can also be very helpful.** The psychological impact of seeing a steady stream of 'perfect' photos of 'perfect' children with their football and dancing trophies, can falsely reaffirm that your child is missing out on milestones or opportunities. It can simply add to your insecurities and anxieties. Switch off the screen and enjoy being present with your child/ren: delight in the moment and make your own memories, your own way.
- **Breathe. Simple breathing exercises can help to calm you down.** Practise slow breathing when you need to reduce your physiological arousal. You can also share these techniques with your child.
- **Try some mindfulness techniques** if you find yourself with time on your hands at home, or even in the carpark before you go to work.
- **Exercise.** It can take your mind off things. A run may give you the space to clear your head and organise your thoughts and feelings. Swimming can be relaxing and help your breathing. A class may give you the opportunity to meet new people and make new friends. The effect of exercise on helping with anxiety and depression is well known and you will feel better for it afterwards.
- **Listen to your child.** Are they having fun at school? What do they like most about their new classroom? What is their favourite thing to do? If you know your child is happy, it may help you to relax and be happy for them.
- **Check in with your child's teacher.** They will understand that you're feeling anxious. Sometimes just a knowing look or smile can reassure you that your child is doing ok. Arrange an informal chat after a few weeks to ensure that all the plans you have put in place are actually working. Everything doesn't have to go through the formal processes. At parents' evening, talk about your child's progress in school and not their FOP. Listen to the teacher tell you what your child is doing well, and celebrate it!

Nothing in life is to be feared, it is only to be understood.

Marie Curie



- **But...trust your instincts.** If you think something isn't working, or if there is some part of the plan you or your child think it isn't helpful, say so. Change what needs to be changed.
- **In many cases, one of the parents of a special needs child has to stay home for practical reasons.** If you aren't working or looking after younger siblings, join a group or volunteer. Get out and about, meet new people. You'll be helping other people as well as giving yourself something new to focus on.
- **If your child does have younger siblings, use the time they are at school to do things with the children you may not be able to do if your child with FOP is with you.** Go to a play-centre or a playgroup. It can be impossible to go to a playgroup if you are worried about your child with FOP tripping on toys, yet still need to keep your eye on a roaming toddler. Take them to the park on their bikes or scooters. Focus on your other child/ren while you can. Enjoy making memories with them.
- **If you haven't had the time to build friendships because of the time you have dedicated to caring for your child with FOP, use the new-found time to go out and meet new people.** You may find comfort and support in groups and coffee mornings that are organised for parents of children with additional needs. Whilst they won't understand FOP, they will understand the daily struggles you face, and the emotional impact of bringing up a child with additional needs. Libraries can be a good starting place to find out about new groups local to you.
- **Use the free time to go and have coffee or lunch with friends.** Enjoy a hot cup of coffee and catching up with people, without the interruptions from your little one!
- **Alternatively, use the time to take a break from thinking and talking about FOP by joining a group where no-one knows your situation: take some time to just be you.** You will be better placed to cope with things if you are refreshed.
- **There are lots of websites and apps which offer guidance, support and ideas for self-care.** The Blurt Foundation has some excellent, free online support guides and information, particularly around the area of self-care. Use the newly-found 'me time' to put some suggestions into action.

Finally, and most importantly, if your anxiety gets to the point where you feel that simple 'catch-all' strategies aren't working, or that you can no longer cope, speak to your GP or medical professional. Being a parent is the toughest job any of us are likely to do. You need to look after you, so you can continue to be your best for your child with FOP, and your family.



I was really worried about my brother when he went to the hospital, but my teacher talked to me on our Wellness Wednesday walk, and I felt a bit better about things.

Leo aged 8,
brother to Oliver who has FOP.

Sibling anxiety

The impact of a sibling having a rare condition such as FOP cannot be overlooked. Whilst much attention will be given to ensuring that the child with FOP has the best support possible in a setting, the needs of the sibling also need to be considered.

Whilst parents will naturally take steps to ensure that all the children in the family feel loved, secure and valued, it is only to be expected that at certain times, siblings of children with FOP may go through their own periods of anxiety or stress. It is helpful for the siblings' educational professionals to have some understanding of FOP and the impact that has on the wider family life.

- **The parents of a child with FOP may find it helpful to keep the teachers of all their children 'in the loop' regarding the health and wellbeing of the FOP, how it is impacting their homelife.** For example if the child with FOP is going through a period of illness, then it may be affecting bedtime and sleep patterns for all the children.
- **A sibling of a child with FOP may not want to tell their parents if they are upset or worried for fear of putting additional pressure on their families.** They may be able to 'hold it together' whilst at home. It may be that the school is the first place where a sibling's anxieties and worries become apparent.
- **If an child with FOP is going through a flare up and is clearly in pain, it is likely to have an impact on the sibling.** Teachers should be aware of this so they can look out for signs of the sibling needing more reassurance. It may have an impact on how the siblings relate to other children in the class, or to how focussed they are on their own studies. It may also affect their ability to complete home work or study. The sibling needs support, strategies and a listening ear rather than detentions and consequences.



- **If an child is taking part in a clinical trial, it may have an impact on the logistics at home.** If they are having to travel to the hospital for check ups, it may be that the siblings have to be cared for by family members or friends, thus disrupting their usual routine. This can be unsettling for many children and it may help them if their teachers are aware of the situation. Knock-on effects may be that homework isn't completed, or certain equipment is forgotten. Sensitivity to the needs of the family must be shown at this already emotionally challenging time. Again, efforts should be made not to penalise the sibling if they are not keeping on top of things at this time.
- **The fear of the unknown may also be distressing for the sibling.** It will be helpful if age-appropriate measures are taken so that the sibling knows where they can turn if they are having a bad day. It may be a teacher or TA for a younger child, or a school counsellor if the child is older.
- **Siblings may be aware of other children speaking cruelly about their sibling with FOP.** This would understandably be distressing for them to overhear other children making comments or jokes. Any bullying, of the child with FOP or their sibling, either directly or through more subtle ways such as exclusion, should be dealt with firmly, fairly and immediately, in line with the school's bullying policy.
- **A sibling may appreciate the opportunity to speak candidly with an adult outside of the family,** where they can express their true feelings, including anger, about FOP and the impact is having on their and their family's lives.
- **If the school is aware of a change in circumstances at home,** it may be helpful for the teachers to sensitively approach the sibling to just 'check in' with them, to show that a listening ear is available to them if they need it. Opening the channel of communication may be welcomed by a sibling who is reluctant to ask for help.
- **If the family is going through a difficult period at home,** the sibling may appreciate some nurture-time with a group of close friends at school during playtimes and lunch times, to give them some space away from the hustle and bustle of a busy playground.
- **It may be useful to find a support group for the children,** so they can learn strategies to help them cope with their sibling's diagnosis whilst living their own life to the full.

Self-esteem

Young children by nature are naïve, innocent and worry-free. They are constantly told 'Well done!' and get smiles and cuddles for the smallest of achievements. As children grow up, they start to become more aware of themselves and begin to realise what they can and can't do: some children take this all in their stride, others find it more difficult to handle. Certain things come easier to others, and this is the same for all people in all walks of life.

But as children with FOP get older, their ability to do even the simplest of tasks can be cruelly taken away from them. Suddenly, running in the park with their friends isn't an option anymore; maybe they can no longer bend down to put on their socks; maybe they can't turn around to listen to their teacher in class. All of these things will have a huge impact on a child's self-esteem. Most people compare themselves to others, it is part of human nature, and social media only serves to compound this. It seems to be stating the obvious to say that children with FOP shouldn't compare themselves to others: clearly it is neither realistic nor helpful. But by simply saying this to a child or young person with FOP and expecting them to respond with, 'Oh OK then, I won't' is disrespectful and shows a lack of understanding of the condition.



That's not to say we shouldn't try to address low self-esteem in a child or young person with FOP, in fact the opposite: we should be wholly aware of the effect of FOP on a child's emotional state and be sensitive to the early signs that it may be becoming a significant problem for them. By tackling low self-esteem early, more complex issues such as depression or anxiety may be prevented from developing.

Supporting a child to set realistic but achievable targets for themselves is one way of giving children the chance to succeed and enjoy the feelings associated with that. Celebrate what the child can do, rather than focussing on what they can't. Whenever possible, focus on the ability of the child rather than the disability that can be FOP: endeavour to stop FOP from defining the child. There are many self-help activities and suggestions available out there, some more suited to a child living with a condition such as FOP than others. Anyone who understands FOP knows there is no quick-fix to address the emotions of living with it, but that doesn't mean there aren't things to celebrate in every day.

As always, if the negative feelings of self-esteem start to interfere with day to day life, ask a GP or mental health professional for support.



I enjoy everything about school. I love it! If I had to choose my favourite thing it would be handwriting and playing with my friends

Millie, age 8,
with FOP.

Building resilience

Life is difficult. The world can be a scary place. It is full of ups and downs, with no two days the same. We have all been through it. Taking care of your own life can be tricky enough before you even think about taking care of a child. And then you have a child with additional needs and it seems like nothing makes sense.

It is navigating through these difficult times, finding a way through these challenges, that some people seem better equipped to deal with than others. We all have to find a way to go on with our lives and some people manage this better than others. This is sometimes referred to as resilience.

Resilience is the ability to have a positive outcome after a difficult situation. It's not just about getting back to normal after a setback. It's about learning from the challenge in order to become stronger and more able to face the next challenge. Children who are resilient are braver, more curious, more adaptable and more able to extend their reach into the world. It is arguable whether it is even possible to 'teach' resilience. Some people seem intrinsically more able to cope with things, are naturally 'more resilient'. However, when living with a condition such as FOP, being forced to learn to live with a 'new normal' can come around far too often. Learning how to handle these difficult and emotionally demanding situations is far from easy, and personality most definitely has an influence on developing resilience.



What is resilience? Resilience is different for everyone. For me, being resilient is getting up everyday when life challenges you, even on those days you feel you can't. It's weathering the storm of life and coming out the other side, stronger than ever. It's knowing within yourself that you can do this and growing stronger each time life throws a curve ball. It's about learning from what is happening and becoming a stronger person because of it. It's about determination, not giving up, acknowledging what is happening to you and changing things so it doesn't happen again. It's about loving yourself enough to wake up each day striving to be happy. It's about wanting to live life to the fullest.

Lara, mum to Jarvis, age 7, with FOP

Most parents worry about their children, childhood is most definitely changing: as parents there isn't much you can do about that. But you do have the opportunity to provide them with the tools they may need to navigate the challenges that school, adolescence, life – and in the case of our rare children - FOP may throw at them. Whilst wrapping your child up in cotton wool may be the preferred option for many parents, in reality we all know that won't help in the long term and ultimately could bring its own challenges further down the line.

However much we want to, we cannot prevent adversity, and children living with FOP are under even more stress than most children and adults will ever know. Therefore, what we must do, is allow our children with FOP to develop the strengths and acquire the skills they will need to cope, in order to be prepared for future challenges – of which there will be many. Clearly, this is easier said than done.

For this reason, the topic of resilience is in many ways too big, too personal, and too complex a topic for this book. It is also highly insensitive and inaccurate to say that with a bit of positive thinking, everything will be ok for children living with FOP. We all know that it not the case. By the time a child with FOP reaches secondary school, it is likely they will already have encountered more than their fair share of setbacks and challenges, both physical and emotional. They may have had to change their goals and aspirations, not through defeat or failure but necessity. This will be heart-breaking for both the child with FOP and their family.

Perhaps then, it is more accurate to say that it is independence which needs to be nurtured within a child who has FOP. Whilst meeting the safety needs of a child with FOP, it can be easy to inadvertently take away their independence and the child can become dependent on an adult doing everything for them too. But while ever a child can do things for themselves, they should be expected and challenged to do so.

There are any number of adults living with FOP who have found creative ways to continue to carry out daily tasks such as dressing for themselves, defiantly standing up to FOP. Facing up to the emotional challenges of living with FOP will be a far more demanding task, but again this is not a reason not to endeavour to build such resilience in all our children. Maybe so long as we equip children with confidence, happiness, encouragement and love, hopefully resilience will develop.

And of the adults living with FOP, they are some of the most resilient and inspirational human beings you will ever have the honour to meet.







Practical considerations

Home-School communication

The obvious need for effective communication between the family and the educational setting is highlighted throughout this book. How this is achieved will need to be worked out between all those involved, as every child and every situation is different.

Once the initial settling in period has passed, it would be lovely to assume everything will go according to the plan. However, when living in the real world, that is rarely the case. As mentioned earlier, the family living with FOP will likely appreciate the reassurances that everything is fine at school, or that another quick meeting would be useful. Whilst it may have seemed a good idea to implement certain practices at a planning meeting, reflections on their usefulness after a couple of weeks in school may reveal that these practices need to be tweaked to ensure the setting is in fact meeting the needs of the child.

Primary school teachers can be very busy with other parents and children at the beginnings and ends of days, and in some schools, parents may not have face-to-face access to the teachers at all. Reasonably, parents may not want to be discussing personal information about their child in a playground of other parents or be seen as 'that needy parent'.

At secondary school, parental contact with teachers is even more difficult to arrange due to the number of teachers and size of the building. The social standing of a child with FOP is also a bigger consideration as they may not want their peers to see their parents constantly in school, talking to the teachers.

It is the duty of the school to ensure the parents feel they are able to approach the school with any concerns, and to facilitate opportunities for the school and the family to reflect on what's going well and what needs to be changed.

Home-school books

It is not uncommon for there to be a number of pupils in a class to have a home-school diary which is completed at the end of the day. It can be a useful tool to send messages to and from home, to either celebrate and encourage a child's achievement, or perhaps mention something that happened during the day.

Teachers can use it to ask the parents a quick question, and home can use it to send in messages to the setting that may have an impact on the child's day. Teachers can be very busy at the end of the day, so it may be decided that it is part of the child's TA's role to complete the diary.

Where the child is older, there could be an agreed pocket on the front of the backpack where the book is stored. The TA could have permission to discreetly take it out, make a quick note, and put it back in, without drawing attention to its use.

There is no need to complete the diary every day if that isn't deemed to be helpful. It should be a tool that improves communication and provision, rather than an onerous task to be completed every day. However, some parents may not feel the need to have such a book.

Emails/electronic messaging

Electronic methods of communication are becoming increasingly popular with educational settings and it may be decided that this is an effective and discreet way for the home and school to keep in touch on an informal basis.

Some schools share teacher/school emails with the parents. Information regarding the child's needs could also be shared in this way, although there should be no expectation on the teacher to read or respond to the message outside of the normal working hours. Since the content of the emails will contain personal information, they should be sent through the school's secure email system to ensure they are GDPR compliant.

Notification of bump or accident

It will need to be agreed with the family and the setting what degree of 'bump' requires a phone call home. Some parents and/or schools might want to agree on a precautionary phone call home after any tumble, other parents may be ok with no notification if it's only a minor scrape. The school may want to feel reassured that they have made the correct treatment decision. It may be a useful exercise for the family and the setting to write their own agreed plan of what they deem to be significant enough to warrant a phone call home, as opposed to just jotting it in a home-school communication book. This can then be incorporated into the individual healthcare plan. Obviously, in the event of a more serious incident a phone call home would, without doubt, be made.

Attendance

It goes without saying that regular attendance at school is vital if your child is to receive the education to which they are entitled, and to enable your child to achieve their full potential. However, the variability and unpredictability of FOP means that 100% attendance for the child is near impossible.

Along with the regular bugs and viruses that go through any school and that affect all children, children with FOP may have to contend with additional appointments to FOP specialists (which can be an overnight journey away to the Royal National Orthopaedic Hospital, Stanmore, London), audiologists, podiatrists, as well as an increased number of dental appointments, and possibly visits to a counsellor, to name but a few. All of these things can have a significant impact on a child's attendance, and all of which are out of their control.

In addition to medical appointments, a child with FOP may have increased absence due to the pain associated with flare-ups. They may also be unable to attend school for a full day if they find the experience too tiring and need to rest to avoid fatigue, which itself can lead to another flare-up. Anxiety can and will affect a child's attendance. The child's studies and timetable will need to be reviewed to ensure that there is minimal disruption to their learning.

It should be noted that it is not generally acceptable practice to penalise children for their attendance record if their absences are related to their medical condition, e.g. medical appointments, and are out of the child and family's control.

Where schools reward pupils for 100%, or near-perfect attendance, allowances need to be made for a child with FOP to have their attendance recognised and celebrated, taking into account what is reasonable and achievable for them, rather than the generically expected 100%.

Extended absence

From time to time, a child or young person with FOP may suffer from a flare or series of flares that mean they are unable to attend school for extended periods of days or even weeks. It is essential that the parents keep in close contact with the school and that the lines of communication are kept open: working together will ensure the best outcomes for the child.

Schools will have a policy on supporting a child with a medical condition and parents are entitled to read it. FOP is considered a disability and as a result, a school has to make 'reasonable adjustments' to ensure that the child isn't discriminated against as a result of the condition.

If the child is likely to be off school for more than 15 days, the child's school and local council will provide support to make sure that their education doesn't suffer.

For further information, visit [gov.uk/illness-child-education](https://www.gov.uk/illness-child-education)

If parents need assistance with any aspect of arranging off-site schooling, or if they need practical or emotional support, they should get in touch with the charity Contact, or the local authority's Parent and Young People's Partnership service.



Uniform

The majority of schools in the UK require pupils to wear a uniform. However, for a child with FOP, certain adaptations and allowances may need to be made.

Some children with FOP with additional bone growth or altered body shape may need to wear variations to the uniform that allow them to move as freely as possible.

The fabric of the uniform may also need to be taken into consideration to ensure the comfort of child throughout the day.

There are also age-appropriate factors to be taken into consideration: whilst it may be ok for a teacher to assist a child with dressing or fiddly buttons at primary school, once the child reaches secondary school they may not want to be known as the student who has to have someone else dress them. Top buttons in particular can be a challenge for a child with either limited reach or shortened thumbs. Clip-on ties are readily available and may be a simple solution.

Sensitivity and flexibility will need to be shown to a child with FOP if they are going through a flare-up. They may need to wear alternative clothing if they are in discomfort and pain and the regular uniform does not accommodate these factors. In the event of the child being allowed to wear non-uniform clothes, is it essential that all members of staff are aware of the plan, so that a child with FOP isn't challenged by a member of staff and required to repeatedly explain themselves. Sensitivity in such matters is key.

Some high street stores are now producing adapted school uniform ranges. Visit the FOP Friends' Pinterest page for more details.



Isla loves school and asks her mummy if she can go every day!



Wheelchairs

The use of wheelchairs for young people with FOP depends on the rate with which the condition has affected their mobility and movement. It may be that a child needs to use some sort of walking aid or device to improve their balance and stability.

For some children and young people with FOP, they may only need a wheelchair for some of the time, depending on their health and mobility on a given day. This needs to be handled with sensitivity. It may be that the child prefers to use the wheelchair whilst getting around the school, but still wants and needs to keep active so chooses to walk at the times when they feel it is convenient and safe to do so. Again, it is imperative that the school works with the child; listens to their thoughts and feelings; and takes on board what the child is saying.

Whilst the UK now has laws that mean public buildings need to be wheelchair accessible, there are a number of practicalities regarding the size of classrooms and the number of children they are expected to accommodate. If a child with FOP needs to be using a wheelchair for some or part of their day or week, then careful consideration and planning will need to be done to ensure that this can be seamlessly facilitated in order to cause the child with FOP the minimal amount of disruption or distress.

Another consideration also needs to be the design of a chair for a child with FOP. Very often, wheelchairs for people with FOP need to be adapted to provide appropriate support for the user's leg. If the additional bone growth means that the child's leg needs to be permanently extended and supported, then the wheelchair design will need to be larger than a standard NHS-issued wheelchair. This will have significant implications for the classroom size, seating arrangements, dining arrangements and also moving around the school.

Whilst younger children may be happy to be pushed in their chair by an adult, an older child may not wish to have that constant intervention. Power chairs give older children independence and freedom, or they may choose to be taken around the school by some of their friends. The social implications of this are significant, especially as the child gets older and moves on to high school. The child may find other pupils 'stare' at them and it could have implications for their enjoyment of school and their emotional well-being. Schools should ensure that, as part of their ethos, a positive and inclusive learning environment is promoted at all times.

Because of the potentially over-sized nature of an adapted wheelchair, some standard-issue wheelchair tables may not be ergonomically suitable for the child. Always consult an OT or advisor to ensure that all furniture is matched to the child's physical needs and is reviewed regularly. Furniture across the school will need to reflect this, including lunch rooms and science / technology rooms.

It is also worth noting that, if a child or young person with FOP is using a wheelchair, it is important that that the toilet facilities are matched to their needs. Assessments need to be carried out to see what additional support the child will need. They may be able to transfer independently, or they may need additional assistance. Ensure that the disabled toilet facilities are able to accommodate the pupil, irrespective of their preferred side to transfer from chair to toilet.



Personal Hygiene

Reference should be made to the school's Intimate and Personal Care policy when planning for the child with FOP's needs. The local council will also be able to advise educational settings where needed. All staff with responsibility for the personal and intimate care needs of the child will need have received the appropriate training to ensure they are fully aware of best practise. Guidelines need to be in place to safeguard both children and staff.

With a young child, they may know no difference and be quite comfortable with an adult assisting them with their daily toileting routines. Similarly, a young person with FOP may have had assistance all their life and as a result are quite comfortable discussing their needs and asking for help and support. However, for some children with FOP, where the onset of impact is later in their teen years, they may feel very self-conscious and embarrassed if they need to ask for help with matters of personal hygiene. Every effort must be made to ensure their feelings are recognised and their needs are discreetly met so that they are able to attend school and that it does not become a barrier to their education and success.

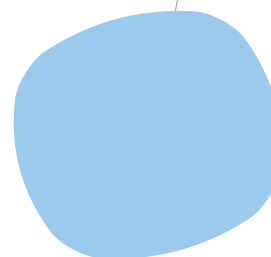
This will most likely be achieved by working closely with the pupil with FOP, the parents, a school nurse, and teachers or practitioners with whom the pupil feels most comfortable. Communication and sensitivity are key.



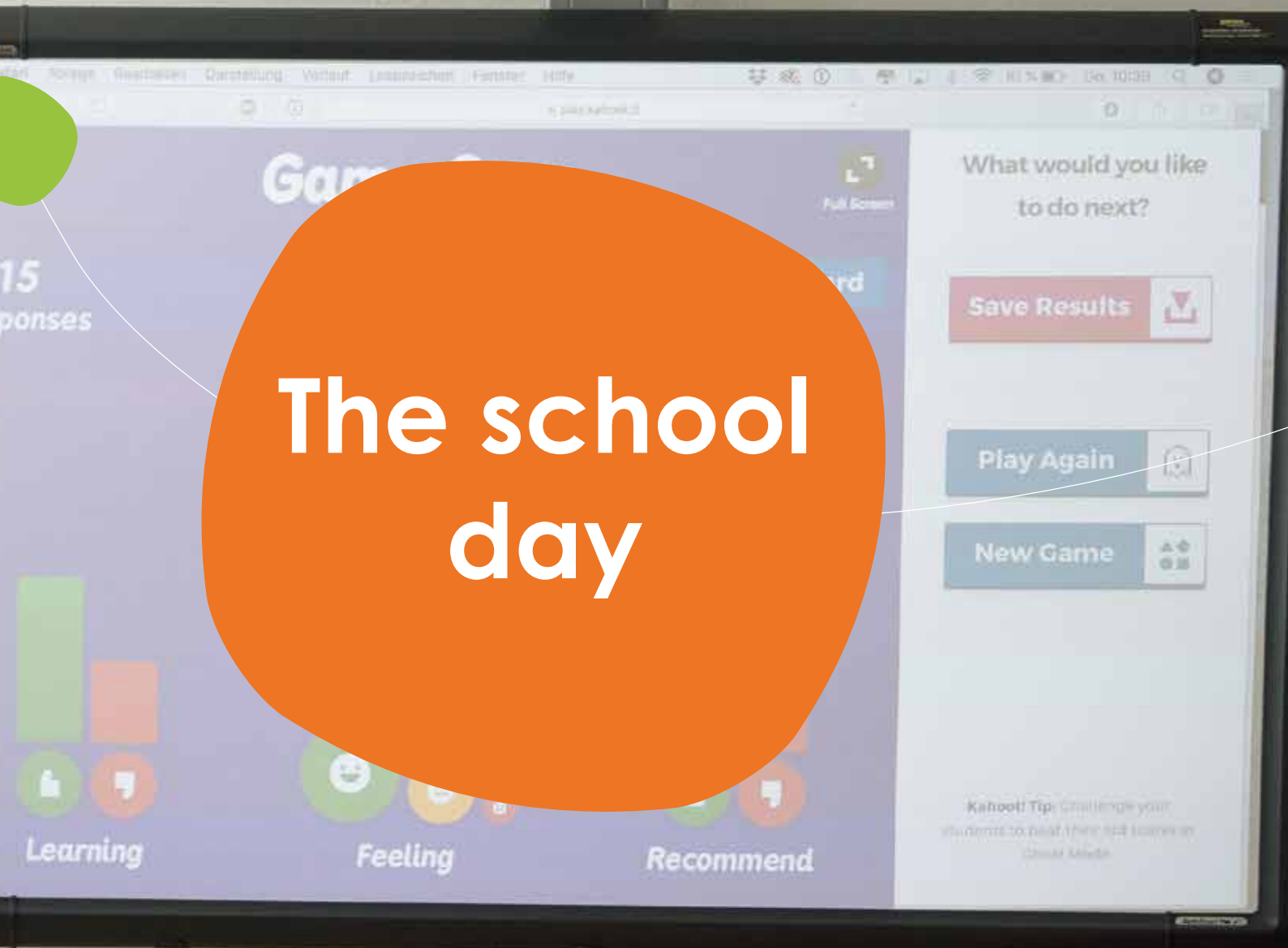
Points for discussion with the child and their family

- A child with FOP with stiffness in the arms and shoulders, may not be able to clean themselves after using the toilet. Provision for this, taking into account the setting's Safeguarding and Intimate Hygiene policies.
- They may struggle to reach a regular height toilet so may need to use alternative facilities to the children's toilets. Building work may need to be undertaken to adapt facilities to meet the child's needs. An OT should be consulted before any work is carried out to ensure that the adaptations are sufficient and to advise where necessary.
- Where the child needs assistance with transferring from the chair to the toilet, the OT can give advice in relation to the child's specific needs. Moving and training handling can be arranged through the local authority's Health and Safety department for the designated members of staff.
- As pupils get older and more self-aware, especially in secondary school, it may be necessary to allow the pupil to use a different toilet where they have more space and privacy, even if they don't need an additional adult to assist them. This may involve allowing them to use the disabled toilet even if they don't need a wheelchair. Alternatively, the bathroom reserved for visitors may be better suited to the student to allow them the space and privacy that they require. It can take child with FOP longer to use the bathroom, so they may feel more comfortable if they don't feel like people are 'waiting' for them.
- Common sense would dictate that care, sensitivity and discretion must be applied when arranging the provision for young women with FOP who are menstruating.

- The setting should work closely with the OT to look at adaptive devices available to enable the child with FOP to be as independent as possible and to carry out as many personal hygiene tasks as they are capable of.
- Conversations in the private Facebook groups could offer some suggestions and 'hacks' from other members of the FOP community on how they manage with self-cleaning. Very often, people with FOP design their own devices to make things easier for themselves. Discreet and convenient storage of personal hygiene equipment for the young person may need to be facilitated.
- Depending on the age and level of difficulty a child is having, a Closomat toilet which washes and dries, could be a solution and may allow the child or young person more independence.
- The presence of washing facilities poses an immediate and significant risk of a slip hazard due to water on the floor, liquid soap spillages, and discarded wet paper towels. Non-slip flooring should be installed, and the area closely monitored to prevent unnecessary accidents.
- Relevant members of staff need to be aware of the child's needs so that further embarrassment isn't caused by other members of staff challenging the child with FOP.
- Where the child requires a member of staff to assist with personal hygiene, it is essential that a small team of adults, trusted by the child or young person, are trained to provide the level of intimate care required. This should be in line with the setting's Intimate Care policy. This should be reviewed regularly to reflect the child's changing needs.







The school day



Take a walk!

Before a child with FOP begins their time in any educational setting, it is imperative that the parents, along with the SENDCo, educational practitioners, therapeutic professionals, and the council's SEND advisor take a walk through the school to assess the set up with specific reference to the child's needs. It may also be helpful to take additional walks with the child to see how they will be able to negotiate the environment.

Secondary schools love to put on Open Evenings to showcase their school in the best possible light with well-presented students doing exciting experiments with Bunsen burners. But, when selecting a secondary school for your child, you are well advised to view the school during the day. This will allow you to see in real life how busy the corridors are, how the students move around the building, and to identify if the school will meet your child's physical, as well as learning, needs.



The Early Years Learning Environment

Everyone knows that a dynamic, effective Early Years learning environment is one filled with toys, activities, and lots of children busily going about their day: little people moving from one experience to the next, chattering, playing and exploring their new worlds. It is truly mesmerising to observe. However, as the parent of a child with FOP, it is highly likely all you can see is one trip hazard, one slip, one accident, waiting to happen. Finding the balance between giving your child the same opportunities as any other pre-schooler, whilst protecting them from irreversible dangers, may seem impossible.

Working with the childcare setting it is more than possible to create opportunities for your child to grow and learn, both in independence and skills, whilst keeping them safe.

The key to making a child's time in the Early Years setting effective, enjoyable and memorable, is communication between the family, the setting's management, all the staff, and the child's key workers. When a child with FOP joins an EY setting, it is essential that all members of staff are made aware of the child and the condition, prior to the child starting. They should all be given a basic overview and explanation of FOP and the risks associated with it. They should understand how this might impact the organisation of the environment, activities, and other children. They should also know which member of staff has key responsibility for the child in the case of an accident or incident. This training should be regularly reviewed as part of good practice. FOP Friends can assist settings with training guidance.

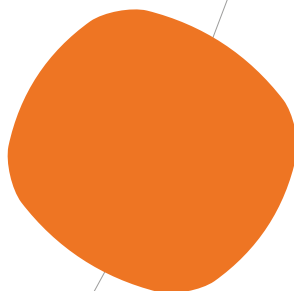
The more you read, the more things you will know.
The more that you learn, the more places you will go.

Dr Seuss

At all times, the focus should be on **inclusive** experiences for the child. It is up to the professional skill and judgement of the setting managers and key workers to adapt the activities and environment to enable all children to participate and succeed safely, rather than finding alternative and 'safe' activities for the child with FOP to take part in. An educational regime of reading books on a cushion or colouring in, is going to have a detrimental and irreversible effect on the child's learning and social interactions for the rest of their life and must not be allowed to happen.

Children 0 – 4 with a disability are entitled to additional support. There is specific guidance for practitioners on the Foundation Years website, which may also be of interest to parents. The information is based on the statutory requirements and looks at various aspects of the reforms and how they apply to EY settings, supporting practitioners to provide an inclusive and high-quality education for all pupils.

bit.ly/sen_and_disability_in_the_early_years_toolkit



The role of the key worker

In an Early Years setting, all children are allocated a key worker. Depending on the organisation of the setting, it may be decided that the child with FOP needs a named 1-to-1 key worker, or that their needs can be met by the regular key worker.

Whilst it may feel like the child's key worker needs to be by the child's side at all times to protect and prevent harm, careful thought and consideration needs to be given to the social and emotional development of the child. It is through talk and play with peers that children build friendships and learn those all-important life skills such as turn-taking, listening, and mediation, to name a few. But perhaps most importantly, it is those times when children play with others, that friendship bonds are developed and nurtured. If there is always an adult there to mediate the conversations and conflicts, then the children will never learn those skills themselves. Children need to be able to speak freely amongst themselves, to be silly and giggly, to truly develop friendships. If there is always an adult present hovering over the child with FOP, then as the children get older, their peers may choose to play elsewhere so they are not under the constant gaze of the 'teacher'. This denies the child the opportunity to learn how to make friends and keep friends, and the consequences and implications of this will last far beyond the Early Years setting. The child with FOP may then find that they are no longer part of friendship groups and not invited to playdates and parties.

One of the main role of the key worker is to constantly assess the environment and settings for real risks and hazards for the child with FOP, but when the child is engrossed in an activity with others, the key worker must step back and observe from a distance, to allow the child to truly engage with the activity and their friends around them. Unless the child is at risk of physical injury, then there is no need to constantly interfere and interject: the child with FOP has the same social needs as any other child. These must be respected and protected.



The Environment

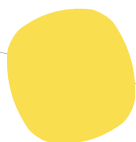
Most of these suggestions are simply 'good practice' in a high-quality educational setting, but it is worth thinking about these things when developing a plan for a child with FOP to attend a setting:

- Take a walk around the setting and look for edges or corners that could pose a problem for a child with FOP if they fell onto it. Corner-rounders are readily available from IKEA and other online retailers. Foam insulation pipes can be slit and put along edges to protect the child.
 - Rugs look great on the floor in reading areas but can pose an extra hazard. Consider fixing them to the floor or removing them altogether.
 - Look at the toy storage. What may be a reachable height for a normal child, a child with FOP with arm restrictions may not be able to reach all the toys.
 - Some classroom furniture can be bought cheaply from high street stores, but the stools and chairs may not have enough stability for a child with FOP. Ensure that all occasional furniture such as tripod-style stools are safe to have in the classroom and aren't going to over-balance.
 - If the child with FOP has mobility restrictions, ensure that they are still able to access and enjoy the various role play areas. Areas that require crawling or scrambling for the child to enter, may not be suitable for a child with FOP and may make the child feel excluded. Teachers will need to be creative to ensure all areas are enjoyed by all!
- An OT will be able to visit the setting and advise on adapted furniture available and suggest ideas for grab rails and stools in the toilet areas, and other areas as appropriate. Swivelling chairs can allow a child to turn around if they have restrictions in their neck and shoulder area.
 - Toileting will need to be discussed in a sensitive manner with the parents and child if appropriate. It can be very difficult for young children to not get water or liquid soap on the floor when washing their hands, so key workers will need to take extra care when a child with FOP is using the toilets.
 - All key workers need to pay special attention to all floor areas around the setting. Water and sand can make the floor extra slippery, as can children walking back indoors on a rainy day. Consider installing special reduced-slip flooring.
 - Toys that aren't put away are a significant trip hazard and can cause a child to fall over.

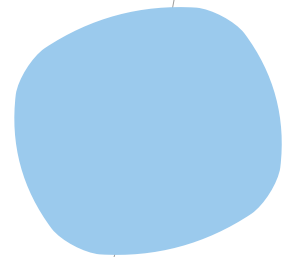


Activities and Learning opportunities through play

- While most 3-year olds can walk, run and climb, they are still developing their gross motor skills, so tumbles and falls are part of their everyday life. This needs to be taken into consideration. It may be that the parent/s have taken the decision for the child to wear a soft helmet to prevent against any head injuries.
- Assuming there are no physical restrictions, a child with FOP can safely use a trike, or other wheeled toy. Obviously, there is a risk of the child falling off the toy, which would need to be decided between the parent and setting. A further risk is of another child scooting into the child with FOP and either causing a significant bump or causing the child with FOP to fall off. Adaptations could be made to allow the child with FOP to use the bikes at a quieter time, with just a couple of their friends, rather than at busy times when all the children are scooting around like crazy.
- As part of the setting's behaviour management policy, the key workers need to impress the importance of no hitting, throwing toys, or biting, with the children. If there is a child who is prone to biting or throwing toys erratically, consider the grouping of the children to reduce the likelihood of the child with FOP being a target.
- Adapt parachute games so that all children are not under the parachute at the same time or aren't running towards each other, thus increasing the chances of a bump between a child with FOP and another. All children enjoy playing with the parachutes. It is essential that the key workers find inclusive games so that the child with FOP can take part, rather than exclude the child because it is 'too risky'. A child with restricted arm movement may be unable to shake the parachute so the key worker needs to find a solution, perhaps standing behind the child and shaking the cloth for them.
- Physical activities can take place on the grass to provide a softer landing for the child.
- Most Sports Days in EY settings are fun events where the focus is on getting children involved and everyone receives a medal at the end. This is particularly important when there are children with physical limitations taking part. Can the children have walking races so that all children can join in? Consider the obstacles when designing the races. Can the child with FOP pull something over their head or will they need additional assistance?
- Weather can provide all sorts of fabulous learning experiences for children. Welly walks are great fun for all children (and adults!). A child with FOP may need more guidance when walking in cumbersome footwear so additional supervision may be advisable. Also take note of slippy underfoot conditions such as wet leaves.



- Snow play is fine for children with FOP, soft dusty snow can provide much delight and sensory enjoyment. However, take extra care with icy surfaces. Where snowball fights are permitted, ensure that hard or icy snowballs aren't thrown at the child. Use a tree or something else for the target. If extreme snow conditions are experienced, additional risk measures will need to be taken. If it is not possible to clear the ice, or the snow is too deep for a child with FOP to negotiate due to their mobility, then a 'snow day' plan will be needed. Also, children with restricted shoulder mobility may not be able to throw snowballs.
- Soft artificial snowballs can be purchased cheaply in shops and online. Whilst they don't offer the full sensory experience of playing with the real thing, for children who aren't able to go outdoors they do give them an enjoyable opportunity to join in with some safe, silly, wintery fun, throwing or rolling them at targets (or teachers!), or building with them.
- Many children enjoy dressing up as part of their imaginative development. Extra sensitivity may be needed for a child with FOP if they are not able to put on and take off a costume. Also, consider if a costume is more difficult to walk in, or has straggly parts that can be tripped over. Avoid having ill-fitting 'dressing up' shoes that may cause the child to topple over. Can a favourite costume of the child be adapted with velcro to enable them to dress and undress independently?



Moving on... the FOP classroom: suggestions for inclusion

Whilst FOP is not a reason for a child to have difficulties with their learning, there may be a number of challenges posed by FOP that need to be managed in order to reduce the impact of the condition on their learning opportunities. Teachers should have the same high expectations for a child with FOP as any other child in their class. However, that's not to say that a child with FOP won't have a specific learning difficulty in addition to their FOP. Teachers and parents should be aware of the progress that the child is making, and if they have concerns that their academic attainment is falling being age-related expectations, then appropriate learning interventions should be implemented.

Some of these suggestions are specific to a child with restricted or limited physical mobility, other suggestions simply come under the umbrella of 'high quality inclusive practices' that most teachers will already be using for a number of children within their classrooms.

The variable nature of FOP makes it tricky to categorise these considerations into 'For Infants', 'For Juniors', 'For Secondary School Pupils' and so on. Rather, practitioners should familiarise themselves with all suggestions, implementing or adapting them as necessary to meet the needs and age of the child at that time.

- Locate the child's peg at the end of the row so they aren't unnecessarily jostled in the cloakroom. Allow the child to go out a few minutes before the other children so they can get organised first, before the rush.
- Think about the height of the pegs and storage: a child with FOP may not be able to bend or stretch to reach.
- Sloping writing boards may assist a child with restricted shoulders or arms. A book stand may assist when reading or copying from a book or worksheet.

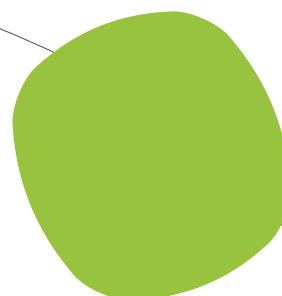


- There are number of extendable devices readily available on the high street. They can be easily adapted to make reaching tools to enable a child with FOP to grab something just out of reach rather than always having to ask for help. A magnet can also be attached to pick up smaller metal objects.
- Children with FOP often have shortened thumbs, and occasionally they can turn in like the classic FOP toes, so they may need different pencils and crayons, depending on the degree of limitation. The child may also benefit from Fine Motor Skills exercises.
- Think about the movement of people around the room: position the child so that they won't be constantly 'bustled past' or knocked by equipment, backpacks, or opening and closing doors.
- Locate essential resources near to the child to reduce the need for them to move around the classroom.
- Bending down to pick things up that have rolled off the desk may be difficult or impossible, depending on the stiffness of the child. Consider providing shallow trays or using velcro on equipment so it can 'stick' to the desk. Non-slip matting can be purchased cheaply and would help to prevent stationary falling onto the floor.
- A child with FOP may have restrictions with the movement in their neck and upper body, so ensure they are seated in a position within the class that enables them to see everything, and the whiteboard with minimal need to turn in different directions. A swivelling chair may be a solution to this problem.
- Around 50% of children with FOP have some degree of hearing loss; many wear hearing aids. The adaptations here need to be the same as would be made for any child with reduced or limited hearing, with the caveat that a child with FOP may not be able to 'turn to see the speaker' and therefore use lip-reading and visual cues to assist them.
- Allow the child to take photographs of diagrams, charts or information from the board to reduce the need to write
- A teaching assistant may be able to transfer some relevant information onto a small whiteboard to enable the child to copy more easily rather than constantly looking up and down at the board.
- A child with FOP may find it easier to use a writing programme such as Clicker, or a laptop with Word when older, to complete longer pieces of writing. However, typing an extended piece of writing may be tiring for a child with FOP and could cause muscle fatigue, especially if additional bone growth has restricted their arm movement to create an uncomfortable typing position. Consider using a 'speech to text' app.
- A child with FOP should not be kept in at playtime to complete work. There are many reasons why a child with FOP may not be able to keep up with their peers in the classroom, and they should be encouraged and challenged to work to the best of their ability, at their own pace. If a child has a consistently slower work rate than their peers, the teacher should look at the organisation of the lessons and requirements of the tasks to see what can be done to support the child to help them to complete the necessary work in the allotted time.



- Secondary-school students with FOP may need to leave lessons 5 minutes earlier than other students to avoid jostling on the corridors and stairways. Whilst this is common practice in many secondary schools these days for students with many different needs e.g. children with autism disliking the crowds and the associated noise, the teacher may decide it's appropriate for the whole class to leave a few minutes early to prevent the child being singled out.

- Consider providing the student with duplicate textbooks, a set for home and a copy in each lesson, so that they don't need to carry additional weight around in their backpack.
- If the child will be sitting on the floor for a long time, check their comfort. Are they able to sit unsupported? Would a cushion or small chair help? This will also apply in school assemblies, especially where children are expected to sit on a cold, hard floor.
- Position the child with FOP near a cupboard, so that they can lean against it, can be a discreet way of offering back support.
- Teachers should consider a range of strategies when choosing a child to respond to their question. A 'pick-me' stick or a flag may be of use for the child to draw attention to the teacher that they wish to contribute. The teacher could use names on lolly sticks as a way of selecting a child to respond, or an automated name-picker on the interactive whiteboard, to decide who to invite to answer a question rather than asking the class to raise their hands.
- Children with FOP may suffer from fatigue, and their daily timetable may need to be reviewed. When a child is in active flare, they may become more tired, and need a quiet area where they can rest and even lie down in a comfortable position.
- An occupational therapist will be able to come to school to assess the child's physical needs with respect to furniture, including adapted chairs (style, comfort, height) and desks. Also consider the child's needs when they will be using other parts of the school such as the dining hall and a computer suite, providing duplicate furniture if necessary. For example, a spinning chair would enable a child with FOP with restricted neck or shoulder movements to turn around and look at different speakers or parts of the classroom with ease. However, larger pieces of furniture often have, by design, extended feet and steps for stability which can subsequently pose dangerous trip hazards themselves. It is of utmost importance that the shape, style and size of the furniture is evaluated with this in mind.
- Living with a condition such as FOP may have a significant impact on a child's concentration. If they are constantly thinking about how they are holding their body or their equipment to reduce the strain; or if they are in discomfort or pain, it will clearly impact a child's ability to concentrate and focus on the task in hand. Teachers need to be aware of this and review the strategies currently in place. That said, FOP is not a reason for a child to underachieve just because they think they can get away with it.







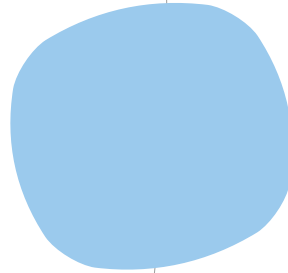
Assessments and examinations

A child with FOP may need additional time for tests, formal assessments, exams, or work that requires extended writing. It should be explained to the child that it is in their best interests to give them the best chance to demonstrate their full understanding. They also need the chance to get used to these accommodations; applications will need to be made to the appropriate examining bodies in a timely fashion.

Another consideration for a child with FOP is their comfort if they are to sit in exam-conditions for a sustained period of time. It may cause additional stress and tiredness on their body, and this fatigue may have a negative impact on their ability to produce their best work in the assessment.

Adaptations should be considered ahead of time, including:

- a separate room for the child to sit the exam, so they can move about if necessary
- comfortable and adapted furniture that supports the physical restrictions of the child's body
- a scribe
- the use of technology, if appropriate and fair to do so.



What about a Teaching Assistant?

Any dynamic educational setting is fraught with hazards as they provide exciting learning opportunities for the students as they excitedly move around and grow. The case for having a Teaching Assistant for your child with FOP has both pros and cons, and also depends on the mobility and the age of your child.

If your child has an EHCP, it may be stated that they will require the assistance of an additional adult. This adult may be referred to as a Teaching Assistant, Learning Support Worker, SENTA, Educational Assistant, Classroom Support Assistant, Teacher's Aide, to name but a few.

An additional adult can be most helpful when navigating the challenges of a busy learning environment. Many teachers are now expected to teach classes of at least 30 pupils, if not more. An extra pair of hands to implement many of the suggestions for adaptations as included in this guide, will be invaluable.

In my experience of working with children and young people with medical needs and disabilities over the years, well-meaning but overzealous support workers who velcro themselves to the children create a learned helplessness where the child feels they can only function with support. This has far reaching implications for the child.

SEN Advisor

A teaching assistant can, amongst other things:

- Provide an extra pair of eyes to potentially avert an accident.
- Carry out in-the-moment risk assessments.
- Provide reassurance to the child when trying out new things. They can encourage the child to develop a 'have-a-go' attitude rather than 'opting out'.
- Adapt activities to allow the child with FOP to participate alongside their peers.
- Remind other children of how we play games, throw balls, and include others safely in our play.
- Keep floors and walkways clear of toys and slip hazards.
- Go outside before the children to assess the the weather conditions and the suitability of the floors e.g for ice, pooled water, wet leaves etc.
- Prevent other children driving trikes, scooters etc. into the child with FOP.
- Pass equipment or reach for things outside of child's reach.
- Assist with personal hygiene matters.
- Assist with dressing and undressing for PE/ Games lessons.
- Assist with the setting up of scientific equipment.
- Deliver small group intervention programmes such as fine motor skills or gross motor skills activities.
- Complete the Home/School diary; reply to any messages.
- Liaise with the family on an informal basis.
- Take equipment from one room to another in preparation for lessons.



Along with the other, more detailed suggestions in this guide, it is clear that having a teaching assistant for the child with FOP can significantly increase their learning opportunities and enable them to access most, if not all, of the curriculum in the same way as their peers.

However, there are some caveats. Constantly having an adult 'helicoptering' over a child can actually create a different set of problems for a child:

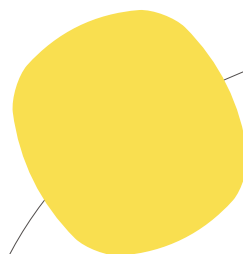
- Children bond and build friendships with other children when they are engaged in free conversation and child-led play. If there is always an adult present, children may feel like they can't speak openly to each other, use 'silly' words. For example, young children love to make bathroom jokes but may not feel able to do so in front of a teaching assistant. Therefore, they may choose to play elsewhere so that they can make the jokes, thus excluding – albeit unintentionally – the child with FOP. Over time, the child with FOP may then end up left out of all conversations with their peers.
- Children pick up the mannerisms and speech patterns of those they play with. Therefore, if the child is always speaking with and listening to adults, they may end up imitating the style of a 'grown-up'. This may then lead to the child being unable to speak to their peers without using an authoritarian tone, thus causing further socialisation issues.
- Learning to take turns and resolve conflicts is an essential part of play. If the child with FOP always has an adult there as a mediator, they will not acquire and develop the necessary life skills.
- A child will quickly learn to ask for assistance if they think an adult will do everything for them! Teaching assistants need to be aware of creating learned helplessness in a child. FOP is cruel and will steal a child's independence soon enough. It is imperative that the teaching assistant encourages the child to do as much as they can for themselves, while they can.
- If a child gets used to always having an adult by their side, they will quickly lose the ability to work independently. Once this habit is set, it can be very difficult to break.

- If a child thinks they have an adult who will come along and explain 'what the teacher said' again to them, the child with FOP may start to disengage with class discussions, safe in the knowledge they will be told everything they need to know later in the session.
- Just because the child has FOP, doesn't mean they will find learning challenging. Some class teachers group pupils on tables according to ability. In these situations, it is important that the child's teaching assistant isn't deployed to support other children with learning needs. This can result in the child with FOP completing tasks that aren't challenging enough for them. The teacher should set equally high expectations for the child with FOP as any other, according to the child's actual ability, not their perceived ability.

When a child with FOP is in a safe space, be it engaging in small-world play on the carpet with some friends, or working through a calculus problem with a thinking buddy, the teaching assistant can step back away from the situation and let the child learn, just like the other children.

Where it is decided that a TA is in the best interest of the child, plans need to be in place for someone else to step into the role in the event of their absence. This person needs to be knowledgeable about the child, FOP, the role, and the emergency procedures, in order to continue to provide excellent support for the child. It is not advisable that an agency staff member is employed as the child's TA; there should be another member of staff from the school who knows the child and has an understanding of the condition re-deployed from their regular role, and the agency TA tasked with carrying out the more universal role of a teaching assistant.

Review the impact the teaching assistant is having on the child regularly. Don't be afraid to change their role every year to reflect the child's age and restrictions – or lack of. As children get older and 'hanging out' and being accepted increases in importance, the parents and professionals need to listen to the child's needs, and to take them on board by finding a way to make their wishes a reality.



Exercise

The innumerable benefits of exercise that we all know about are also applicable to a child with FOP. Exercise promotes a healthy body and mind, but specifically can strengthen the lungs and improve breathing. Exercise is an important part of keeping a child with FOP as fighting fit as possible. A healthy child is much more able to ward off coughs, colds and other seasonal bugs and viruses. It can also help children maintain a healthy weight.

But perhaps most importantly, exercise and moving around – either indoors or out – is great fun! It can help to keep a well mind and is useful in alleviating depression and other mental health issues. It's a great thing to do on one's own, or with friends!

Whilst the child with FOP isn't likely to be signing up for the football or hockey team, there are so many other ways they can get active and be involved. As long as a child with FOP is exercising safely and within their own abilities, then it can be encouraged and enjoyed.

Exercise can be organised or casual. Children running around with their friends during playtimes or free-play sessions is just as good for a child's health as taking part in a formal coaching session. Risk assessments need to be made about the surface, trip hazards, and bump hazards, but after that the child with FOP can just get involved! Having playtimes on a grassed field provides an extra level of safety, above tarmac.

Children with FOP can take part in coaching sessions and games, with other children in the group being aware of the child's additional needs. Children with FOP should be encouraged to take part in as much as possible, for as long as they are capable. Coaches do need to be mindful if balance is an issue for the child. Whilst parents need to take into consideration the risk of falling over or being hit with a ball, a child with FOP is perhaps more likely to simply trip over their own feet for no reason and cause themselves an injury. If the child wants to have a go, then the coach and the setting need to work out the how.

Children with FOP also need an outlet for their energy, the same as any child. If they aren't allowed to expend any energy during the school day, by sitting in lessons and then staying in a quiet area at playtimes, it will begin to have a negative effect on their learning and behaviour. It may also affect their enjoyment of school and they may find it harder to concentrate during afternoon sessions. By the end of the school day they may feel like a coiled spring. Finding a way to release this energy throughout the day needs to form part of the child's EHCP.

At the other end of the spectrum, care also needs to be taken that the child with FOP isn't fatigued or tries to do too much. This can happen on the part of the coach pushing the child, but also can be self-inflicted with a wilful child with FOP not wanting to take things easy or take a break! Maybe they just 'want to play like everyone else'. There is the risk of flare-ups if the child carries out repeated movements, maybe with a bat or racquet that unduly targets specific muscles. Distracting the child from taking part, or persuading them to take a break, will need sensitive handling so not to affect their self-esteem or cause too much disappointment and distress for the child.

Children with FOP can also use bikes, adapted bikes and scooters. Again, this exercise is fun and helps to improve their breathing and lung capacity. It may be that as FOP takes hold, they have to spend more time indoors in front of a screen. However, while the child can get outdoors, get active and take part, every adult needs to find a way to make that a reality.

Sport is an integral part of our everyday lives: you only need to look at how ingrained football is in our culture, or how excited we get as a country when we win a gold medal at the Olympics, to see how important it is to us all. Whilst exercise and sport are different things, there is clearly an overlap. FOP will most certainly limit the level of skill a child with FOP can achieve in a sport and this is likely to prevent them from being selected to represent the school in team sports. However, inclusive sports are more popular than ever and the child with FOP needs to be offered the opportunity to experience that feeling of being part of a team: being included, being accepted, being a winner.



CHAMPION
BASEBALL

The PE curriculum

Writing a set of guidelines about inclusive practice for children with FOP in Physical Education lessons is next to impossible when you consider the complexity of the condition; the physical limitations of every child; the confidence of every child, and the risks associated with the condition; and the variable nature of the condition. Despite these challenges, it is not acceptable to require the child to sit out of a PE lesson in order to 'keep them safe'.

It will take a number of conversations between the teacher and the parents to establish what a PE lesson for a child with FOP will 'look like', and to tailor the teaching and learning to the child's physical, social and emotional needs.

In addition to quality first teaching, a child's physical limitations must be the first consideration. Depending on the age of the child, there may be some, minimal, or no physical restrictions to take into account.

The 'natural' progression of FOP is from the neck down, so the child with FOP may already have difficulties in lifting one or both arms above their heads, as well as be unable to fully or wholly turn their head due to neck restrictions. This will affect their participation in both sports and gymnastic activities. Because of this pattern of progression, it is important that the child with FOP doesn't put undue weight or stress on their neck, head or shoulders.

One key indicator of FOP is the malformed and shortened big toes. This can result in impaired balance for the child with FOP and their foot grip in gymnastics may not be that of other children. As the child gets older, it may be that they feel self-conscious about being 'different' to their peers.

As part of a teacher's professional development, where teachers have little or no experience of working with a child with a complex medical condition and/or physical restrictions, it may be worth getting specialist 'inclusive PE' training for all relevant members of staff. Again, the family could be invited to some or part of this training to make them available to the teachers to answer specific questions or concerns.



General considerations for PE

- Getting changed. A child with FOP may need additional assistance to help with getting dressed and undressed in preparation for the lesson. Due to shortened thumbs, they may find buttons and shoe laces tricky. They may also need assistance with taking clothes off overhead. Again consult the schools Personal and Intimate care policy for guidance.
- Teachers need to be aware of a child's sensitivity to their body shape. Children who have had flare-ups, especially across their back and shoulders, may have new bone growth left behind, causing lumps that make the child feel self-conscious. Alternative arrangements may need to be made discreetly, that are sensitive to the child's feelings.
- Children will need to be appropriately supervised in a communal changing room to ensure that the behaviour is appropriate and safe. 'Kids will be kids', and at times may take the opportunity to engage in horse-play by throwing items of clothing around the changing room "for a joke, Miss". Clearly, the risk of an accident on a hard floor for a child with FOP with limited ability trying to retrieve their clothing is too great to take, not to mention distressing. In some situations, it may even be deemed as bullying.
- Ensure all sports clothing is fastened securely so as not to get caught on equipment, or trip the child with FOP, and cause an accident.
- Muscle fatigue is a real risk for a child with FOP. Take care the child doesn't over-exert themselves or perform too many repeated movements.
- Warm-ups and stretching is ok, but the child with FOP should take full responsibility for how far they move themselves. All actions need to be active on the part of the child. At no point should anyone (coach or peer/pupil) perform physio-type movements or stretches on the child with FOP. There should be no resistance on the part of the child with FOP.
- A child with FOP should never be asked to 'challenge themselves' to push their body further than it comfortably wants to go. The focus of the PE lesson is for the child to participate, not to reach the 'next level'.
- A child with FOP may want to join in with their classmates to assist with the getting out and putting away of the equipment. Wherever possible, this should be facilitated within the limitations of the child. Care should be taken that the child doesn't get knocked by other children moving heavy pieces of gym equipment. Common sense should also prevail when deciding which pieces of equipment to allocate to the child: perhaps the child could put away the first or last piece of equipment.



However, it may be the case that, if the child is largely dependent on the use of a wheelchair, consideration may need to be given to excusing the pupil from PE, or parts of the curriculum, altogether. Other FOP-appropriate and approved physio sessions could take place; they could be given extra study time; or perhaps they could take an extra class in a subject of their interest.

The TOPS Sports programme, amongst others, gives many suggestions as to how a child in a wheelchair can be included in mainstream games lessons. Paralympic sports are becoming increasingly popular and are now enjoying a high profile in the media. Whilst their disabilities and challenges are different to those faced by children and young people with FOP, they still offer inspiration to many.

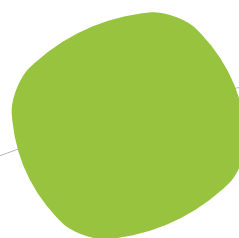
Dance

Curriculum dance offers a number of opportunities for a child with FOP to enjoy movement and exercise. The sessions can be easily adapted to meet the ability of the pupil. As well as having the opportunity to physically express themselves, they can make valuable contributions to the choreography and music choices. Introducing ribbons, scarves, tambourines, dustbin lids and brushes (think Stomp), or other props, can allow the child with FOP to express themselves without the need for full movement. Also, there are now a number of commercial dance companies of able-bodied and dis-abled bodied dancers who tour the UK showcasing their art, providing inspiration for all.

Gymnastics

The following guidance should be read with an understanding of the child's FOP limitations and abilities, and in agreement with the parents and child. A child with FOP is unlikely to have the same balancing ability as a child of their age. This can increase the likelihood of accidents, especially where equipment (even of a low level) is being used. The adaptations should be regularly evaluated to ensure they are still meeting the needs and ability of the child.

- A child with FOP can use age-appropriate equipment. They should be encouraged, with appropriate supervision, to take part in climbing and walking along low ramps unaided.
- If a child has physical restrictions, they may want to take a doll or bear into a gymnastics lesson so that the child can manipulate the toy to complete the exercises.
- If a child has suitable balance, or while holding the hand of a TA, the child can jump off low-level equipment that is covered with adequate padding such as gym mats. All children should be taught to jump and land safely, and not to fling themselves off the equipment and across the mats. NB: It should be noted that gym mats will not protect any child from injury if falling from a height.
- Extra care should be taken with children 'taking turns' on the equipment so that the child with FOP doesn't feel rushed at all, nor should anyone just jump off equipment without waiting for the child to fully leave the area.



- Children with FOP should not climb wall bars/ frames or ropes of any height.
- Forward and backwards rolls are not advisable as they put too much strain on the neck and shoulders. Ask the child to explore different ways of rolling.
- Headstands or any activity where the child has to bear weight on their head and neck should not be permitted.
- In paired work, the child with FOP should not be 'moved' into any position by their partner, nor be allowed to take the weight of another child on their body.
- If the child with FOP cannot take part in either a lesson, or an element of the lesson, consider other ways of enabling the child to take part. The child could take on the role of a 'coach' and look for children who are working towards achieving one of the learning outcomes of the lesson, or they could be given an iPad to take photos of the children being successful in their learning, to share on the school's social media account or as part of the children's learning portfolios.
- High-quality PE lessons in the primary school should focus on the child exploring different methods of travelling, balancing, making shapes and so on. The child with FOP should still be encouraged to experiment with all these areas at their own level of mobility, and their achievements celebrated and recognised.

Games

Games lessons can easily be adapted within the remit of quality first teaching. Teachers should be mindful that a child with FOP may have limited movement in their upper bodies so the use of equipment such as bats and rackets may be challenging for them. Assess each piece of equipment on its own merits.

- Children with FOP may well be able to throw and catch as well as their peers. Give them the opportunity to demonstrate what they can do, not what they can't.
- Use soft or firm-foam balls to reduce impact. Easy-catch balls can also increase a child's chances of success. These balls can be used for all the children in skills session, so as not to highlight the needs of one child over another.
- Avoid warm-ups where the children all run around in different directions as this can increase the likelihood of pupils bumping into each other.
- Provide lighter-weight equipment such as foam bats or shortened racket handles to reduce the strain on the child's muscles.
- Remind all children of the need for the safe use of equipment i.e. not wildly swinging bats around if not playing, to avoid any child (but particularly the child with FOP) being struck accidentally. No throwing of the bats if a child is 'out'.
- For invasion games, put the children into smaller groups e.g. 2 v 2 or 4 v 4 rather than a full team, to reduce the number of children running around the child with FOP.
- Conduct lessons on the field as often as possible to provide a softer surface for play.
- Adapt the rules of the games to accommodate all pupils. Challenge the children to come up with their own set of rules.
- Play Walking Football or Walking Netball as an alternative.

Where the child with FOP is not able to participate, either due to physical restrictions or too great a risk of injury, find alternative ways for them to be involved, such as scoring or assistant referee.



Inclusive sports

There are any number of inclusive sports now available for commercial purchase.

Boccia is a seated bowling game, played at the Paralympics, which would enable the child with FOP to compete against their peers on an 'even playing field'. There are also inter-school opportunities for teams to compete against each other.

New Age Kurling is also becoming increasingly popular with children of all abilities. This is played inside.

Both games are seated so can be played in a wheelchair if necessary. They also have further adaptive aids such as bowling ramps and push-tools in case the child's stiffness impacts their ability to take their turn.



Swimming

Swimming lessons form part of the KS2 and KS3 curriculums. The child's stiffness and movement restrictions will be the first consideration as to whether the child can participate in these sessions. Assuming that the child is able to participate on some level, FOP poses an obvious number of risks which need careful consideration.

However, swimming also offers many well-known health benefits for children with FOP as well as being a lot of fun, so it is essential that everything possible is done to enable the child with FOP to participate safely and achieve.

Risk assessments travelling to and from the pool need to be carried out, including steps on and off the bus/coach.

- Changing rooms: the risk of slipping whilst getting changed is significant. Adaptations will need to be made for the child. This could include using a disabled changing room and a spare towel placed on the floor to prevent slipping.
- A child with FOP with additional bone growth may have understandable body-image issues. Wearing swimwear is a sensitive and emotive issue for many children, especially of secondary school age. Particular sensitivity needs to be afforded to children who are self-conscious about their 'different' body shape.
- Children with FOP may need additional assistance with undressing if they have restricted movements and are unable to dress and undress, especially as swimwear can be particularly stretchy and clingy. Equally, they may need additional assistance with re-dressing with the damp skin making putting clothes on even more challenging, especially socks. They may need to leave the pool a few minutes earlier than their peers to give them extra time for dressing. This should be planned in conjunction with the school's Intimate and Personal Care policy.
- Can the child wear pool shoes or some other footwear whilst moving from the changing room to the poolside to reduce the chance of slipping?
- Classroom management will need to consider the movement of all children between areas to ensure the child with FOP isn't pushed or rushed, causing them to slip.
- Is it necessary for the child with FOP to shower after swimming, where the floors can be unpredictably slippery due to shampoos and other products spilt on the floor?
- A child with FOP may need additional assistance to get in and out of the pool safely. This may involve the use of additional stairs, a different entry and exit point, or a hoist, depending on the child's restriction.
- Restricted neck and shoulder movement can cause problems for the child in terms of their breathing, it also puts them at a higher risk of injury, so the swimming instructor needs to be aware of this.
- A child with FOP may struggle to do certain strokes with any accuracy so allowances need to be made. Some children with FOP have restrictions in their necks so they can't look up to swim on their fronts, or twist to do the correct breathing for a front crawl.
- It is generally not recommended that children with FOP are asked to swim too great a distance. Allow the child to rest when they ask to rest, but also timetable some rest time into the session in case the child with FOP is over-enthusiastic and reluctant to take break.
- If a child with FOP needs to swim under the water for prolonged periods of time (if this is the most comfortable position due to fusing of the neck bones) they should be permitted to wear goggles if that is more comfortable for them, even if goggles are not generally permitted in a lesson. This would be deemed a reasonable adaptation.
- When learning or performing any life-saving skills, it is essential that no child pulls, tugs or twists the child's body. Extra care should be taken during free-play swim sessions so that the child isn't jumped on by accident.
- A child with FOP may well be able to jump into the pool unaided and may enjoy doing so. Work closely with the child's abilities and limitations.



Other sports

Other sports that form part of the National Curriculum programmes of study can be considered once appropriate risk assessments have been carried out.

- Cross-country courses need to be assessed for trip and slip hazards, particularly after extreme weather. The distance of the course also needs to be considered to ensure the child with FOP isn't over-exerted or fatigued. Would a walk be a more appropriate activity?
- Athletic activities may provide challenges and increased risks. Any child with FOP that has been impacted by the condition is unlikely to have the mobility and movement to take part in athletic sessions. Again, review each activity on its own merits with the ability of the child with FOP in mind. Find other ways for the child to be involved. Whilst the child may not be able to take part in some of the running and jumping activities, they may be able to take part in the field events such as throwing the foam javelins. Review each activity on its own merits with the ability of the child with FOP in mind. set challenges appropriate for the child, and if necessary find other ways for the child to be involved.
- Outdoor and Adventurous Activities or OAA provide opportunities for children with FOP to succeed. Orienteering and map reading are great activities for children with FOP to join in with. Specific considerations are covered in the Residential and School Trips section.



Sports day

Sports Days are run in different formats in different schools. With the younger children, it is often the case that they have a non-competitive element to them and the focus is on participation rather than winning. In these cases, the child with FOP can join in happily with their friends and enjoy the occasion: parents can join in too!

As the children move through primary school, competition and winning often become increasingly important and, at this stage, the feelings and physical limitations of the child with FOP need to be taken into consideration.

It should be remembered that it is likely the child with FOP has spent most of their life hearing "Don't run...slow down...take care!". To then expect the child to stand on the starting line in front of parents and peers can be a stressful experience for the child as well as their parents. If the child with FOP is happy to just 'have a go' and do their best, then fine. But if the child is reluctant and distressed, then the school needs to allow the child to sit out of the races they are unhappy about. It is important that the child with FOP is still able to participate in the Day.

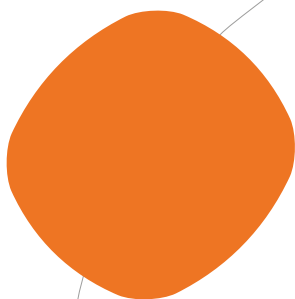
Ideas may include:

- Taking part in the field events such as throwing or jumping, with adaptations as necessary. Often these aren't as heavily spectated, so the child will feel less like they are being watched.
- Official photographer for the event. Allow the child to take photos of the races with the iPad.
- Handing out stickers on the finish line (take care they aren't knocked over by children running too fast to stop).
- Writing the scores on the board.
- Supporting the teachers with letting them know which group is running next.
- Selling refreshments with the PTA.

However, as has been repeatedly noted, all children with FOP are impacted in different ways, and it may be that a child with FOP wants to take part. In which case, after the necessary considerations with the parents and the child, go for it!

Once children move onto secondary school, participation in the Sports Day often becomes increasingly competitive and participation becomes optional. At this point, the decision to take participate will lie firmly with the pupil.

As children move through the school, it is likely that children with FOP will begin to notice that they don't have the same physical and sporting capabilities as their peers. It is imperative that the child's self-esteem is taken into consideration so that any feelings of inadequacy or anxiety are minimised and handled with sensitivity and understanding. The child with FOP should be encouraged to take part in as much as they can, it is understandable (and to be expected) that the child will be nervous and apprehensive.



Forest school

One of the latest trends schools are embracing is the Forest School approach. This gives children the opportunity to take the classroom outdoors and learn new skills. These sessions can be weekly or termly, depending on the school and the year group. It's exciting and the children adore getting out in the fresh air. Most schools carry out the sessions year-round, with the view that there is no bad weather, just bad clothing! Which child doesn't love finding sticks or the jewel that is a conker? Often sessions are concluded with a campfire and toast. It's what school should be about!

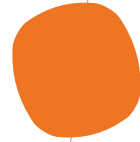
- Children are encouraged to wear wellies. A child with FOP may need additional supervision walking in footwear they are unused to as they be more prone to tripping. It may be that the child wears an old pair of trainers if it means they are steadier on their feet and just accepted they will get muddy.
- Waterproof overclothes are also advised. These may need adapting to accommodate the child, and they may need additional assistance and time for dressing.

- By the nature of the task, the floor around the trees will be uneven and bumpy, with sticks, holes and trip hazards too numerous to mention. Navigating these challenges will need to be agreed with the leader, TA and the family. It may be that an adult provides additional physical support i.e. holding their hand, or they may choose a less-uneven pathway.
- If a child is in a wheelchair, can the PTA be involved in creating a woodland path? Or perhaps it could be a project that the Y6 children plan, design, implement and evaluate, to make their school inclusive for all.
- Activities that involve the children moving around the woodland floor to explore and solve challenges will require forethought on the part of the leader and the TA. Every effort should be made so that the child can join in with their friends. Perhaps their tasks can be completed in a clearing in the woods?
- Climbing trees often forms part of the sessions. The leader will have risk assessed this activity for the safety of all the children in the class, but additional consideration will need to be taken for the child with FOP. The instinctive reaction is often a resounding No! But again, this is a situation that requires conversations between the parents and the school. There are a number of parents of children with FOP who are in a situation where their child has the ability to climb a tree and are happy to take a considered-risk approach. Other parents may feel this is too great a risk, or beyond the abilities of their child, and prefer them not to take part in the tree climbing. Modifications to consider may include having an adult next to the tree to support if require, or to choose a lower-level tree. Perhaps the child could walk along a fallen tree with the assistance of their TA. Weather conditions may also be a factor if the bark is slippery.



- If a child does fall over in the woods, there is the increased risk that they could land on something hard or protruding like a branch, thus causing direct injury to the child.
- Where parents are unsure about how far to let their child participate, they could either take a walk through the forest setting prior to a session, or they could support another session (even with a different class) so they can make their own judgements.

When children are subjected to formal methods of schooling and testing from such a young age, the opportunity to get outdoors and learn is one of the highlights of the week for many children. It regularly features in the end-of-year reflections of all children as one of their favourite points of the year. Because of this, every effort must be made so that the child with FOP can make the same memories as their friends.

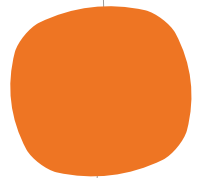


Music

Music is so beneficial to the development of the whole child. From listening to quiet music to start the day; the pride in learning to play an instrument; being part of something amazing when you play in the school band; or to the feeling of belonging when you sing in the school choir, music plays such an important part in school life. Music also has benefits for developing the brain as it involves both sides.

The importance for a child with FOP however is even greater: it can help to encourage good breathing and improve lung capacity. FOP restrictions around the ribs and chest area can cause complications for children with FOP, leading to breathing difficulties. For further information, see the IFOPA Guidebook.

Whilst physiotherapists can advise a series of breathing exercises, singing in choir or playing a musical instrument such as a trumpet, clarinet, oboe etc. can really encourage deep breathing and be far more enjoyable for a child. Electronic instruments are also widely available and although these do not strengthen the child's breathing, they do allow them to take part in a music-making experience. Some children with FOP learn to play the drums, which is a great way for them to take out some of their frustrations! The endorphins released whilst making music in a group or alone, combined with the feeling of being a part of something special, make music a perfect pastime for anyone.



The use of technology

Technology is changing at such a pace that it is nearly impossible to include a chapter in a book on the topic, without it becoming instantly out of date. However, there are some ideas and practices schools can adopt that may enhance the learning of a child with FOP and enable them to access a broad and balanced curriculum. The school's ICT coordinator should be able to advise on up-to-date hardware, software and Apps that are readily available.

Some suggestions for making ICT work for a child with FOP:

- Where a child with FOP is unable to lift their head to see an interactive whiteboard (IWB), the content can be mirrored or streamed to a device on their desk, at their eye-level.
 - Software is available that allows all children to have the IWB content streamed to pupils' desktop tablets. All children can then interact with the content and send their contributions back to the master screen for sharing and discussion.
 - Word processing software programmes are available from a basic level and early age (e.g. Clicker programmes), through to Word for older students. Allow pupils to produce longer pieces of work using a word-processing programme to reduce fatigue and to enable them to demonstrate their understanding of the topic.
 - There is a wide range of input devices that can work in place of a traditional mouse for pupils with arm or wrist restrictions e.g. tracker balls, touchpads.
 - Allowing a child with FOP to use a tablet as a camera to record events they are not able to participate in (see Sports Day, PE, and Residential sections) allows the child to have a central role within the activity. The nature of a tablet seems to draw children to it, therefore other children in the class will be eager to engage with the child with FOP to "let me see the photo you've just taken". This immediately includes and involves the child within the activity and raises their profile.
- As a follow-on to this, a child with FOP who has an interest in IT could be permitted to transfer the photos into a PowerPoint for sharing with the class and parents. This could be done in a lunchtime session with other students, again providing opportunities for the child to be genuinely engaged with other children and become a valued member of the class.
 - They could use recording equipment to narrate their story or creative writing piece to produce an audio version of their work.
 - Speech to Text software is also available which may be of use to a child with FOP, especially older pupils who have been tasked with completing longer assignments. For some children with physical restrictions, even typing can cause fatigue over prolonged periods, especially where additional bone growth has led to a typing position becoming uncomfortable.
 - Consider scanning relevant chapters of textbooks for the child with FOP and emailing them home, to reduce the need for them to carry additional and unnecessary heavy books.



Off-site learning

The educational and social benefits for children with FOP attending a school trip or residential are just as important as any other child. A day away from school is always something to be looked forward to, and some of a child's deepest learning is done outside of the classroom. Schools are required to make reasonable adjustments for all pupils when organising an educational visit. It is unacceptable practice for a child with FOP to be excluded from a trip or residential, or for a school setting to put up unnecessary barriers that make it difficult for a child with FOP to have the same experiences as their peers. It is not reasonable for a school setting to require a parent to attend with their child, unless this is part of their normal practice.

It should be assumed that the child with FOP will take an active part in school trips, competitions, and residentials, unless there is a medical reason not to.

Educational visits

Schools often visit the same locations year on year, so it is likely that there will be a member of staff who can advise what the venue will be like and assist with the writing of the risk assessment. If not, it may be helpful to make a site visit prior to the trip.

Venues in the UK are required by law to be disabled accessible, so it will be things specific to FOP that need to be given due care and attention:

- Ensure that the transport to and from the venue is suitable for the child's physical needs. The length of the journey needs to be given consideration as a child with FOP may become uncomfortable in one position for long periods. Is the transport accessible for the child? Consider the organisation of the children when getting on and off the bus.
- A child with FOP may be uncertain if visiting a new place. They may be less sure with their footing and more prone to falling over or tripping up. Supervision should be adjusted accordingly.



- If the location is new to the school, then it may be necessary, depending on the restrictions of the child, to do a site visit to assess access to the toilet prior to the visit to ensure the child's needs can be adequately and appropriately met.
- If the educational visit is an outdoors activity day, please see the guidance on residential for further suggestions.
- When out and about, one risk that needs to be considered is bustling crowds of people. Ensure the child isn't put in a position where they can get knocked by a member of the public, a pushchair, or a backpack.
- All of the child's medication needs to be taken on the trip with instructions for administration. Instant cold icepacks or sprays can be purchased from climbing/ outdoors stores.
- As always, if there are elements of the visit that a child with FOP cannot reasonably participate in, then alternative arrangements to include the child must be implemented so the child gets an equally enjoyable and educationally valid experience.
- Talk through the risk assessment with the family to ensure they are happy with the provision being put in place, and to reassure them.
- If the trip is a visit to a theatre or stadium, consider access and the use of stairs for the child with FOP. The child may need more time to get up and down the stairs. There is also the risk of a child behind them pushing past and causing an accident. However, moving the child with FOP to sit away from their friends may make the trip less enjoyable for the child and cause them to feel isolated, so consider ways to enable the child to sit with the rest of the class if possible. Ideas could include getting to the venue earlier than other schools or the general public to give the child with FOP plenty of time to navigate the stairs at their own pace, and plan to leave after the majority of the crowds have left.

I want Ellis to have
amazing memories
of school
not memories of
things he "watched"
from the sidelines.

Suz, mum to Ellis,
age 9 with FOP



Residentials

Often, schools organise residentials for the purpose of delivering the National Curriculum outcomes for PE, which require children to “take part in outdoor and adventurous activity challenges both individually and within a team” (NC in England 2013 Statutory Guidance: Physical Education Programmes of Study). Residential visits also provide all children with the opportunity to develop their independence and resilience. Sleeping away from home for one or more nights is a big deal for any child, not just a child with FOP!

Children with FOP can take part in adventure residentials! Rather than ruling out the whole trip, take each activity and assess each on its own merits for risks specifically associated with FOP.

It can be beneficial to have a meeting with relevant medical professionals, the parents, and the members of staff who will be attending the residential, prior to the trip. This provides the opportunity to discuss the health care needs of the child that are usually done at home. It also gives the school ample time to arrange for any additional training if necessary, and assist with the completion of the required risk assessments.

Once the programme of activities has been set by the host accommodation and the school, the parents and educational professionals can work together to decide the best course of action for the child: which of course should be inclusion wherever possible.

In many cases, the school will have visited the host residential site for a number of years. In these situations, it may be helpful to have experienced members of staff to take part in planning and risk-assessment meetings, along with the parents, and the educational professionals who will be accompanying the child with FOP on the residential. Whilst the majority of places in the UK are now ‘wheelchair friendly’, if the activity is based around a hike or walk, there will be adaptations that need to be made. Uneven flooring can be a challenge for children with FOP and cause balance and tumbling issues.

The ‘risk element’ of most activities at these adventure centres has been carefully considered and calculated for all children. For most children, the incorporated ‘challenge’ is the inclusion of height, speed, depth, (e.g. caving), or the unknown.

Children with FOP are no different. However, what does need careful consideration when discussing if a child with FOP should take part in activity, is the restrictions of the harness; and the impact of the landing (when they come to the end of the challenge e.g. a zip wire, will they ‘crash’ into a safety mat, thus creating an additional risk for a child with FOP?); are other children more likely to bump into them in the course of the activity. As always, the needs, restrictions and comfort of the child with FOP must come first.

Whilst the global aim of these residential trips is for all children/students to challenge themselves and face their fears, it should be made explicitly clear to all adults (particularly the enthusiastic centre staff) involved in the implementation of these trips, that if a child with FOP does not want to push themselves, then they should be heard and their wishes respected. For a child with FOP, the bravest thing they may do all week is get on a bus without the safety blanket of their parents. All adults should remember that child has spent their life being told “Take care”, “Don’t run...”, “Don’t fall over...” so to be told you must jump off a high tower whilst wearing a harness is more than asking them to take a leap of faith! Celebrate what the child with FOP has achieved.

If there are activities that a child with FOP cannot participate in, or that they choose not to engage in, then the adults present need to adopt a creative approach and find ways to include the child with FOP in those activities, or find other challenging activities to have a go at (perhaps repeating an activity they have already taken part in, but with a different group). This may be as simple as getting the child with FOP to act as the photographer for the event and give them the iPad to take photos which can then be uploaded to social media to celebrate the team’s achievements. As already mentioned, children seem to be drawn to screens so, by entrusting the child with FOP to take photos, their peers will naturally want to see their picture, thus engaging and including the child with FOP in the day.

It may be that the child with FOP prepares for the activity and dons all the protective wear, but never completes the activity. This is ok. This is a huge step for that child, and they should be commended for pushing themselves a little bit further than the bubble that can be FOP.



Playtime in the primary school

Playtime is a crucial time of the day for any pupil, and the same is true for a child with FOP. All children need the opportunity to take time out from their studies and build important friendships with their peers. The learning opportunities and experiences for children to develop their physical, social, and life skills during these unstructured times must not be underestimated. It has been recognised that children with disabilities are often excluded from playgrounds and don't have the same opportunities for play as their peers.

Playgrounds are busy and noisy places, often with over 100 children running around excitedly. In many settings, playtimes are split into Early Years, Key Stage 1 and Key Stage 2, or they have separate areas for each of the phases. Obviously, as the child gets older, the risk of a more significant fall by being knocked over by a fast-running child cannot be ignored.

However, opportunities for a child with FOP to join in with their friends, to build and nurture those all-important relationships, must be provided. The feelings of a child with FOP must be taken into consideration, and at no point should they be made to feel like they have been excluded from 'joining in' with their classmates. Every effort needs to be made so that the child with FOP can take part in child-initiated play, with any adult supervision being as light-touch and unobtrusive as possible.

Clearly, as the children get older, and more of the games centre around running, tag, and 'messaging around', the alternatives being presented need to be exciting and engaging so that the other children choose to take part. Also, as children get older, they don't want an adult around all the time inhibiting their conversations, so discretion on the part of any supervising adult is essential.

Weather

The inclement British weather can pose additional problems for children with FOP. A teacher or TA should continually be aware of the conditions underfoot to ensure there are no increased risks of slipping from ice, snow, leaves, or wet floors. A child with FOP will enjoy a welly-walk in the rain as much as the next child. However, they may need additional supervision when walking in larger footwear such as wellington boots so be aware of the increased risk of taking a tumble. Also, care needs to be taken as the children return to the building to make sure mud and leaves aren't brought in, causing the floors to become slipperier than normal.

Snow play is great fun for all kids, and children with FOP are no different. It can be great fun to hang out, making footprints and snowmen. The sensory benefits of playing in snow brings so much delight to all children. Much consideration needs to be given to snowball throwing and whether it is safe for a child with FOP to participate in such an activity. It almost goes without saying that no snowballs should be thrown at a child with FOP for risk of ice inside. Sensitivity should also be made when playing in the snow: is it appropriate for everyone to make snow angels if the child with FOP whose arms are restricted can't join in? Common sense and sensitivity should prevail at all times.

Ideas for inclusive provision:

- Walking playtimes. Choose one session a week where there is no running on the playground. Instead, provide additional activities that all children can take part in.
- Consider the timings of playtimes. Can the child's class go out at a different time to the other classes to enable the child with FOP to play on the main playground but with fewer children, or with just children of the same age, playing?
- Whenever the weather and conditions permit, children should be allowed to play on grassed areas rather than concrete surfacing.



- If funds allow, consider providing an area with soft floor-covering.
- Provide a quiet area where all children are encouraged to relax and hang out (see zones).
- Where climbing frames are available, consider allowing the child with FOP to play on the frame with just a few children who understand their needs and won't rush the child. A TA can provide any necessary reassurance, and guide the child along the equipment if desired.
- If there is a climbing/obstacle course, check the course for additional slip hazards, especially after wet or icy weather. A child with FOP can be shadowed and encouraged to enjoy the course, with a TA providing appropriate support and encouragement as necessary.
- Where extremes of weather, such as high snowfall, make it too difficult for a child with FOP to negotiate the outdoor play space, an engaging and interesting indoor alternative should be made available for the child with FOP and their friends.

Zones

Some schools have had success with introducing 'zones' in the playground, where different activities are enjoyed in different spaces. All children, including those with additional physical or medical needs, would be able to access these areas. All pupils could also be encouraged to play in these areas over the course of a week or term in order to broaden their own experiences, to try other activities not just football, and to make new friends.

These zones can then have requirements such as no running, or no ball games. A Quiet Zone would provide additional opportunities and activities for children of differing ages and abilities.

However, while a quiet area may seem like an obvious solution that would enable a child with FOP to get out at playtime, it's imperative that there are sufficient activities and opportunities for play in the area to encourage other children to choose to go and play in the area with the child with FOP. All children need fresh air if they are to concentrate in their lessons. If the area is perceived to be 'boring', then the child with FOP runs the risk of being isolated at playtimes with no-one other than their TA to keep them company, thus denying them the

opportunity to build friendships and develop their social and communication skills.

Some suggestions for games within a no-running zone:

- Targets and challenges: Who can get the most bean bags into the bucket? Who can knock down the most cans in a Tin Can alley?
- Water-bottle toss. Provide sealed water bottles so the children can flip them and get them to land on the base. Randomly, they'll play this for hours!
- Boccia. An inclusive sport which is also played 'competitively' in inter-school sports competitions. Sets of balls can be purchased.
- Soft sponge balls for throwing / catching / penalties
- Shooting basketball hoops with a sponge ball
- Craft activities or clubs
- Chalk drawing
- Lego
- iPads
- Chess
- Giant games e.g. Connect 4, draughts
- Incorporate the latest craze: bring fidget spinners, Rubix Cubes, collector's cards or stickers into the area, to create an attraction or club for the other children



Transition from Primary School to Secondary School

In many ways, the 'primary school' years are arguably easier days to manage and plan for, than when the children are preparing to move on to secondary school (or in some areas middle school then secondary school).

Whilst in a nursery or primary setting, the child with FOP will usually have just one teacher for the full year which makes planning for the child's provision relatively straight forward. Arranging meetings with the teacher and the TA to share information and to formulate plans can be done quite informally. However, as the child moves into secondary school, the number of teachers who require informing of the condition and making aware of all the specifics, increases ten-fold, as do the anxiety levels of the parents, and potentially the child.

The transition to secondary school therefore needs much forethought and planning to ensure that all the teachers are aware of, and educated about, FOP and the child to which it relates. This process needs to begin at the end of Year 5 and then followed on at the beginning of Year 6. Plans and processes need to be developed in plenty of time, to ensure all aspects of the child's care and transition are being taken into consideration.

As with choosing the right primary school for a child, the parents will need to visit a number of secondary schools to see which they feel will best meet both the educational and physical needs of their child. As mentioned earlier, visit the school at different times of the day to observe the flow of the students around the building. Meeting with the SENDCo prior to selecting a school can also be useful, as some schools may have more experience than others of teaching children with additional medical needs.

Consider the physical layout of the school, because it may not be possible to make structural changes to meet the needs of a child with FOP. Is it fully disabled accessible? Are some lessons taught on upper floors? If the child with FOP requires a lift, is one available?

What is the pastoral support like at the school? Although FOP is rare, children with additional physical and emotional needs are not. Does the school have schemes in place to support children who are not as able to join in with everything? Is there a place where the child with FOP can go and take some time out? Speak to other parents in the area who may have children with additional needs: would they recommend their child's school (although this comes with the caveat that not all parents are easy to please all of the time!)?



Speak to your child! This may seem obvious, but which school would they like to go to? Talk about why, and ensure that they feel like they are involved in the process.

Once the school has been selected and the child with FOP has been granted a place, planning can begin to prepare for the child attending the school in September.

It is worth mentioning that whilst email is a quick and efficient method of transferring information and documents, nothing can replace the effectiveness of in-person meetings. Invite the secondary SENDCo to transition meetings and get them to observe the child in action. The information gleaned from observing a child in a familiar setting can reduce the need for pages of written reports about what a child can or can't do. It is also helpful for the secondary school to meet the child away from the classroom, so their views can be taken into consideration.

Perhaps one notable factor to consider is that whilst a primary school teacher has 30 pupils in her care, a secondary school teacher will see and teach significantly more pupils in the course of a week. It is therefore of utmost importance that all teachers who will have any responsibility for the child with FOP, are aware of exactly who the child is and that they familiarise themselves with the EHCP prior to the child starting in their class: this must be their priority.

As part of the transition, a timetable of the child's upcoming classes should be obtained and then a meeting be held with all the relevant teachers, coaches and TAs. All information regarding the child, the condition that is FOP, the management of FOP, and what to do in an emergency, needs to be passed on to all the teachers, ideally along with a photo of the child. This information should be given to the teachers before the summer holidays to give them time to read and process the information, ask any necessary questions, and for relevant training to be implemented.

Before the new school year starts, the teachers can then be reminded of the procedures by management or the SENDCo to ensure they fully understand the situation. The school should also have systems in place so that, in the event of a supply teacher covering a lesson, the cover teacher will receive all the necessary and essential information so that no lapse in provision occurs.

When timetabling the lessons, the secondary school may wish to consider putting as many lessons on the ground floor as is practically and realistically possible.

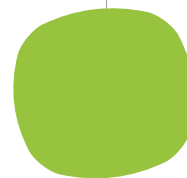


As part of the preparation for the new school year, it may be necessary to do subject-specific risk assessments for equipment that the child may not have encountered whilst in primary school. This may include things like food technology equipment or using equipment with resistant materials such as power tools. Advisors from the Local Authority should be able to assist with this.

Initially, the child with FOP may be overwhelmed with the number of teachers they meet over the course of a day or a week. It may therefore be helpful and reassuring for them to have a go-to person, that they know understands about FOP and the condition, who they can ask for if necessary.

It may also be useful for the child to have additional transition mornings or days in the secondary school so that they can get used to the increase in the number of people moving around the building, and simply the busyness of a significantly bigger school setting. They may choose to take a friend or their TA with them, or even their parents.

At the beginning of the new school year, as part of the whole school INSET, all teachers and staff – including those who aren't expected to have direct contact with the child - must be made aware of the child with FOP, and the plans that have been implemented. This will enable the child to have as successful and enjoyable start to their secondary school journey as is practicably possible.



Break and lunchtimes in Secondary School

As children move into secondary school, the nature of breaks and lunchtimes changes from crazy running around to hanging out. This has the potential to lend itself more to the needs of the child with FOP, so inclusion with their peers can be more pupil-led.

- The school's general behaviour management policy must ensure that pupils walk in the corridors and on the stairs at all times. This policy must be enforced at all times, especially at break and lunchtimes. Secondary schools are big places and house a large number of pupils. The risk to a child with FOP being knocked into by an older pupil at unstructured times cannot be ignored.
- Cold and damp weather can aggravate FOP. Ensure there is somewhere warm and dry the child with FOP can hang out with their friends. This may be a games room, library, or ICT room.
- General outdoor seating may not be suitable for a child with FOP with restricted movements. Picnic-style tables with fixed benches may be challenging or impossible for the child with FOP.
- Lunch rooms can be busy and hectic places. Arrangements may need to be made to accommodate the child with FOP so they aren't pushed around in a busy dining hall. As with the picnic tables, dining tables with fixed stools may not be suitable so the OT will need to advise on appropriate furniture whilst ensuring that it doesn't make the child with FOP 'stand out' from the other pupils. Being accepted is a huge part of secondary school, so every effort should be made to facilitate this from the classroom to the dining room and beyond.
- A child with FOP may struggle carrying their own tray in the canteen and need assistance from an adult or they may prefer a friend to help them out.
- They may have restrictions in their jaw which will have implications for their eating. They may also need adapted cutlery or drinkware. It may take the child with FOP longer to eat their lunch compared to other children. The school may need to provide additional dining facilities so that the child can eat at their own pace and without feeling like they are being stared at by other children.
- A full day at school can be physically demanding for a child with FOP. Depending on their health, which may change by the day or week. They may benefit from having somewhere quiet and comfortable where they can take some time out during lunch or break times. This may help them access the afternoon sessions and improve their concentration levels if they feel more rested.



Education post-16

The SEN and Disability Code of Practice 2016 contains the statutory guidance in relation to pupils accessing an education post-16. It advises educational settings to identify, assess and provide support for students with SEND.

As young people move into this phase of their life, they should be facilitated to participate in the discussions about what they want to accomplish in their life, their needs, and what support they feel they will need to achieve these aspirations. Conversations about what the child is interested in, and 'what they want to be when they grow up', can be started at any age. However, once they get to Year 9, the child can begin to look at the realistic options available to them, and the best path to take on the step of their learning journey.

By having these conversations well in advance, it enables the proper planning to be put in place and allows the young person and their family to express their views and have them taken into consideration. At the Year 9 Annual Review of the child's EHCP, a Transition Plan should be drawn up.

During the Transition Review meeting, the young person and their family must consider to following:

- Their next steps: young people must remain in education or training (apprenticeship) until they are 18
- What education, training and employment opportunities are available to them
- How they can become more independent, where that is reasonably and practicably possible for a person living with FOP
- What their aspirations are
- What qualifications and skills they will need to achieve their goals
- A health pathway to include a review of the factors relating to their health
- What will make them happy, safe and confident about their future

All agencies that may play a major role in the child's life, post-16 should be involved in this process, along with the local authority and/or school's careers service.

As the child approaches post-16 provision, there are a number of options available to them:

- 'Mainstream' providers, such as further education colleges and schools
- 'Special schools'
- Independent Specialist Provider – day and residential places
- Employment with training, also known as an apprenticeship

The Preparing for Adulthood programme (PFA) is a programme funded by the Department for Education as part of the delivery support for the SEND reforms. It brings together a wide range of agencies with a wealth of experience in supporting young people to become happy and successful adults who are in paid employment and enjoy positive relationships with others and their community.

Their website is an excellent starting point for both young people and their families as they being to navigate this road.

 preparingforadulthood.org.uk



The emotional impact of these discussions should not be overlooked, for both the young person and their parents. It can be easy to tell a young person that they 'need to be more independent', but when a condition such as FOP has taken away some of their movement, the reality is far from that. Sensitive handling of these conversations is imperative, as what road-maps and pathways will work for many children with SEND, may not work for a child with FOP. Sadly with FOP, nothing is ever easy.

A young person with FOP may, quite reasonably, be very apprehensive about being encouraged to be 'more independent' and may need additional counselling or support to address and work through these feelings. If their parents have always needed to be their main carers, moving out might quite simply not be an option. Other emotions a young person may encounter is one of regret or disappointment: they may reasonably feel like FOP has restricted their life choices and options, and this too might cause emotional distress or feelings of frustration for the young person. Where parents or an educational practitioner feels like the decisions the young person is being required to make are causing them undue stress or unhappiness, advice should be sought from a GP or mental health professional. The emotional wellbeing of the young person with FOP must be the first priority.

Similarly, there aren't many parents who truthfully look forward to the day their child flies the nest, and when supporting a child with a condition such as FOP has been such a large part of their life, it is understandable that the emotions of 'empty nest symptom' and worry will increase exponentially. They too may need additional support to take care of and nurture their emotional wellbeing for the benefit of the family as a whole.

Higher education

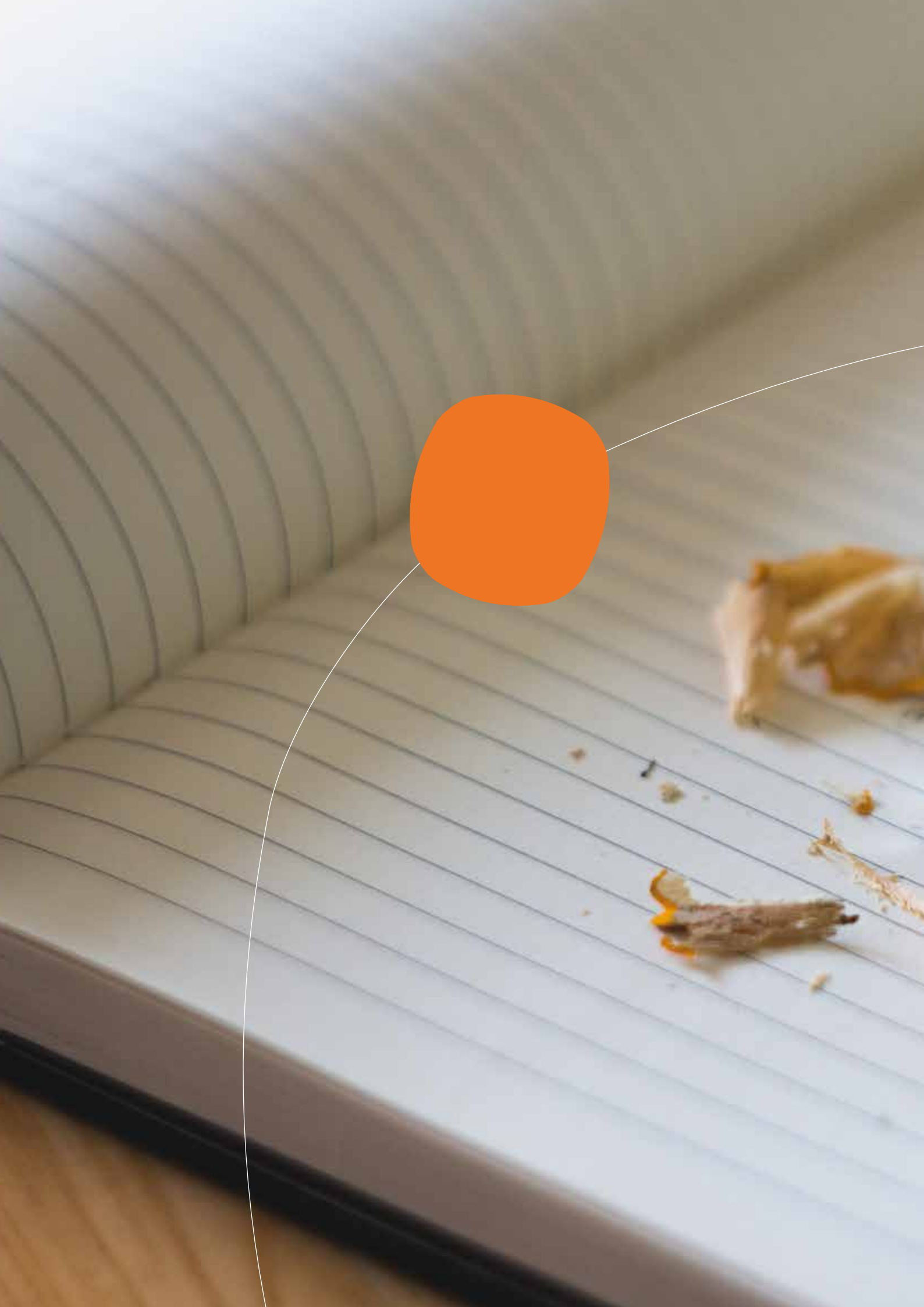
The decision to go on to higher education is not an easy one for any parent or young person to make: college or university isn't for everyone. Some people are more practical, hands-on individuals who would rather be in a work place than a library. Life is about achieving your own goals, not someone else's. There are also financial and practical implications that need careful consideration. Colleges and universities are required to put systems in place to accommodate the needs of students, both academic and residential. Every university and college will have a disability advice and support service, the details of which will be found on their own websites. There is also more information on the UCAS website.

When considering their future, young people with FOP can take inspiration from other people before them who have been successful at school and secondary school: some young people with FOP have gone on to university, whilst others have established themselves with successful careers.



Life is not easy for any of us. But what of that? We must have perseverance and above all confidence in ourselves. We must believe that we are gifted for something and that this thing must be attained."

Marie Curie



Adaptive solutions



There seems to be no end to the number of adaptive products available for children with additional physical needs, and when you start to look you can quickly become overwhelmed. An experienced paediatric occupational therapist will be able to assist with the larger pieces of equipment. There are links to some providers on the FOP Friend Pinterest page. However, the unusual progression of FOP may mean that off-the-shelf products aren't suitable for a child with FOP and a bespoke piece of equipment is a necessity.

For day-to-day living devices, very often it is necessity, and the ingenuity of the child themselves or their parent, that leads them to create their own solutions.

Being in problem-solving mode develops independence and leads to empowerment.

**Amanda Cali,
FOP Mum and Advocate**

Furniture

When selecting furniture for a child with FOP, it is imperative that the furniture is carefully matched to the child's physical and comfort needs. An experienced occupational therapist needs to get a good assessment of what a child's functional limitations are and what it is in the environment that is causing barriers for that child. When selecting adaptive equipment, risk assessment of the furniture also needs to be carefully considered, as some chairs may appear suitable but may have a wide base that sticks out, thus causing an additional trip hazard.

Also, it may be appealing to choose a chair based on a recommendation from another parent, but as with everything FOP-related, what works for one child may not work for the next.



Finally, all equipment needs to be regularly reviewed for suitability, both to take into consideration the year-on-year growth of the child, and any changes to their mobility and restrictions.

- Wide-based step stools around a toilet can provide greater stability
- Height adjustable chairs can be sourced to meet the needs of the child
- A swivel chair can allow a child to rotate freely to turn to see the speaker
- A height adjustable table can be useful if a child uses a wheelchair some days but not others, depending on their wellbeing and fatigue that day. If the child is using a power chair or an adapted chair, ensure the furniture is compatible with the chair
- Multiple chairs may need to be purchased for different locations around the school
- Split tennis balls can be fixed to the legs of all chairs to reduce the noise around the classroom for a hearing-impaired child. They also serve to protect a child from more serious injury if a child inadvertently puts a chair leg onto another's foot and sits down
- Sometimes, a simple stool with appropriate cushioning may be needed for the child to rest their leg on, to enable it to be elevated. Any unnatural and uncomfortable position the child is required to sustain for any period of time has the potential to cause fatigue and potentially trigger another flare-up

Daily solutions and 'hacks'

- Velcro school uniform: elasticated waists, hidden velcro behind buttons.
- Velcro can also be used to attach small equipment to the desk such as calculators.
- Extra-large non-slip bathmats can be taken to swimming lessons for the changing area.
- A pick-me stick can be a useful way of getting the teacher's attention. Perhaps have a selection of these available to other children too, so that they don't feel singled out.
- An extendible magnetic grabber can be useful for picking up smaller items.
- A longer grabber could be stored near to the child to enable them to reach items on the floor or higher up.
- On-trend wheeled backpacks are available and can help with transporting items to and from school.
- An angled desktop stand can ensure that a laptop or tablet is positioned comfortably at the correct angle for the child's movement.
- Non-slip matting can also be cheaply purchased. This increases the grip on the table-top and can help to prevent books, papers and equipment from sliding off the desks, out of the child's reach.
- Triangular pencils and crayons can help a child as they don't roll off the desk quite as easily. They can also help a child improve their pencil grip, as can ergonomic pencils with pre-carved grooves. Where the child's thumb and finger-length allows, these pencils can help to promote a dynamic tripod grip. Pens (with right or left orientation) are also available for when the child is ready to move on.
- Thudguard baseball caps (there are also others available online) can be a discreet way of providing protection.

A general Pinterest search can also provide a number of inspirational solutions. Whilst FOP is rare, there will be many people living with similar daily challenges who have already found a solution to a problem and are happy to share it.





Beyond the school gates

We all know that learning doesn't stop when children leave the school gate. There are any number of clubs, groups and organisations that a child with FOP can enjoy and participate in, and there are more clubs and opportunities out there to consider than just football, swimming and ballet.

As young people with FOP move into adulthood, they can become increasingly isolated due to their lack of independence, their dependence on others, and their frustrations of living with a condition such as FOP. Having a strong network of friends around a young person can help them develop a sense of belonging and their influence on a person's emotional wellbeing is almost immeasurable: we all know from our own personal experiences how much we value our own friends. Good friends can assist the young person with getting out and about, and this in turn can help prevent mental health issues associated with loneliness. Whilst many of us have 'friends' on social media or 'virtual friends' via the internet or gaming, most of us value and cherish having people to hang out with, or turn to, in real life.

The Scouting and Girlguiding associations offer an almost unlimited range of activities, experiences, and new things to learn, and most of which are (or can be adapted to be) suitable for a child with FOP. The precautions, principles and considerations mentioned earlier in this guide can readily be applied to a child attending a Scout or Guide meeting. Children can join the organisations from the age of 5 or 6, although in many areas the groups are oversubscribed so parents are well advised to put their child's name on a list early. As part of their inclusion policy, Scout and Guide leaders have the flexibility to adapt the challenges accordingly to ensure every young person faces a similar degree of challenge, so the requirements of some badges can be adjusted to enable a child with FOP to enjoy the same level of success and earn the same number of badges as their friends.

As mentioned before, music is an excellent and enjoyable way for children with FOP to strengthen their lungs, either by singing or playing a wind instrument. There are many choirs and youth music groups in every local area which could be attended by a child with FOP. The nature of these sessions would mean the child would need limited supervision (for example, compared to a sports club), thus enabling the child to have some freedom to socialise with others without the need for an additional adult close on hand.



Horses are the most amazing creatures and make great companions. They are intuitive beings and can respond to a person's behaviour and emotions. A child with FOP may benefit from such a connection, not to mention the simple enjoyment and exhilaration from riding a horse. Riding for the Disabled schemes run all around the country, with many children with FOP already enjoying such experiences.

Animal therapy programmes, where the child helps to care for animals at a local petting zoo or farm, can also be a great way for the child with FOP to get out of the house, meet new people, and develop their self-esteem. Many of these places are experienced in working with children with additional needs so will be used to adapting their practices.

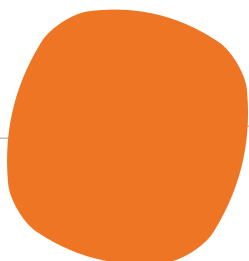
All-ability cycling clubs are increasing in popularity around the country. They offer the opportunity for all people, regardless of age or ability to get out on a bike and get some fresh air and have fun! They usually have a variety of bikes: tandem bikes, trikes, quads, rickshaws and more.

There seems to be no way these days to keep children away from technology and gaming, and whilst consideration needs to be taken when deciding which games to allow the children to play, there are also any number of positives someone with FOP can take from the gaming community. If a child enjoys computers, then they could access coding clubs which are now available around the country. This allows the child to learn a new and valuable skill which will stand them in good stead in their future for employability, but by attending classes they also get to benefit from in-person social interactions, making friends with other children and young people who have a similar interest. What should also be noted is that the increase in popularity of online communities through gaming means that people who are limited in their ability to get out and about are making lifelong friendships in a virtual world.

Drama clubs can be another great way for a child to develop their confidence, self-esteem, and to develop friendships. They are usually well-organised and structured, potentially allowing the child with FOP to attend with minimal or no additional supervision.

If the child with FOP is relatively unimpacted, then the parents may take the decision to allow them to join in with the same sports clubs as their siblings and classmates. Swimming lessons are a good way to improve the general health and breathing abilities of a child with FOP, as well as to just have fun. The advice in this guide can be a useful starting point to open the dialogue with their coaches regarding the best way to provide an inclusive sports experience as possible. There are many children with FOP who are currently active members of their local sports clubs.

It is understandable (and almost to be expected) that a child with FOP will be apprehensive about starting a new club or group, and their parents are likely to have similar anxieties. But the benefits of being a part of a group, and making and hanging out with new friends, make the journey worthwhile. It is much harder to encourage a child to make new friends as they get older, so by equipping them with the skills and experiences from a young age, they are more likely to have the confidence to join in with groups as they get older.







Focussing On the Positives

All children are different. All children with FOP are different. They all have their own strengths and their own interests. At present, there is nothing to suggest that a child with FOP is any more or less intelligent than the next. Teachers must have the same expectations and aspirations for their FOP pupil as for every other pupil in their class. In fact, a quick snap-shot survey of people with FOP showed graduates from several different universities including the University of Oxford; A-grade students from primary schools; A-level students moving on to university; and other FOP students graduating top of their class. One student with FOP graduated from medical school and is working to become a paediatrician, whilst another student with FOP has graduated from law school and is about to begin their career as a solicitor. The bar has been set high for the next generation of children with FOP!

All children with FOP and their parents want and need is to be treated like everyone else. They have the same aspirations and dreams as the next child: they need to be believed in. However, when you are faced with a pupil who is living with an illness as complex and emotionally challenging as FOP, it is easy to see only the FOP and not the child.

The parents of children with FOP will tell you that they are incredibly proud of their child and their achievements. They are astounded on a daily basis by their child's ability to grow and adapt to whatever challenges FOP may throw at them and are amazed and inspired by their resilience and refusal to be beaten by FOP.

A child with FOP just wants and needs to belong, in the same way any child does. A teacher of a child with FOP has the chance to support that child, to help them realise some of their dreams, to give them a sense of belonging, and to be a part of a most special learning journey.



Jess is an accomplished photographer.

Ali is great with animals. She has been showing rabbits at country fairs and competitions for three years and is planning to add another breed to her herd.



Zip loves to fly drones, and swim.

Sona enjoys taking part in theatre classes.

Avi is a great artist.

Isla has beautiful handwriting and is a great reader.

Alisha is a skillful climber.

Joe sings in his school choir and plays the piano and the cello. His teacher has got him a super-cool electric cello!





Miriam studied at both Stanford University and the University of California, Davis. She crochets in her spare time.

Jarvis is awesome at 10-pin bowling.

Millie loves riding her bike!



Ellis is a keen horse-rider and wannabe-Jedi-in training.

Oliver is amazing at archery and badminton.

Sienna loves science both at school and at home.

Lucy graduated from Oxford University in Biomedical sciences.

Annalese plays the clarinet and is in the local jazz band.



Hamish studied Business and Finance at college, graduating with a distinction.





Appendices

Appendix 1: Glossary

ALN

Additional Learning Needs, ALN, is an alternative term for SEND.

Chronic illness

FOP is defined as a chronic illness because it is a life-long condition. The term is usually applied if a disease will last longer than three months.

Flare-up Or 'flare'

In the case of FOP, a flare-up is a swelling that appears upon the sufferer's body. The swellings can vary in size. They can appear after a knock or impact, or spontaneously. They can be red and inflamed. They are also often warm to the touch.

In the event of the school setting observing what they believe to be a 'new' flare-up, parents should be contacted immediately.

FOP

The abbreviation for the rare genetic condition fibrodysplasia ossificans progressiva (Pronounced Eff -Oh -Pea).

Healthy Young Minds

Healthy Young Minds was previously known as CAMHS (Children and Adolescents Mental Health Service). Through the NHS, they provide a comprehensive and targeted intervention service to promote the emotional and psychological wellbeing of children and young people. Referral to Healthy Young Minds is usually through the GP.

GDPR

General Data Protection Regulations. The GDPR sets out requirements for how organisations handle and process personal information. In the case of the child with FOP, this will be personal information, information relating to their academic achievements, and medical information.

Individual Healthcare Plan

An Individual Healthcare Plan, or IHP, is a document that is designed to keep children with medical conditions safe, well and involved in school. It sets out a child's medical needs and how they should be handled. This is especially important with conditions such as FOP, where it is ultra-rare, and people are unlikely to have ever supported a child with the condition before. This plan makes it easier for everyone who is involved in the child's care and education.

Local Offer

The SEND Local Offer offers information to parents in a single place. The Local Offer requires local authorities to publish what services and support they offer to children with SEND. It helps children, young people and their parents understand what services and support they can expect from a range of local agencies, including their statutory entitlements. This support spans education, health and social care.

Ossification

The process when the body creates new bone.

Parent

Where 'parents' are referred to in this guide, it means any adults who have parental responsibility for the child.

Parent Partnership Service

The Parent Partnership Service has now been renamed the Information Advice and Support Service, IAS Team. Sometimes it is referred to as the SENDIASS.

Prednisolone

A strong steroid administered to children with FOP during a flare-up. Sometimes this may be referred to by its American name, 'prednisone', or abbreviated to 'pred'.

SEND

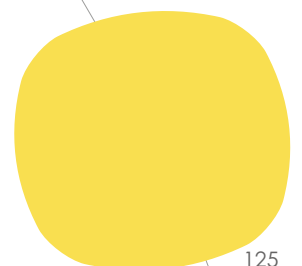
Special Educational Needs and Disability.

SENDCo

The Special Educational Needs Coordinator is often referred to as the SENDCo. They are the member of staff in an educational setting who is responsible for coordinating and overseeing the processes and paperwork to ensure the child receives the support they need and to which they are entitled.

SENDIASS

The SEND Information Advice and Support Service, have local services around the country. (sometimes previously referred to as Parent Partnership Service). The Information, Advice and Support Services Network provide training and support to local IAS services.



Appendix 2: Library

Further information about FOP

What is FOP? A Guidebook for Families

A comprehensive guidebook about FOP. This book answers many questions commonly asked by families and medical professionals about FOP. It has information and guidance from internationally renowned specialists such as Professor Fred Kaplan. It also includes articles by parents of children affected by FOP. It offers reliable insights into this condition. It is free to download, and a copy should be made readily available in every setting.

bit.ly/whatisfopguidebook_ifopa

What is FOP?

Questions and Answers for the Children

This is a guidebook written for an audience of children ages 7 -14. Younger children can read this book with adult supervision. It is advised that parents read the book before sharing it with their child. The book was written by Sarah Steele and her mother Marilyn Hair. They hoped that the book would answer some of the questions children or their siblings may have about living with FOP, as well as giving ideas about how to live with the mysterious condition that is FOP. This is free to download.

bit.ly/whatisfop_forkids

Medical Management of FOP: Current treatment guidelines

The latest guidance for medical professionals, and the current treatment considerations, published by the International Clinical Council on FOP.

ifopa.org/for_medical_professionals

Statutory Guidance

ENGLAND: Special educational needs and disability: A guide for parents and carers

This is the 2014 Department for Education guide for parents and carers of children and young people aged 0 – 25 years who have SEND. It explains the how the system that supports children and young people with disabilities is intended to work. It provides information covering the whole system.

bit.ly/DfE_SENDCode_GuidanceForParents

ENGLAND: Special educational needs and disability code of practice: 0 to25 years January 2015

The government's Statutory guidance that outlines what organisations which work with and support children and young people who have special educational needs or disabilities must provide. This Code of Practice relates to Part 3 of the Children and Families Act 2014.

bit.ly/SEND_CodeofPractice_2015

ENGLAND: Supporting pupils at school with medical conditions

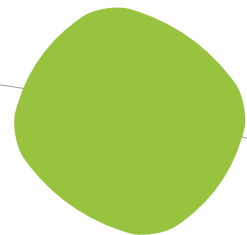
The government's statutory guidance for governing bodies of maintained schools and proprietors of academies in England. December 2015

bit.ly/supporting_pupils_with_medical_conditions

NORTHERN IRELAND:

A useful support book for parents and carers on the SEN process. It includes links to further support and advice.

bit.ly/senac_guide_2017



WALES: Additional learning needs (special educational needs) 2018

The Welsh government's statutory guidance for supporting children and young people aged 0-25 with additional learning needs.

beta.gov.wales/education-skills

WALES: Additional Learning Needs factsheet for children, young people, parents and carers

A simple factsheet outlining how the changes will affect people using the system.

bit.ly/wales_aln_factsheet_families

SCOTLAND: Additional support for learning: statutory guidance 2017

The statutory guidelines for Scotland, which explains the duties of the education authorities to support children and young people's learning.

bit.ly/scotland_additional_support_for_learning_2017

enquire.org.uk

SCOTLAND: Enquire Parents' Guide

An easy to read guide for parents and carers, outlining a child's rights, the duties of the local authority and other information relevant to parents of children with additional needs.

bit.ly/enquire_parents_guide

SCOTLAND: Enquire factsheet: Children's rights to education and additional support in school

A clear factsheet to explain the rights of a child to access an education that meets their needs, relating to Scottish law. It also explains how to exercise those rights.

bit.ly/enquire_factsheet_rights

Additional information

The young person's guide to the Children and Families Act 2014

The Department for Education's guide to the Children and Families Act 2014, explaining the new law to children. It is a summary of what children need to know about the Act. It is written in clear, easy to understand language, with children and young people as its audience.

bit.ly/young_persons_guide_children_families_act_2014

Childcare for families with disabled children

A printable document that explains how to access free childcare for two to four-year olds. It outlines your entitlements and discusses barriers you may encounter when looking for childcare for your disabled child.

bit.ly/childcare_disabled_families_two_four_years

Some SEND Myths

For parents who may be struggling to access the support and provision they need for their child, here are some SEND myths explained by the Council for Disabled Children.

bit.ly/SEND_myths

Guidelines for writing an EHCP

Guidance and examples of how to write an EHCP, with tips and suggestions. Written in a clear and reader-friendly style.

bit.ly/example_ehc_plan

Home to School Transport

A leaflet from Contact which explains the process for getting school transport for your child, along with advice if the council are not willing to provide the service.

bit.ly/england_contact_school_transport

My Rights Your Responsibility

A set of six leaflets from the Council for Disabled Children. These guides have been written for parents of disabled children. It provides information on their child's rights to access activities, community facilities and other service. The guides can be downloaded and printed.

bit.ly/cdc_rightsandresponsibility

Appendix 3: Useful Links



FOP Friends is the UK's charity for people affected by FOP. It offers advice and support to families and patients with FOP. It actively fundraises to support the research into a treatment and a cure for FOP. It also aims to raise awareness of the condition to prevent misdiagnosis.

FOP Friends
1 Cumberland Road, Sale
Cheshire, M33 3FR

 fopfriends.com



There are a number of closed and private Facebook groups for people with FOP and their families. This allows people who are affected by FOP to connect with each other, share information and ideas, but most importantly offer friendship along this challenging journey. There is a Parents' group, a Dads' group, and a Mums' group. There is also a group for FOP Ladies (from aged 13 onwards) to discuss issues of a personal matter. These are people who truly know what you are going through and can be there for you. Contact FOP Friends to be invited to these groups.



Visit our Pinterest page for up to date information, ideas, and links to useful pages to support you and your family to live with FOP.

 pinterest.co.uk/fopfriends

Further reading about FOP

The following information was correct at the time of going to print and is provided in good faith. FOP Friends can accept no responsibility for the advice, information or views given by these external organisations.



The International FOP Association, or IFOPA, is the international organisation to bring together people who are affected by FOP. It supports FOP research at the University of Pennsylvania School of Medicine, and it is a source of comfort and support for those who suffer from FOP. Their vision is a cure for FOP, accessible worldwide.

 ifopa.org

 together@ifopa.org



There is an excellent and experienced FOP medical team at the Royal National Orthopaedic Hospital (RNOH), Stanmore, London. They are led by Dr Richard Keen. In addition to caring for patients with FOP, they are also the UK clinical trial site for current pharmaceutical drug trials.

To contact Dr Richard Keen, Dr Jude Bubbear, Dr Jacobs at RNOH Stanmore:

 rno-tr.metabolicsecretary@nhs.net

General organisations to support families and educational professionals



The Anna Freud National Centre for Children and Families is a children's mental health charity. They provide a range of specialist types of support for children, young people and families. Their overarching aim is to build resilience and to help children and families who are in distress.

annafreud.org



Bringing Us Together is a website run by parents of children with SEND. It offers a range of tips, ideas, and information when dealing with the paperwork and appointments involved with raising a child with SEND. They are also involved in a number of projects that support families. They believe that every parent they meet is bl**dy awesome!

bringingustogether.org.uk



Cerebra's aim is to provide high quality health and social care information for the parents and carers of children aged 0-16 years with neurological conditions. Whilst not specifically FOP, their website contains useful help and support that is relevant for any parent of a child with additional needs.

cerebra.org.uk

Child Law advice

Child Law Advice is operated by Coram Children's Legal Centre. They provide specialist advice and information on child, family and education law to parents, carers and young people in England. They can offer impartial legal advice on child, family and education law. They have a selection of free information pages on their website regarding child, family and education law. They also have advice and assistance for young people.

childlawadvice.org.uk/



Part of the NSPCC, Childline offers a free, confidential listening ear for children and young people at any time of day or night. There is also a vast range of online information and guidance to support children who are going through difficult situations and battling challenging emotions. Bigger issues that are covered include depression, bullying, sex and relationships, and body issues. It also provides guidance for young people post-16 on topics including money, employment and education. The content is aimed at older children, young people and young adults.

childline.org

contact

Contact (used to be Contact a Family) is a national charity that supports families of children with disabilities. They offer a range of services and they have a comprehensive selection of advice and information on their website. They have advisors to speak with, who will help you with the SEND process or any other difficulties you may be experiencing.

contact.org.uk



The Council for disabled children is an umbrella body for the disabled children's sector. They bring together professionals, practitioners and policy-makers.

They have a range of information and resources on their website for parents regarding the SEND process and guides to the Code of Practice. They also have an excellent leaflet: My Rights Your Responsibility which explains a child's rights to access activities, community facilities and other service.

councilfordisabledchildren.org.uk



The Disabled Living Foundation is a national charity that provides impartial and expert advice on independent living. They have a vast knowledge of daily living equipment available. They can advise on suitable equipment as well as if a supplier is reputable. They also offer a range of free factsheets to provide general advice on a range of daily living equipment.

dlf.org.uk



This is a specialist law firm who provide legal advice to parents. However, their website has a range of free information for parents. They have SEN resources for download and FAQs relating to the SEND Code 2015

specialeducationalneeds.co.uk

ENQUIRE

Helping you understand additional support for learning

Enquire is the Scottish Advice Service for additional support for learning. Their website contains lots of useful information about the Scottish system where you can download the Enquire Parents' guide to additional support for learning.

enquire.org.uk



This is a website dedicated to providing information about the Early Years Foundation Stage, for practitioners and parents. There is a section on SEND in the EY, as well as blog updates with the latest guidance and news about SEND in an Early Years setting. There are also links to other sites.

foundationyears.org.uk



The Health Conditions in School Alliance is a group of organisations, charities, health care professionals and trade unions who work collaboratively to make sure children with health conditions get the care they need in school.

The site is aimed at schools, to offer guidance and tools to support them to look after children with health conditions.

medicalconditionsatschool.org.uk



Mentally Healthy Schools brings together quality-assured information, advice and resources to help primary schools understand and promote children's mental health and wellbeing. Their aim is to increase staff awareness, knowledge and confidence to help schools support their pupils.

mentallyhealthyschools.org.uk



Home-Start is a national family support charity with centres all around the UK. They offer support, practical help, friendship, and guidance for families of young children who are facing challenging times.

home-start.org.uk



The IASSN provide a range of support to local IAS Services to help them improve the provision for children, young people and their families. You can find your local IAS from the link:

councilfordisabledchildren.org.uk/information-advice-and-support-services-network



Independent Parental Special Education (IPSEA) offers free and independent legally based information, advice and support to help parents get the right education for children and young people with SEND. They also provide training and have a range of downloadable guides and resources on their website.

They offer a telephone advice line for parents to offer legally based information and advice on an educational issue that is the result of a child's special education need or disability.

ipsea.org.uk/



Nasen is the National Association of Special Educational Needs. It is a charitable organisation that supports practitioners with relevant information to help them support pupils with additional needs. They have a range of factsheets and guidance on their website.

welcome@nasen.org.uk



The National Network of Parent Carer Forums (NNPCF) is the independent national voice of parent carer forums. They aim to support families living with special educational needs and disabilities to provide them with the best possible outcomes for children and young people. They have a range of resources online which may be a source of information and support for parents. They provide local links to parent forums, so families can develop friendships with other families in similar situations.

nnpcf.org.uk



A general website for parents with information about all aspects of their child's education. There is a section on Additional Support, with further information about the statutory requirements as well as how to get support for your child.

education.gov.scot/parentzone/additional-support



This programme is funded by the Department for Education with the aim of providing support to prepare young people for adulthood with paid employment, good health, independent living options and friends, relationship and community inclusion.

www.preparingforadulthood.org.uk



The Special Educational Needs Advice Centre (SENAC) is a charity in Northern Ireland. They provide confidential, independent advice and advocacy on behalf of children and young people with special educational needs and/or disabilities who attend schools in Northern Ireland.

senac.co.uk



The SEND Parent's Handbook is a Facebook page for families of children with a range of SEND. Whilst this is not an FOP-specific group, the articles and blog posts may be of interest to parents who are supporting their child with additional needs. Sometimes the posts offer knowledge, advice, a motivational 'thought for the day', and other times it's just good to know you're not alone on this journey and there are other parents fighting similar battles to you.

🌐 facebook.com/thespecialparentshandbook/



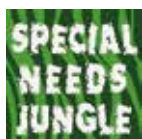
SENDirect is a project of the charity Contact. They can help you find the right support, services and information for your family. They can help you find and compare accessible services and activities to meet the needs of your child. Some of the services it signposts users to are free, others are paid services. Users can search their local area for the services.

🌐 sendirect.org.uk



SNAP cymru is a charity based in Wales. They provide information, advice and support for parents, children and young people who have special educational needs or disabilities. They provide a range of impartial, confidential services, free of charge, including a helpline for advice and support, and independent specialist advocacy.

🌐 snapcymru.org



This is a parent-led, not-for-profit organisation that provides information, guidance and resources for parents and carers of children and young people with SEND. They also have useful guidance and flow charts to help parents navigate the SEND process in England.

🌐 specialneedsjungle.com



UCAS is the Universities and Colleges Admissions Service. It's the centralised service that students use to apply to university. They have information to advise and support students living with disability, apply to university or college.

🌐 ucas.com/undergraduate/applying-university/individual-needs/disabled-students



Wraparound Partnership is a social enterprise working to help individuals with SEND and their families reach their full potential. They can provide information and support for the EHCP process, however there may be a charge for this.

🌐 wraparoundpartnership.org



Championing advice and counselling

Youth Access is an advice and counselling network. They believe that every young person has a right to access free, high quality advice and counselling. Working with their members, they promote the Youth Information, Advice and Counselling Services (YIACS) model as part of local services for young people everywhere. They can signpost young people to a service near to them.

🌐 youthaccess.org.uk



Young Minds is a national charity which is fighting for a future where all young minds are supported and empowered. They aim to "make sure all young people get the best possible mental health support and have the resilience to overcome life's challenges."

Their website talks about the feelings and symptoms related to mental health topics and explains how young people or their carers can get the support and help they need. There is also a parents' helpline

🌐 youngminds.org.uk



Appendix 4: Example emergency poster

EMERGENCY MEDICAL INFORMATION

Name: Madison James-Fleck
Date of Birth: 1st January 2012
NHS Number: 701 251 1234



Madison has: FIBRODYSPLASIA OSSIFICANS PROGRESSIVA (FOP)

FOP is accelerated by trauma (including intra-muscular injections) so handle Madison gently at all times and prevent falls. Evaluate the emergency and

Protect the life of Madison as if FOP was not an issue.

PLEASE: follow these emergency guidelines at all times. Any unnecessary physical trauma to Madison can cause irreparable restrictions to her body and movement.

- 1. Avoid deep tissue trauma** including intramuscular (IM) injections, if possible.
- 2. Stabilise & treat.** No IM injections; venipuncture, subcutaneous & intravenous medications are ok.
- 3. Take intubation precautions:** Protect the jaw and get expert anaesthesia assistance since the jaw and neck may be completely or partly locked. **If airway management is needed, the preferred approach is naso-tracheal intubation with fiberoptic guidance.** Many FOP patients have restricted jaw and neck mobility, so intubation must be done in as gentle a fashion as possible. **Follow intubation by steroids (prednisolone 2mg/kg/day for 4 days) to prevent fatal airway swelling from the trauma**
- 4. Consulting of expert doctors is strongly recommended** regarding potential risks of any surgical or medical interventions being considered.
- 5. Consider administering prophylactic (precautionary) steroids in cases of major trauma**

Madison has the following FOP-related physical restrictions. She needs careful handling and positioning on a trolley or bed.

- Her left arm is locked at the elbow
- Limited neck movement
- FOP bone protrusions on her back
- Mild scoliosis of the spine

Allergies: None known

Medications: None. Ibuprofen and/or prednisolone as needed as per guidelines

Weight: 24kg (on 10/12/18)

If time permits, please take Madison to the **Royal Manchester Children's Hospital** where expert treatment will be available. If injuries are potentially life-threatening, please take to nearest Accident and Emergency Department. **The North West Ambulance Service has a marker on Madison's home and school addresses.**

EMERGENCY CONTACTS

Kate and Simon James-Fleck	0161 284 5519 / 07945 645 354
Dr Richard Keen (RNOH, London)	020 3947 0100
Dr Frederick Kaplan (Philadelphia, USA)	001 215 294-9145 (clinical office) 001 215 545-0758 (home)
Dr Khan (Royal Manchester Children's Hospital)	0161 234 5678

FOP is a rare genetic disorder characterized by progressive bone formation in muscles, tendons, and ligaments, leading to progressive loss of mobility.

FOP is a disease in which the body produces not just too much bone, but an extra skeleton that immobilises the joints of the body, leading to stiffness and permanent immobility. Extra bone growth can occur without any warning or as a result of trauma, which can be as minimal as a knock, bump, fall or forced movement to locked limbs.

Efforts to remove this extra bone are fruitless and will cause more bone to grow. Malformations of the great toe are commonly noted at birth. Ectopic bone formation usually begins in the first decade of life and progresses episodically in characteristic anatomic patterns.

To view current treatment guidelines, including medical management information for medical professionals, go to:

www.ifopa.org/for_medical_professionals

Additional contacts:

Alison Beresford (auntie) 07708 833 007

Cate Dowell (auntie) 0161 249 5123

Dr Elise Frier (GP) Conway Road Health Centre 0161 246 5678

Home address: 84 Highfield Road, Sale, Cheshire, M33 4HB

School address: St. Mary's Primary School, Sale, Cheshire, M33 5CG

A paramedic or emergency medical professional is likely to have no knowledge or understanding of the implications of FOP.

The adult in charge of Madison's care, must take on the role of advocate in the case of an emergency, prior to the parents arriving or an FOP expert being consulted.

Appendix 5: Presentation from a child with FOP

One of our FOP friends, based in America, wrote this presentation herself and spoke to her class about her FOP:

Dear Class,

Just think about how no two snowflakes are alike.

No two children are alike.

It's our genes that make us, us.

Not the jeans you wear!

The genes that are in our bodies.

My genes mean I have some special care needs. I'm a little more delicate than the rest of you. Please be careful around me.

I have an aide, Mrs. Davey, who is here to keep me safe. Many of you may know her already!

So, I skip some activities that could be dangerous, like running or wild activities in gym.

I like to say that I'm allergic to bumps.

You can help keep me safe by:

- Giving me extra space when possible
- Don't be too rough around me
- Push in chairs when possible

At recess I do calmer activities like nature walks. I would welcome the opportunity to play with each of you!

It's important for everybody to follow the school rules, especially my class, such as:

- no running in the classroom or halls
- clean up toys or tripping hazards on the floor
- Make sure chairs are always pushed in when possible
- Clean up spills as soon as possible

I am happy to answer any questions.

Thank you for listening.

Sienna



Appendix 6: Gallery of friends

Thank you to all the children and adults with FOP, and their friends, who have allowed us to feature them in this guide.

Edison Acosta Bedford

Elise Acosta Bedford

Millie Barker

Harry Bedford-Gay

Leo Bedford-Gay

Oliver Bedford-Gay

Ava Borradaile Falp

Jarvis Budd

Caleb Burgess

Alex Chamoto

Miranda Friz

Ash Gilmore

Ellis Grant

Antonio Gonzales

Zip Gordon

Rion Henry

Joey Hollywood

Noor Khan

Ashley Kurpriel

James Orme

Sienna Otto

Hamish Patel

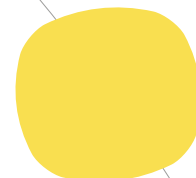
Avi Sanghera

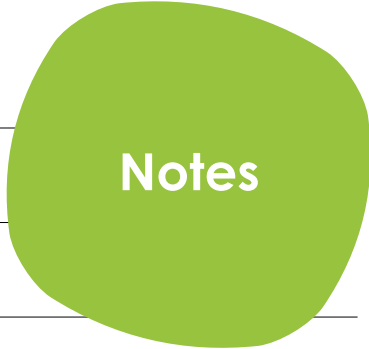
Jaxon Theoret

Louise Wedderburn

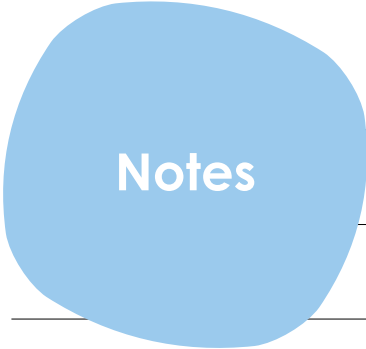
Isla Williams

Alisha Wilson





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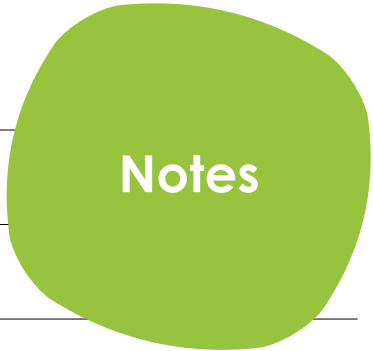


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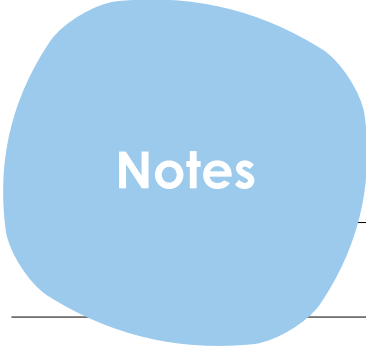


Notes



Notes

Lined writing area consisting of 21 horizontal lines.



Notes



- +44 (0)300 323 9989
- info@fopfriends.com
- @FOPFriends
- /FOPFriends

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