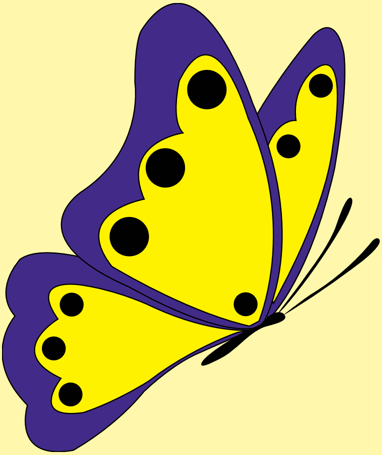
Young People & Fibromyalgia

Including - pull out section for teaching staff p13-16
Information for parents/carers p23-28

FIBROMYALGIA ACTION UK

Registered Charity No. 1042582



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This information booklet is in three parts. Most of the information is for young people like you. The middle pages are for you to pull out and pass on to the staff who teach you. At the end are pages for your parents or other people you feel would benefit from understanding more about fibromyalgia and how to cope with it.

What is fibromyalgia (fi-bro-my-al-gia)?

Fibromyalgia is a chronic (long term) pain condition. The pain is mainly felt in your muscles and tendons. It feels like you are sore all over, as if you have run a marathon the day before or you have the flu. Your limbs ache and sometimes feel too heavy to move easily. You can also feel very tired and have difficulty sleeping at night. Your head can become muzzy making it difficult to think clearly and remember things. Symptoms can come and go over time and vary from person to person. Sometimes it feels like the pain is moving around your body from one area to another.

Main symptoms:

- widespread pain throughout the body
- disturbed sleep
- always feeling tired

Other common symptoms:

- morning stiffness
- pain when you exert yourself
- headaches
- difficulty concentrating (fibrofog)
- light-headedness
- feeling worried
- being bothered by chemicals, light, sound, smells, noise
- numbness and tingling
- irritable bowel syndrome (IBS)
- irritable bladder
- cold sensitivity
- restless legs

What causes fibromyalgia?

The exact cause of fibromyalgia is still unknown. However, people with fibromyalgia feel a lot more pain than other people. This is because pain signals in fibromyalgia are amplified. It is as though someone has turned the switch to full volume. So the nervous system, that carries pain signals up the spinal cord to the brain, is constantly set on maximum. Pain or touch, that would not bother other people, becomes painful and troublesome to a person with fibromyalgia. It is like being as sensitive as the princess in the fairy tale The Princess and the Pea who could feel a hard pea concealed under many mattresses.

This sensitivity of the nervous system can then affect other areas of the body. It can make the bowel or bladder sensitive leading to irritable bladder or irritable bowel syndrome. It can keep the body on maximum alert, as though you are living in a cage with danger and can't escape. This can make it difficult to fall asleep and stay asleep. It uses up a lot of energy leaving you feeling tired and anxious.

Also, the body's natural ways of reducing pain and making us less sensitive are not working properly. These rely on chemicals such as serotonin and dopamine, which are lower than normal in people with fibromyalgia.

Who gets fibromyalgia?

Anyone can develop fibromyalgia although it is far more common in girls than in boys. It is often triggered by an infection, an accident or intense stress, which kick starts the process leading to the symptoms of fibromyalgia. Often young people develop fibromyalgia as teenagers.

Doctors think that the differences in our genes and the environment that we live in can make some people more likely to develop fibromyalgia than others. Sometimes, fibromyalgia can be seen to run in families, which supports this idea.

How will my doctor know I have fibromyalgia?

The first port of call is always your GP. GPs should follow what they do for any childhood condition, treat it as a general thing at first and then if it doesn't clear up refer you on to a community paediatrician (pee-dee at-ri-tion child specialist) at your local hospital. It can be frustrating if you feel your GP is not responding and has little knowledge of fibromyalgia. However, your GP may not have a detailed knowledge, as their job is to identify that there is a problem and to refer on to a specialist. GPs see a wide range of children, the majority of whom, despite having aches and pains, do not have fibromyalgia. In fact, a GP could expect to come across only one or two children with fibromyalgia in their whole career.

The community paediatrician at your local hospital will do a general overall health check. If fibromyalgia is suspected then you can be referred for a further check or for treatment.

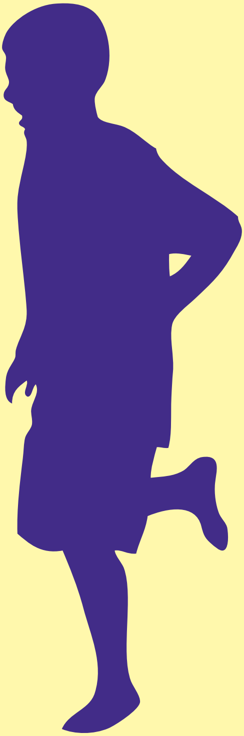
Fibromyalgia is usually diagnosed by a paediatric (pee-dee-at-ric) rheumatologist (roo-ma-tol-o-gist). The doctor will look at your medical history and listen to your account of your symptoms. Then the doctor may make a physical examination. Certain areas of your body are pressed to see if they are particularly tender. These tender areas are called tender points. These areas need to be found above and below your waist and on both sides of your body. If there are at least five tender points (11 in adults), then the doctor will consider a diagnosis of fibromyalgia. Before giving a diagnosis it is important that he/she rules out other conditions which may be causing your symptoms, like juvenile arthritis, lupus or connective tissue disease.

Some doctors are cautious about labelling a young person with fibromyalgia. This is because many young people can get better and doctors do not want a young person to see themselves as having an adult condition they may not recover from. For this reason doctors tend to use terms like diffuse idiopathic pain syndrome (DIPS), soft tissue rheumatism or chronic pain syndrome instead. If the symptoms carry on into adulthood then a diagnosis of fibromyalgia might be made at a later date.

Doctors don't always explain things clearly so don't be afraid to ask the doctor questions. It is a good idea to write down any questions you have before your appointment so that you remember to ask them.

Will I get better?

Young people can get better over time. Young people have a better chance of recovery than adults with fibromyalgia. This is because young people are still growing, so their nervous system is changing and developing all the time. Some young people still have grumbling symptoms beneath the surface which may flare at a later date, or may disappear altogether. At the moment there are no scientific studies that have followed children with fibromyalgia closely over long periods of time.



What treatment is there?

Treatment is aimed at reducing the pain and other symptoms so that you can regain the best quality of life possible. It is possible to get life successfully back on track, either with symptoms disappearing or with them well under control. The most successful form of treatment involves a group of specialists working together to teach both you and your parents how to manage your symptoms and your daily activities. It is essential that both you and your parents become active members of the team and work together with the specialists.

The team of specialists usually includes:

PAEDIATRIC RHEUMATOLOGIST OR PAIN SPECIALIST

The rheumatologist or pain specialist may prescribe you medication to help you manage your symptoms. Doctors tend to be cautious about giving medication to young people. However, your doctor may decide that you need help coping with certain symptoms like pain or getting to sleep. The most common medications used for treating fibromyalgia work to reduce pain, relax muscles and encourage sleep. One type of these medications is called tricyclic antidepressants. This doesn't mean your doctor thinks you have depression. These only treat depression at high doses. At low doses they simply reduce pain and encourage sleep. You may experience side-effects like a dry mouth, morning sleepiness or dizziness with these drugs. However, these side effects should get less or disappear after several weeks.

It is possible that you may develop depression due to living with chronic pain, but this will need to be tackled separately.

PHYSIOTHERAPIST (FIZZ-I-O-THAIR-RAP-IST)

A physiotherapist will work with you to set out an exercise programme including stretching, strengthening and aerobic exercise. At first, exercise can seem like the last thing you want to do when you are in pain. However, it is very important because muscles that are not exercised become stiff, weak and tight, which then causes more pain. Stretching will stop your muscles tightening up and becoming shorter. Strengthening will keep your muscles strong. Aerobic exercise, like walking or cycling, will keep your lungs and heart healthy. It is important to start slowly and gradually increase over time, working at a pace that is right for you.

PSYCHOLOGIST (SI-COL-O-GIST)

Anyone coping with pain needs to learn coping skills and how to deal with emotional issues straight away and effectively. Having a psychologist involved in your treatment does not mean that the doctor thinks that your symptoms are all in your head or are simply due to stress.

A psychologist is there to teach you and your parents about fibromyalgia and ways that you can manage the pain and fatigue. Often they use a therapy called cognitive behavioural therapy (CBT). This looks at how your thoughts, feelings and actions go together, and how your thoughts and emotions can be barriers to what you want to do. It is learning about those barriers, facing the challenges they present and tackling the fear you may feel. It is also learning to be creative in the way you think, being flexible and doing things differently, problem-solving and developing good communication skills.

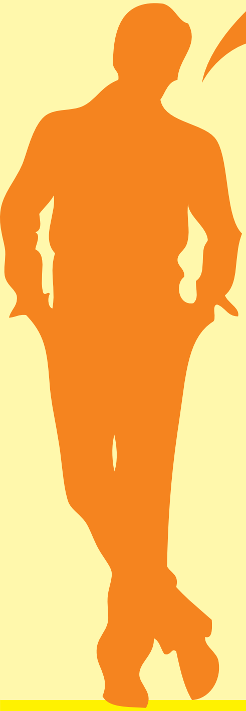
Activity management

Learning to pace your activity so that you can keep going throughout the day without increasing your levels of pain or making yourself exhausted is very important. It can be quite a difficult thing to learn as the level of activity one person can cope with may be quite different to what another person can cope with. You basically have to work out your own boundaries and experiment with how much activity you can do before causing your symptoms to flare up. Remember that a flare up is not something to be afraid of, it is something to be learned from. Sometimes, parents will worry and not want you to try out new activities because they don't want you to be in more pain, which is perfectly understandable. But if you think you can do something it is important to give it a go as in this way you will learn what you are capable of and how much activity you can comfortably do in a day. If you are trying a new activity start by doing it for a few minutes the first time and see what happens, then gradually increase the amount of time.

Where will I go for treatment?

Most often, you will receive treatment at your local hospital where the paediatric rheumatologist, physiotherapist and psychologist are based. Sometimes though, if you live in a rural area, for example, your local hospital may not be able to offer suitable treatment. You may be referred to a residential pain management programme at a specialist hospital to receive intensive treatment. You and one of your parents will stay there for a period of time. Two hospitals in the UK which offer excellent residential programmes for young people are Great Ormond Street Hospital and the Royal National Rheumatology Hospital in Bath.

Stephanie: *" I use heat patches on my back especially during the winter. I have found physiotherapy, hydrotherapy and a pain management course helpful. I would recommend the pain management course to anyone as it covers everything. I do take some medicines, painkillers and tablets to help me sleep, but I don't like taking medicine as a long-term solution. My best coping strategy is distraction, whether it's listening to music or talking to family and friends or going out and just getting on with things."*



Reuben: *"I find a thermal heat pad and an infrasound vibrator the most effective treatment. I also take vitamin supplements and herbal remedies. I haven't found medication or alternative therapies very useful."*

Carla: *"I use heat. I have a hot bath or use a hot water bottle. I do have certain people I can talk to about my fibromyalgia, which helps. I also write poetry about how I feel."*

Holly: *"I take amitriptyline at night to relax my muscles while I sleep and I think it improves the quality of my sleep. I also find trigger point massage and the Bowen Technique useful but they are not available on the NHS. I can't afford them on a long-term basis. I also wear an air ionizer on a cord around my neck when I leave the house as I am very sensitive to chemicals and smoke."*

Good communication

Talking to your friends and family about how you are feeling can sometimes be quite difficult. The problem with pain and tiredness is that you can't see them, so other people don't always realise that they are there. Often with fibromyalgia you look really healthy and some people think that if you look okay you must feel alright. School friends can think you're faking it to get out of classes, especially when your symptoms keep changing, which makes no sense to them in their experience.

Try to explain to your friends the different symptoms that you have and how they make you feel. Tell them that your symptoms can change from day to day, so sometimes you can do things and at other times you can't. You may have to cancel arrangements to meet up at a moment's notice and you find that as annoying as they do. If your friends have no experience of pain then it can be difficult for them to understand and that can be frustrating for you. Try to be patient and be ready to explain if they ask you questions. In the end though, if they are your real friends, they should be supportive of you and be ready to try to understand.

Asking for help when you need it can also be hard. Everybody wants to be independent and nobody likes asking for help but sometimes you don't have a choice. It shows courage and maturity when you can recognise that you need help and you are prepared to ask for it. Often other people are all too ready to help, but they won't be able to guess when you need it, and they won't want to keep asking you. It is up to you. Don't be afraid to ask.

Parents can react in different ways. Make sure you talk to both your parents. They can also find your symptoms as mysterious and confusing as other people, and sometimes are not sure how to react. Holly's parents felt guilty that they could not fix the situation and take the pain away. Julia's parents wanted to be supportive but struggled to understand how she was feeling and what she was going through. Parents want to help but they don't always know how. It is vital to keep the lines of communication open and be prepared to talk about how you're feeling and how they are feeling. If you think they are being overprotective, explain to them that you need to find your own boundaries and work at it together. Work out solutions that will make family life easier and explain to them the best ways they could help you to cope.

Sometimes it can really help to chat to another young person who has fibromyalgia or another form of chronic pain. There are forums available on the Internet, like the FMA UK forum, where you can chat to other people in a similar situation and share how you really feel and the problems you are facing.

Coping at school or college

School/college can present all sorts of problems. You may get stiff and sore sitting in class, find it difficult to concentrate, struggle to carry your books from class to class or simply find the whole day too exhausting. Staying in school is the best option to keep you on track with your education and in contact with all your friends. You will need to look at some practical solutions to make the school day easier for you. The first step is for you and your parents to discuss the problems you are facing with your teacher. It is important that your teacher understands what you are coping with and how they can help you. It may be useful to provide them with some information on fibromyalgia or a letter from your doctor to explain your symptoms and the help you may need in more detail.

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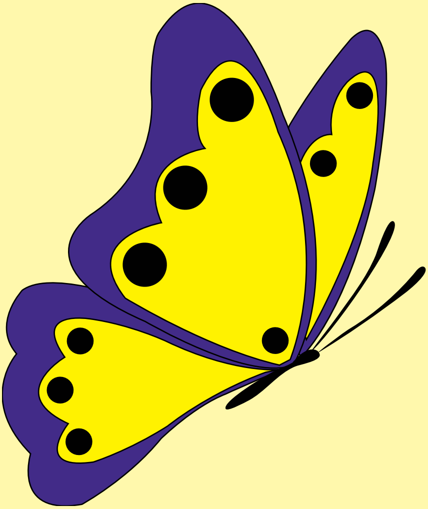
Information for Teaching Staff



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What is fibromyalgia?

Fibromyalgia is a chronic pain condition characterised by widespread muscle pain, profound fatigue and non-refreshing sleep. The pain is often described as aching or burning, just like you feel when you have the flu or have run a marathon the day before. Sleep is commonly disturbed with frequent night-time awakenings and often a person will awake feeling as tired and sore as when they went to bed the night before. The fatigue can vary from simply feeling tired to overwhelming exhaustion, which can come on suddenly as though someone has 'pulled the plug'. These main symptoms can be only the tip of the iceberg however, as there are also a range of other commonly associated symptoms including irritable bowel syndrome, cognitive difficulties and multiple sensitivities. The symptoms of fibromyalgia can vary in intensity from day to day and undulate over time. It can seem as though the pain is moving around the body and as soon as one pain disappears another one arises.

Main symptoms:

- widespread pain throughout the body
- disturbed sleep
- always feeling tired

Other common symptoms:

- morning stiffness
- pain when you exert yourself
- headaches
- difficulty concentrating (fibrofog)
- light-headedness
- feeling worried
- being bothered by chemicals, light, sound, smells, noise
- numbness and tingling
- irritable bowel syndrome (IBS)
- irritable bladder
- cold sensitivity
- restless legs

Possible solutions for coping at school or college

School/college can present all sorts of problems. Pupils may get stiff and sore sitting in class, find it difficult to concentrate, struggle to carry books from class to class or simply find the whole day too exhausting.

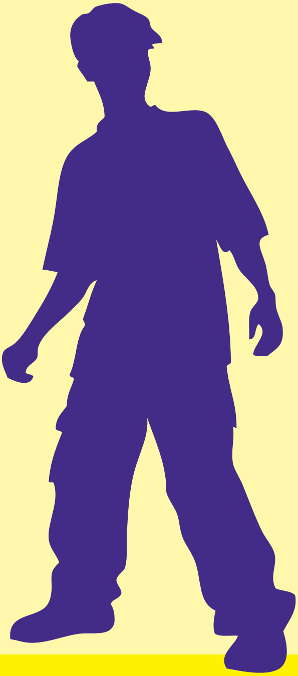
You will need to look at some practical solutions to make the school day easier for them. The first step is for you to discuss the problems they are facing with them and their parents as everyone with fibromyalgia does not have the same symtoms. It may be useful to research some information on fibromyalgia at our website at **www.fmauk.org.**

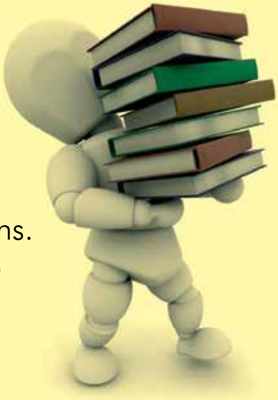
Encourage the pupil to come up with their own ideas and solutions, by going through the school day and identifying which activities cause more pain, what things make them anxious and what time of the day the fatigue gets too much. Here are some ideas and solutions other young people have found useful:

- Permission to leave the classroom whenever needed.
- Permission to use the school/college or staff elevator if one is available.
- Rearrangement of classes to avoid having to constantly change classrooms.
- Using a luggage cart to carry books.
- Having a locker on both floors to avoid carrying so many books.
- Asking for an extra set of books so they have a set to keep at home.
- A support cushion to help them sit more comfortably.

- Using PE lessons to do their own individualised exercise programme.
- Being provided with a quiet place to rest during lunch break or free periods.
- Having a laptop to take notes if they struggle to write.
- Provide printed notes or handouts.
- Arrangements to dictate or type examinations.
- Time extensions for homework and coursework.
- Provide work that can be done at home if unable to attend for several days.
- A part-time timetable with a reduction in the number of subjects taken.

In extreme cases home tuition may need to be considered.





It may be up to you to come up with ideas and solutions, so go through your school day and think about which activities cause you more pain, what things make you anxious and what time of the day the fatigue gets too much. Then, start problem-solving and thinking creatively to come up with solutions. Here are some ideas and solutions other young people have found useful:

Permission to use the school or staff elevator if one is available.

Using a luggage cart to carry your books.

- Having a school locker on both floors to avoid carrying so man books.
- Asking for an extra set of books so you have a set to keep at home.
- A support cushion to help you sit more comfortably.
- Using PE lessons to do your own individualised exercise programme.
- Being provided with a quiet place to rest during lunch break or free periods.

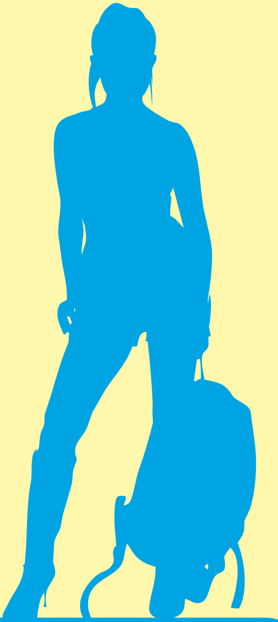
Having a laptop to take notes if you struggle to write.

- Asking the teacher to provide you with their printed notes or handouts.
- Arrangements to dictate or type examinations.
- Time extensions for home work and coursework.
- Teachers to provide work you can do at home if you are unable to attend for several days.

A part-time timetable with a reduction in the number of subjects you are taking.

Stephanie: *"Fibromyalgia can make school very difficult. Fibromyalgia affects my hands so I cannot grip a pencil which means I have to have a computer to type up my notes. I dictated my exams, but it made me feel uncomfortable as I was dictating to a teacher. My teachers are very understanding. They have moved their classes around to accommodate me as I cannot manage the stairs or walk for a long time. There is a department at college called 'learning support' who help me a lot. They send me work home if I am too ill to come into school."*

Holly: *"I asked for an extra set of books so I could have copies of my text books at home and did not need to carry books all the time. I find it difficult to concentrate and remember what I learnt in class. When I come to revise it is like learning the information for the first time. I also struggle with classrooms that have air conditioning as my muscles seize up and the pain is always more severe during these lessons. Most of my teachers are very understanding and will give me extra time to do my work."*



Carla: *"I use a laptop because I cannot write but I can't carry it so people have to do that for me. Music is difficult though because I cannot do everything on my laptop. My teachers are very supportive. I am allowed an extension if I need it and the teachers try to help as best they can. They even allowed me to hold a coffee morning for Fibromyalgia Awareness Day."*

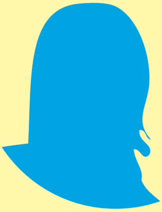
Katie: *"I missed quite a bit of school as I was in so much pain but was able to do my work at home so don't feel I missed out. I found it was difficult concentrating for a period of time and sitting in the uncomfortable chairs at a table for so long really made my back sore. My tutors were very supportive but I never asked for extra time as I didn't want to be treated differently"*

Keeping your hobbies and social life alive

Getting out and socialising can be a bit of an effort when you are tired and in pain, but if you pace yourself and manage your time well you can still enjoy plenty of good times with your friends. Days out or big social events can aggravate your symptoms but if you have a good time then more often than not it is well worth it. Planning ahead is the key.

Here are some ideas and solutions other young people have found useful:

- If you find it difficult to go out in the evening why not invite friends round to your place to watch a DVD and catch up on the latest gossip.
- Organise a night out yourself so you can choose a time that suits you, a place where you feel comfortable and an activity that you enjoy.
- At the cinema sit at the end of a row so you can get up and stretch if you need to.
- Timetable in some rest time in the afternoon so you have the energy to enjoy yourself in the evening.
- You may need to cancel arrangements at the last minute, so explain to your friends that this may happen so they are prepared and don't take it personally.
- For a big event, plan ahead. Take it easy the day before and try to keep the following day free so you can rest if you need to.
- Plan an escape route for on the day in case you want to leave early.



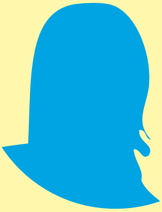
Carla: "My friends are really understanding about how my FM can change, but I find it difficult to eat out at most restaurants because of my IBS. It is better if I organise the night out myself, so I can choose a restaurant that does food I can eat."

Katie: "I have learned who my real friends are. I have some brilliant friends who are really good with my condition, I am very lucky. I work very hard at seeing my friends although I don't think I am always much company."

Jenny: "I used to be really anxious about going out with friends in the evening in case I suddenly felt too tired or in too much pain. Now, I ask my parents to come and collect me if I want to go home early. This makes me feel more relaxed and able to enjoy myself."

If you are a sporty person you may be finding some of your hobbies are aggravating your symptoms. There may be ways round this, like reducing the amount of time you spend doing the activity in one session, before building up slowly at your own pace or adapting the activity to suit you better. If you find that some activities simply aren't worth the extra pain, then have a look round for alternative interesting hobbies. There is a huge selection to choose from."

Stephanie: "I now find tap dancing and ice skating too physical, so I've taken up some new hobbies including jewellery making.
I still enjoy listening to my music too."



“I love music. Playing the flute and guitar now causes me increased pain so I’ve decided to concentrate on my singing.”

“I don’t have a lot of energy for hobbies, but am enjoying learning another language. I also like to go to the zoo on sunny days and sometimes to the circus because those two things don’t make my symptoms worse. I find going bowling too painful on my hands and cinemas are often too draughty.”

“I go to Guides, play on a trampoline, do drama, play netball

Summary

- Young people with fibromyalgia can get better over time.
- Exercise is important to stop the muscles becoming stiff, weak and tight.
- Learn to pace your activity throughout the day.
- Don't be afraid to try new activities.
- Be creative and learn to problem solve.
- Talk to friends and family about how you feel.
- Don't be afraid to ask for help.

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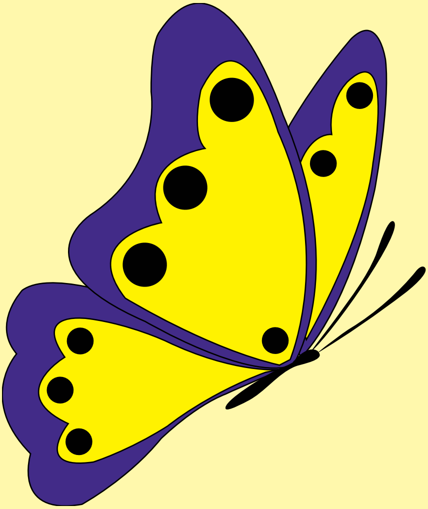
Information for Parents



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Information for parents

Some parents have found themselves in difficult situations, with suggestions that they are encouraging their children to be sick or projecting their own symptoms onto them. If you suspect fibromyalgia it is prudent to do your own research, so that you can ask the right questions and request a referral. If you are concerned or feel you are being dismissed, remain cool, calm and assertive while requesting a referral to a community paediatrician.

It is not uncommon to have visited consultants in various departments before arriving at a diagnosis, as different symptomsare often diagnosed individually. Some doctors are cautious about labelling a young person with fibromyalgia. This is because many young people can get better and doctors do not want a young person to see themselves as having an adult condition they may notrecover from. For this reason doctors tend to use terms like diffuse idiopathic pain syndrome (DIPS), soft tissue rheumatism or chronic pain syndrome instead. If the symptoms carry on into adulthood then a diagnosis of fibromyalgia might be made at a later date.

Activity management

Young people should be encouraged to be as active as possible while maintaining their symptoms to a level they can cope with. This level of activity will differ from person to person and is important not to hold your child back if they wish to attempt new levels of activity. This can be difficult from a parents' point of view as you don't want to see your child in more pain, but it is essential that the child learns their own boundaries and what level of activity they can comfortably sustain before causing a flare up of symptoms. A flare is not something to be afraid of it is something to be learned from. In this way the child will learn to pace themselves through the day, which is one of the key management skills to coping successfully.

Communication

Talk to your child and don't withhold any diagnosis from them. Explain the reasons given for their symptoms simply and clearly and what treatment can be offered to improve the quality of their life. Often it can be liberating to know that the symptoms are not their fault, there is a reason for them and something can be done.

Coping with any kind of illness, especially involving a child, can cause emotions to run high. When it comes to expressing feelings some children talk about how they feel almost incessantly whereas others withdraw into themselves and do not want to talk. As a parent, you know your child and can judge how best to approach the situation to encourage your child to talk constructively about how they feel. Jackie found communication difficult because her daughter did not want to acknowledge the diagnosis of fibromyalgia. Denial is a typical first reaction and often associated with withdrawal. Jackie approached the situation by treating her daughter as normally as possible, asking how she felt but not making a fuss.

Try to keep family life going as normally as possible. The temptation is to protect your child from any further pain, especially if the response from the medical profession has not been sympathetic. While it is important that your child feels supported and believed, being overprotective can be counter-productive. Kirsty found that her daughter wouldn't tell her when she was in pain because she thought her mother would stop her engaging in the activities she wanted to do. Children can be quite resilient and it is important to be led by them as to what they can and can't do. As discussed previously children need to discover their own boundaries and learn to pace themselves, which will involve flare ups along the way. Allow your child to be as independent as possible with you there as a backup support when they need it. Try not to constantly ask how they are feeling, but be prepared to listen when they need to talk.

It is also important for you as a parent to have somebody outside of the situation to talk to and to offer you support when you need it. You could find yourself dealing with all kinds of emotions like guilt, the desire to protect, anger and frustration. You need to express and deal with these emotions in order to be in the best position to support your child. Do not be afraid to seek help from a support group or a medical professional.

Communication between parents is particularly essential if you are separated. Children often comment that the parent they do not live with doesn't understand because they don't see them living from day to day with the pain and fatigue. As you know the symptoms of fibromyalgia are invisible and can undulate over time, so if you're only seeing the child at weekends the symptoms could vary quite dramatically and come across as quite mysterious. Try to ensure that your partner has as much information as possible and a clear picture of the current situation.

How to implement special arrangements for schooling

If fibromyalgia has an impact on your child's ability to cope in the normal school setting, then they are classed as having a 'special educational need'.

Schools have to abide by the *SEND code of practice: 0 to 25 years* which explains the duties of local authorities, health bodies, schools and colleges to provide for those with special educational needs under part 3 of the *Children's and Families Act 2014*. The *2001 SEN Code of Practice* still applies for those who have a SEN Statement under part 4 of the *Educational Act 1996*, rather than an education, health and care (EHC) plan under the *Children and Families Act 2014*.

Under the Equality Act 2010 it is unlawful for any education provider to discriminate between pupils on grounds of disability and other criteria. They are expected to do all they can to meet your child's needs and to make 'reasonable adjustments'. The Act includes the following points:

- Schools will be expected to provide an auxiliary aid or service for a disabled pupil when it would be reasonable to do so and if such an aid would alleviate any substantial disadvantage that the pupil faces in comparison to non-disabled pupils.

- Adjustments should be 'anticipatory' but it is recognised that organisations cannot be expected to anticipate the needs of every imaginable disability.
- Legislation applies to all pupils including prospective, attending and absent, and former pupils who have a continuing relationship with the school. It applies to all student services.
- An education institution should not treat a disabled person 'less favourably' for a reason relating to their disability.

Each school has one person Special Educational Needs Coordinator (SENCO) responsible for ensuring pupils with special educational needs are catered for and any necessary special arrangements are made and carried out. School Action is the term used for making and recording these arrangements known as an Individual Educational Plan (IEP).

If academic progress is not made under these arrangements School Action Plus comes into effect and external support services are used for further assessment and recommendations.

Normally, keeping a good dialogue with the school means your child receives the consideration needed to be able to cope with school.

Other assistance is available to parents through the Local Authority Parent Partnership Service or Independent Panel for Special Education Advice (IPSEA).

You do have the right to request a statutory assessment of your child's needs and to appeal to Special Educational Needs and Disability Tribunal (SENDAT). This should only be used as a last resort.

Websites:

www.ipsea.org.uk
www.gov.uk/children-with-special-educational-needs/overview
www.gov.uk/government/publications/send-code-of-practice-0-to-25
www.gov.uk/government/publications/equality-act-2010-advice-for-schools

Summary

- Maintain a positive outlook.
- Be proactive.
- Be supportive of your child but do not let the symptoms affect your normal family functioning.
- Try to maintain the usual routine (including school) as much as possible.
- Encourage your child to continue as many normal activities as possible.
- Remember children need to be around other children their own age so they do not feel left out of the social group.
- Encourage your child to maintain friendships.
- Do not be afraid to seek advice from health professionals or a support group.

Feedback

Please provide feedback on this resource or any other provided by FMA UK at www.fmauk.org/feedback

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