

Leaflet for people with fibromyalgia



1.What is fibromyalgia?

Fibromyalgia is an abnormality of the pain processing systems. Pain signals to the brain are amplified and the pain control mechanism is compromised because of an imbalance in chemicals and hormones.

This manifests itself in widespread pain, profound fatigue and tiredness, non-refreshing sleep and sleep disturbance,

cognitive dysfunction and not being able to think clearly or remember things (known as fibro fog).

Other conditions may exacerbate fibromyalgia. There is no link to inflammatory or degenerative arthritis.

It is a life changing condition which needs some effort to manage but it can be done! The pain is very real but invisible to others.

2.How is fibromyalgia diagnosed

Fibromyalgia is often difficult to diagnose as the symptoms vary considerably and could have other causes. To confirm a diagnosis, doctors will listen to the person's history. Widespread pain for more than three months in both sides of the body, above and below the waist will support a diagnosis. Your doctor may suggest you have blood tests to rule out other possible causes of your symptoms.

3.What causes fibromyalgia?

It is not clear what causes fibromyalgia, but it is often triggered by some sort of trauma, either a fall, accident, surgery, childbirth, or a severe emotional event such as

bereavement. Sometimes the condition begins without an obvious trigger. Research suggests that there's an interaction between physical, neurological and psychological factors. The

pain and symptoms of fibromyalgia make people feel low and depressed.

Usually, people feel pain when part of the body is damaged or injured. The pain people with fibromyalgia feel is not directly caused by damage or injury to the area that's

hurting. Instead there's a problem with the way the brain and nervous system process pain from that area. As there's no physical damage that can be healed, there's no easy way to stop the pain. This is why fibromyalgia pain can be long-lasting (chronic).

4. Treatments for fibromyalgia

Learning to manage the condition seems to be the most successful way of dealing with fibromyalgia. It is a long term condition and this needs to be accepted by the individual (and family). Patience and positivity are needed. People need to educate themselves about the condition. Medication can sometimes be helpful. Opioids are of no benefit in managing fibromyalgia and should be avoided.

Exercise

Gentle individualised stretching and light conditioning exercise is beneficial, starting low and gradually increasing. Pacing yourself is critical, it is important not to over-do things as this could make your symptoms worse. Aerobic activity may be difficult to begin with but everyone can build up activity gradually and there is potential for great benefit

from regular aerobic activity in fibromyalgia.

Cycling and swimming may not be low impact enough for some people initially. However, very gradually building up over many months, these activities can often help. Immersion in a hydrotherapy pool with gentle exercise is good for many people.

The following pools are available locally for a charge:-

•**Freeways Hydrotherapy**

Pool, Pill Road, Abbots Leigh, Bristol BS8 3RA, 01275 376082

•**Community Hydrotherapy**

Unit, 3 Church Road, Soundwell, Bristol, BS16 4RH, 01454 862490

•**Hydrotherapy Pool**

The Campus, Highlands Lane, Weston, BS24 7DX, 01934 427427

Walking, cycling, yoga and t'ai chi help people with fibromyalgia as they have a low impact on the body and involve stretching which seems to be helpful for people with fibromyalgia.

It is important to try to do the same amount of exercise each day to build up muscle strength and stamina. Increasing exercise little by little will then improve fitness and flexibility.

Ask your GP about 'exercise on referral' or go to bristol.gov.uk/social-care-health/exercise-referral-scheme for more information in Bristol or go to oneyou.southglos.gov.uk in South Gloucestershire.

Psychological support

Counselling and Cognitive Behaviour Therapy (CBT) can be of help to some people as a coping tool. People with fibromyalgia or their carers can get psychological therapy and support by contacting the following NHS funded organisation:-

VitaMinds- Offering 1:1 therapy, group therapy and online CBT courses for those living with Long Term Health Conditions in Bristol, North Somerset and South Gloucestershire.

Tel: 03332 001893 or visit vitahealthgroup.co.uk/bnssg

Other organisations that can help you get more involved in your local community are:

South Gloucestershire 5 ways to wellbeing workshops and peer support groups: Tel: 01454 864005 or visit southernbrooks.org.uk/wellbeing

North Somerset Community Connect Tel 01275 888803 or visit curo-group.co.uk/independent-lives/community-connect-north-somerset/

LinkAge Network - social activities for people 55+ in Bristol
Tel: 0117 3533042 or linkagenetwork.org.uk

Diet

Keeping your weight within a healthy range by eating a balanced diet with plenty of fruit and vegetables is recommended.

Sleep

Poor sleep is a key symptom of fibromyalgia, so getting enough good-quality sleep is an important part of the treatment. However, the pain can prevent proper sleep and this does need to be managed. Make sure the bedroom is dark, quiet and a comfortable temperature, try listening to soothing music or doing some deep breathing exercises before bedtime.

Some people find using an electric blanket can help. Develop a sleep routine, the same time each day. Avoid alcohol, tea or coffee (or any other form of caffeine) late at night. Try to stop smoking or at least don't smoke close to bedtime. Avoid watching TV, using computers, tablets or smartphones in your bedroom.

Getting to know your long term condition

Keeping a daily medical journal will give you and your healthcare professionals an insight into how your condition affects you and what helps you and what makes things worse. Plan your diary to help you pace yourself and to enable you to do things. Remember, don't beat yourself up if you can't

do something, as there will be days when you can. Buying comfortable, cushioned footwear can help some people, as well as wearing light weight clothing. Also choosing furniture and beds with the right level of firmness for you is important.

5.Support available

Helplines

Fibromyalgia Action UK provide a free helpline run by volunteers on 0300 999 3333, Monday to Friday, 10am to 4pm.

Versus Arthritis provide a free helpline, including support for people with fibromyalgia, call 0800 5200 520 on Monday to Friday between 9am and 8pm, or you can email them on helpline@VersusArthritis.org

Support groups

Bristol Fibromyalgia Support Group- Meets on the 2nd Wednesday of the month, 11.15am to 1.30pm For more information and for venue details please email bristolfmeunited@gmail.com or telephone 0796 3937383.

There is also a coffee morning at Costa Coffee, 53, Union Street, Bristol BS1 2DU, on the last Wednesday of the month, 11:30am to 1:30pm (no meetings in August).

Weston Fibromyalgia support group- Meets on the: 2nd Friday of the month for coffee at 11am in Weston 3rd Monday of the month, 1-3pm at Meadvale Community Hall, Redwing Drive, Weston super Mare, BS22 8XJ. 4th Tuesday of the month for coffee at 2pm in Worle. They also have a weekly hydrotherapy group on a Thursday morning. For more details email wsmfibro@gmail.com or telephone Val Bingham on 07411989478.

Kingswood Fibrofriends support group- Meets on the second Wednesday of each month between 1-2:30pm and the last Wednesday of each month between 10:30am-12 noon. Meetings take place at Kingsmeadow @ Madeforever, Fisher Road, Kingswood, BS15 4RQ. For more details, email Fibrofriends@cheerful.com or tel: 0844 891 3749.

Help with transport

Contact these organisations for help with community transport:-

- Bristol Community Transport, Tel: 0117 9020157
- There are 5 community transport services in South Gloucestershire, contact 01454 868009 for more information
- Community Transport in Weston and District, Tel: 01934 611956 Community Transport in Nailsea and District, Tel: 01275 855552

General support

- Carers Support Centre - information, support, advice and groups for carers Tel: 0117 965 2200 or carerssupportcentre.org.uk or carersuk.org
- We Care Home Improvements - a handyman service at a subsidized cost for home owners over 60 yrs and those with an illness or disability Tel: 0300 323 0700 or wecr.org.uk
- North Somerset Council Online Directory** - one stop shop for information on health and wellbeing, support groups, advice etc or nsod.n-somerset.gov.uk
- Equipment and Demonstration Centre, Weston-super-Mare** – with demonstration areas to help you understand adaptations and equipment is available Tel: 01934 888804 or wecr.org.uk/weston-super-mare Open Tue-Fri 10am-4pm
- Nailsea Disability Initiative** (serving North Somerset), providing advice and information including benefits, specialist equipment, respite care etc. Tel: 01275 812183 or email team@nailseadisability.org

Useful websites

- Fibromyalgia Action UK website**, go to fmauk.org
- Fibromyalgia Information Foundation website**, go to myalgia.com
- Versus Arthritis website**, go to versusarthritis.org
- The **NHS website** is for people to find out more about their condition, go to nhs.uk/conditions/fibromyalgia/
- Wellaware** – is a database of more than 6,000 local and national organisations and services that can help, go to wellaware.org.uk/