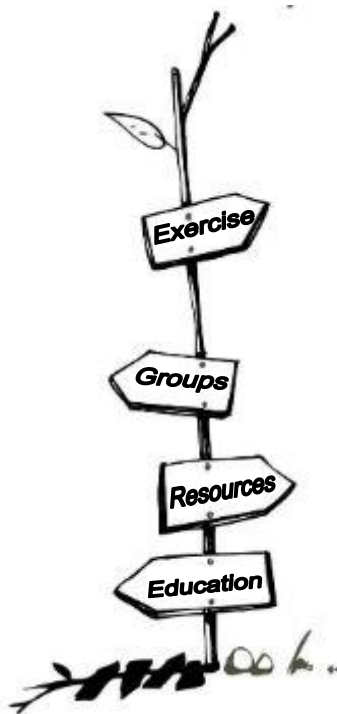




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Bwrdd Iechyd Prifysgol
Aneurin Bevan
University Health Board

Fibromyalgia Options Booklet



Aneurin Bevan University Health Board

You have been given this booklet as you have a diagnosis of fibromyalgia. Fibromyalgia is a condition that can cause widespread pain and tenderness over much of the body. It is a long-term (chronic) condition which has periods of improvement and periods of flare. The condition can improve significantly with the right approach to managing it. Many patients live very successfully with this long term condition, but rarely have a complete cure, and will usually have some periods of time when symptoms flare. Fibromyalgia doesn't cause any lasting damage to the body's tissues.

There are things that you can do to manage your symptoms. It is important to keep as active as you can, as exercise reduces the pain and fatigue associated with fibromyalgia.

Medication for fibromyalgia is often hard to take because of side effects, and is only partly effective. Non drug treatment is the main approach to dealing with fibromyalgia. Research into this condition is ongoing and more effective medication may become available in the future. Unfortunately, at the present time, medication only has a limited part to play in treating fibromyalgia.

Everyone experiences Fibromyalgia differently. This booklet outlines the various options that you can explore to help you manage your fibromyalgia symptoms. All of the options have the potential to help you. No healthcare intervention is without its downsides. In some circumstances it might be side effects, in others it might be that a lot of the work to improve your health has to come from you.

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A free self-management course which provides tools and techniques to help you take control of your health and manage your condition better on a daily basis. For information visit www.eppwales.org

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Free self-help classes including Activate Your Life and Stress Control. For information about the next class in your area go to www.aneurinbevanhb.wales.nhs.uk and search for 'road to well-being' or call your local team:–

✚	Blaenau Gwent.....	01495 363250
✚	Caerphilly.....	01633 618033
✚	Monmouthshire.....	01873 735549
✚	Newport	01633 261867
✚	Torfaen.....	01495 768613

3. ABUHB

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Computerised Cognitive Behavioural Therapy

Free on-line self-help courses. For more information visit www.aneurinbevanhb.wales.nhs.uk

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1. Education Programmes for Patients (EPP)



EPP Cymru provides a range of self-management health and wellbeing courses for people living with a

long-term health condition. The courses focus on making you an expert in living your life to the full with your condition, not about making you an expert in the specific condition you have. These courses include:

- ✚ **Health and wellbeing course** for people who live with a long term health condition. 6 weekly sessions of 2 ½ hours a week.

- ✚ **Introduction to Health and Well Being Course**
3 hour session.

The courses are led by two tutors, who themselves have experience of making life changes as a result of a long-term health condition. EPP Cymru courses are run in suitable venues in local communities and are free of charge.

Chronic Disease Self-Management Programme

Each session looks at ways to help manage the effects of your long-term condition such as:

- ✚ Managing symptoms such as pain and tiredness
- ✚ Dealing with anger, fear and frustration
- ✚ Coping with stress, depression and low self-image
- ✚ Eating healthily
- ✚ Learning relaxation techniques and taking regular exercise

- ✚ Improved communication with family, friends and health professionals
- ✚ Planning for the future

The course does not provide any health condition or treatment information, nor does it look at specific health needs. The courses aim to give participants the confidence to take responsibility for their own care, whilst also encouraging them to work in partnership with health and social care professionals.

Some of the Benefits of Chronic Disease Self-Management Programme

People who have been on this course have reported an ***increase*** in:

- ✚ Feeling of well-being
- ✚ Ability to cope
- ✚ Their belief that they CAN DO something to change their health behaviour

They have also reported a ***decrease*** in:

- ✚ Pain and fatigue
- ✚ Anxiety, depression and breathlessness
- ✚ Visits to GPs

Courses run in venues throughout Aneurin Bevan Health Board. To get more information and/or book onto a course please visit the website **www.eppwales.org** or contact Susan Arnold or Sarah Lewis on **01633 241550**.

2. ABUHB Road to Well-Being

Under the new Aneurin Bevan University Health Board Road to Well-Being programme, free self-help classes and Computerised Cognitive Behavioural Therapy (CBT) are now available. Both the ACTivate Your Life and the Stress Control courses run in venues across Gwent. Both courses are lecture-style, with no discussion of personal problem meaning they are ideal for people who may not normally consider attending a group.

- ✚ There is no assessment, no registration and no waiting list.
- ✚ Everybody is welcome, maybe bring a friend.
- ✚ Just turn up, take a seat, listen and learn!

ACTivate Your Life

This 4 week lecture-style course aims to teach people how to respond differently to aspects of life that many people suffer with, such as mental health problems, emotional issues and chronic pain. Classes are based on Acceptance and Commitment Therapy. Sessions run for 2 hours, once a week, including a comfort break. The classes are supported by PowerPoint presentations, Home Activities and Handout sheets.

Stress Control






Stress Control is based on Cognitive Behaviour Therapy (CBT) and teaches skills based around recognising stress and managing stress. Specifically, each week tackles a different topic that keeps stress going, including

thoughts, actions, sleep problems, panicky feelings and well-being. Classes run for 90 minutes, and include a comfort break.

3. Aneurin Bevan Computerised Cognitive Behavioural Therapy (ABC CBT)

Cognitive Behaviour Therapy (CBT) looks at how we think about a situation and how this affects the way we act. In turn our actions can affect how we think and feel. CBT is a way of changing behaviours and/or thinking patterns. Go to -www.aneurinbevanhb.wales.nhs.uk.

The Road to Well-Being on-line access point can help with the following:

-  A way of effectively managing your wellbeing.
-  A call in, self-referral, program.
-  Work at your own pace.
-  Choose from a small selection of on-line websites that match your needs.
-  Guidance telephone support from a local primary care support professional.

4. Exercise & The National Exercise Referral Scheme (NERS)

Alterations in lifestyle and the introduction of regular exercise have been shown to help alleviate the symptoms of fibromyalgia. Research has shown a connection between increased muscle strength and a decrease in pain. Strengthening postural muscles helps to hold your body in better alignment

to prevent pain. Aerobic exercise (that would get you mildly out of breath) has particularly been shown to benefit people with fibromyalgia. General benefits of exercise are improvement in circulation speeding the delivery of nutrients to organs and tissues which improve their health and your feeling of wellbeing.

It is important to find exercise that is achievable and choose something that you are likely to enjoy in order to maintain motivation. Learning that you CAN do this and seeing an improvement can be motivational in itself. Working in a group or with a friend is also a way of maintaining progress. Whatever type of exercise you choose it is important to measure and pace your activity. Exercise which increases fatigue and or symptoms is doomed to failure! Your baseline is the amount of exercise (time or number) you can do without causing your symptoms to flare. You should start your exercise programme at $\frac{1}{2}$ this amount. Do not worry how much this is; people doing just a small amount of exercise have shown considerable benefits as opposed to none. Once you have accomplished simple exercise you can move to more challenging activity e.g. Tai Chi, Yoga, Pilates, Swimming, Walking....

It is natural to feel some muscle soreness post exercise. This is a good thing; it shows good response to exercise. Muscle soreness means you have exercised sufficiently to strengthen your muscles. Good Luck!

Resources:

~www.swimming.org/poolfinder

~ www.yell.com/s/leisure+centres+south+wales.html

- ~ www.threepeakstrial.co.uk/other-walking-clubs/walking-clubs.htm
- ~ www.taichifinder.co.uk/88-wales
- ~ www.physicalandnutritionwales.org.uk

The National Exercise Referral Scheme

The National Exercise Referral Scheme (NERS) runs for 16 consecutive weeks and consists of 2 fully supervised group-based sessions each week. Each session lasts for approximately one-hour and costs around £1.50. The sessions usually run in Leisure or Community centres but there are some outdoor opportunities available in most areas. Referral is required from a GP or other health professional. For more information visit: <http://www.wlga.gov.uk/ners>.

5. The Pain Toolkit

The Pain Toolkit is a simple toolkit that provides handy tips and skills to support you along the way to managing your pain. Go to www.paintoolkit.org/ for more information.

6. Support Groups

Listed below are some support groups that we are aware of:



Green Valleys Support Fibromyalgia

- ▶ Meetings at the Taff Meadow Community Centre, Pontypridd
- ▶ Contact:- Jojo Tel: 07511537613

<https://www.facebook.com/groups/GreenValleysSupportFibromyalgia/>

Valleys Fibromyalgia Support Group

- ▶ Meetings held in Rhymney
- ▶ Contact: Douglas John McMahon
- ▶ Tel: 0845 3455926/01685 843551
- ▶ email: douglas140@sky.com

Chepstow Fibromyalgia Support Group

- ▶ Contact: April Thatcher on 0844 887 2459 / 01291 622071
- ▶ email: chepstowfibrosupport@googlemail.com

Cardiff & District Fibrofriends

- ▶ Meetings held in Rogerstone
- ▶ Contact: Jeanette Scott
- ▶ Tel: 0844 887 2384/01633 669545




Aberdare Fibromyalgia Support Group

- ▶ Contact: Gail Neal - Tel 0844 887 2446/01685 884410
- ▶ email: gailneal8@hotmail.com

7. Occupational Therapy (OT)

For most patients with fibromyalgia, the condition can be managed in the community with help from the support groups mentioned in this booklet. If you are having particular difficulties at home you may benefit from assessment from a community occupational therapist. OT can help you to manage your everyday activities without increasing your pain or wearing yourself out. During your assessment, you will be asked about how your

fibromyalgia is affecting your daily activities. They will work with you to set goals that are important to you. Their input may involve but is not limited to:

-  Practical advice on overcoming everyday difficulties (e.g. advice on ways to manage pain/fatigue).
-  Demonstrating aids & specialist equipment.
-  Suggesting adaptations to your property.

Listed below are the telephone numbers you can call to request an occupational therapy assessment.

Blaenau Gwent – 01495 327772

Caerphilly – ASDIT call 0800100250

Monmouthshire – 01873 735885

Newport – 01633 656656

Powys – 01874 623741

Torfaen – 01495 762200

8. Further reading & Online Resources

Books

Fighting Fatigue: A Practical Guide to Managing the Symptoms of CFS/ME - Pemberton, S. & Berry, C. (2009) - Hammersmith Press

How to Manage Chronic Fatigue - Craggs-Hinton, C. (2010). Sheldon Press

Say Goodnight to Insomnia - Jacobs, G. D. (2009): Rodale.

Overcoming Insomnia and Sleep Problems - Espie, C. A. (2010)
London: Robinson.

Self- Management of Long-Term Health Conditions - Lorig, K. et al
(2014). Bull Publishing: Colorado

Mindfulness - Williams, M. & Penman, D. (2011): Piatkus.

Websites

~ Arthritis Research UK: www.arthritisresearchuk.org

~ UK Fibromyalgia
www.ukfibromyalgia.com

~ Fibromyalgia Action UK
<http://www.fmauk.org/>

Both of the above websites have forums where you can talk to other people with fibromyalgia.