

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.

As well as the information contained in this booklet there is further information about Fibromyalgia on the Arthritis Research UK website www.arthritisresearchuk.org

For information about why lack of sleep is bad for your health and suggestions to improve it please see

http://www.nhs.uk/livewell/tiredness-and-fatigue/Pages/tiredness-and-fatigue.aspx

Or Google "Tiredness and fatigue NHS"

ABUHB Rheumatology Occupational Therapy Service – October 2017. Review date October 2018

CONTENTS

PAGE No

1. Education Programme for Patients (EPP)

6

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

2. ABUHB Road to Well-Being

8

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:—

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

3. ABUHB 8

Computerised Cognitive Behavioural Therapy

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

CONTENTS	PAGE No				
4. Exercise & The National Exercise Referral Scheme					
A Welsh Assembly funded scheme which aims to					
introduce the benefits of physical activity to people in					
Gwent. Visit http://www.wlga.gov.uk/ners.					
5. The Pain Toolkit	14				
6. Occupational Therapy	14				
OT can help you to manage your everyday activities					
without increasing your pain or wearing yourself out.					
7. Support Groups	15				
Many people find support groups helpful. It is important					
to find a group that suits your needs.					
8. Further Reading and On-line Resources	16				
	40				
9. Occupational Therapy Referral Form.	18				

1. Education Programmes for Patients (EPP)



EPP Cymru provides a range of selfmanagement 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, Sarah Lewis or Jules Horton on 01633 247674.

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 ½ 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.physicaland nutritionwales.org.uk

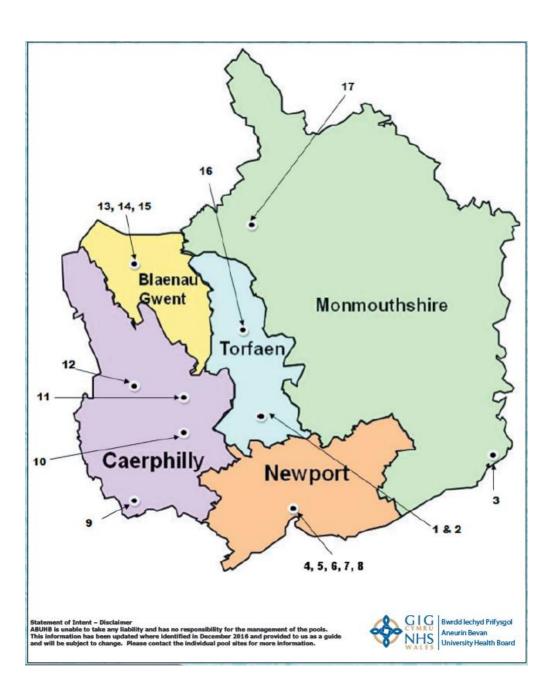
The National Exercise Referral Scheme

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 are 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.

Swimming

Swimming can be an excellent form of exercise for people with fibromyalgia. Even walking up and down the pool can be extremely beneficial for fitness and pain relief. On the following pages is information of facilities within Gwent including access and pool temperature. ABUHB is unable to take any liability and has no responsibility for the management of the pools. The information is provided as a guide and will be subject to change. Please contact the individual pool sites for more information. In addition to the following list Chepstow Leisure Centre (01291 635745) runs ladies only sessions and has wheelchair access.

Key	Pool Name		Walk	Graduated	Vertical	HOIST			General
No	& Contact Telephone number	Access	into Pool	Steps into pool	steps into pool	AVAILABLE Poolside (Contact individual Pool for hoist details	Only Sessions (Contact individual Pool for details)	Adults Only Only Sessions (Contact individual Pool for details)	Temperature Range Updated 2016
1	Cwmbran Stadium 01633 627101	√			√	√	√	√	28.5°C
2	Fairwater Leisure Centre 01633 624135	√			√	√	√	√	28.5°C to 29°C
3	Caldicot Leisure Centre 01291 426850	√		√		√		√	29 °C
4	St Josephs Hospital & Hydrotherapy Pool 01633 820300	√		V		√	√		35°C Constant temperature Hydrotherapy Pool
5	Newport International Sports Village 01633 656757	√			√	√	√	√	Main Pool 27.5°C Teaching Pool 28°C
6	Newport Leisure Centre 01633 656757	√	v	√	√	√		√	27.5°C
7	Bettws Active Living Centre 01633 656757	√			√	√	√	√	27.5°C
8	Llanhennock – Leonard Cheshire Disability 01633 420045	√			v	√	√	√	Constant temperature Hydrotherapy Pool
9	Caerphilly Leisure Centre 02920 851845	√			√	√		√	Main Pool 30°C Training Pool 32°C
10	Risca Leisure Centre 01633 600940	√			√	√	√	√	29°C to 30°C
11	Newbridge Leisure Centre 01495 248100	√	√	√	~		√		30°C
12	Cefn Fforest Leisure Centre 01443 830567	√		√		√		√	Main Pool 30°C Training Pool 32°C
13	Tredegar Sports Centre 01495 353359	√		√	√	√		√	32°C to 35°C
14	Ebbw Vale Sports Centre 01495 357777	v	√	√	√	√		√	32°C to 35°C
15	Abertillery Leisure Centre 01495 357779	v		√	√	√		√	Main Pool 29 °C Training Pool 32 °C
16	Pontypool Active Leisure Centre 01495 742222	√		√	V	√		√	Main Pool 28.5°C Training Pool 30°C
17	Abergavenny Leisure Centre 01873 735360	√		√	√	√	√	√	29.4°C



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. 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 seen in the hospital based Rheumatology clinic, the rheumatology clinician will either advise you on how to manage your condition using the advice in this booklet, or may in some selected cases, feel that a referral to the rheumatology Occupational Therapy team would be helpful. 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. This may involve but is not limited to:

- Practical advice on overcoming everyday difficulties (e.g. advice on planning and pacing activities to manage pain/fatigue).
- Suggesting different techniques to help you complete a task more safely & easily.
- Demonstrate aids & specialist equipment.

The assessments take place at the following hospitals: Chepstow, County (Pontypool), Nevill Hall (Abergavenny), St Woolos (Newport) and Ysbyty Ystrad Fawr (Ystrad Mynach). If you would like an occupational therapy appointment please complete, cut out and return the form at the back of the booklet.

7. Support Groups

Listed below are some support groups that we are aware of. Please contact Nicola May OT on 01443 802573 if you are aware of any support groups we can add to this booklet:

Fibro Warriors Cymru

- An active group based in Ebbw Vale who meet monthly.
- Contact: Fibrowarriorscymru@gmail.com

Fibromyalgia Support Group Cwmbran (FSGC)

- Weekly meetings held at Victory Church, Greenforge Way, Springvale, Cwmbran, NP44 3BA.
- Contact: https://www.facebook.com/groups/theFSGC

♣ 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 8872446/01685 884410
- email: gailneal8@hotmail.com

8. Further reading & Online Resources

Books

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

<u>How to Manage Chronic Fatigue</u> - 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.

<u>Self- Management of Long-Term Health Conditions</u> - 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.

Referral for Occupational Therapy Consultation

In order to ensure Occupational Therapy is suitable for you we ask people to complete the following form.

Name:				
Address:				
Telephone number:				
DOB:				
Today's date:				
When were you diagnosed with fibromyalgia?				
Please list any other health conditions:				
Which do you consider causes you most problems? Pain				
Fatigue				

What services or techniques have you tried in the past to help manage your condition?
In relation to the above question, what two things work well?
What two things do not work well?
What are the issues for you in relation to your current health condition?
What are you hoping to get out of the consultation?
Please return this form to-

Please return this form to

Nicola May Occupational Therapy Department Ysbyty Ystrad Fawr Hengoed **CF82 7EP**

If you have any queries please call Nicola, occupational therapist, on 01443 802573.

Once your form has been received, you will be notified when an appointment becomes available.