

#Fibro2018

02-09 September 2018



FIBROMYALGIA AWARENESS WEEK 2018

CAMPAIGN PACK

DON'T DELAY, CONNECT TODAY



Fibromyalgia Action UK

Fighting for Freedom from Fibromyalgia

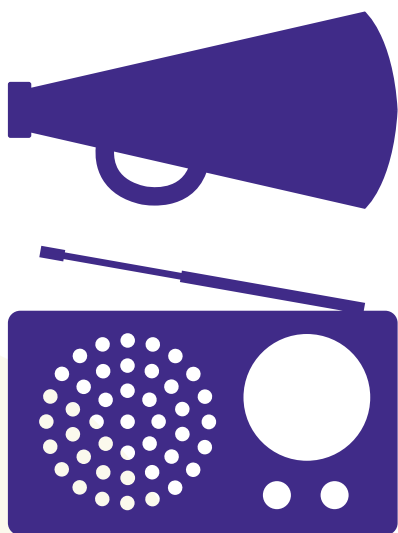
FIBROMYALGIA AWARENESS WEEK IS TAKING PLACE FROM SUNDAY 2ND TO SUNDAY 9TH SEPTEMBER 2018

Thank you for getting involved in raising awareness of fibromyalgia among your community as we celebrate Fibromyalgia Awareness week 2018. Fibromyalgia Action UK's theme for awareness week builds upon the theme for awareness day on May 12th. 'Don't Delay, Connect Today' aims to highlight that early diagnosis and recognition of fibromyalgia, and timely access to evidence-based treatment and peer support, are essential for the long-term health and wellbeing of those living with fibromyalgia and their families.



This campaign pack is designed to help you share the message among your community about fibromyalgia, and

the significant impact that the condition has on their lives of those living with the condition, as well as family and friends of those affected.



WHAT YOU'LL FIND INSIDE THIS CAMPAIGN PACK:

- ✈ Key messages to share.
- ✈ Activity ideas.
- ✈ Materials to download and print.
- ✈ Tips for getting involved online, including email signatures, template social media posts and advice on blogging.
- ✈ How to talk to the media, and a template press release.
- ✈ Signposts to support for people with fibromyalgia.



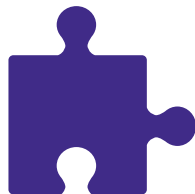
Good luck with whatever you decide to do to celebrate Fibromyalgia Awareness Week 2018. Let us know what you are doing by sharing your news online using the hashtag **#Fibro2018** or by emailing: **head.office@fmauk.org**

KEY MESSAGES

Here are some key messages for you to use to promote Fibromyalgia Awareness Week 2018:

- 🦋 It's Fibromyalgia Awareness Week from Sunday 2nd to Sunday 9th September 2018 - join us in placing the spotlight on fibromyalgia!
- 🦋 The 'Don't Delay, Connect Today' campaign aims to educate the general public, healthcare professionals and policy makers about the importance of early diagnosis and timely access to evidence-based treatment for people with #fibromyalgia.
- 🦋 Fibromyalgia remains undiagnosed in as many as 3 out of 4 people with the condition, with diagnosis times averaging 5 years.
- 🦋 To find out more about Fibromyalgia Awareness Week, please visit www.fmauk.org/campaigns
- 🦋 Join us in raising awareness of fibromyalgia on social media - don't forget to use **#Fibro2018** to join in the conversation!

ACTIVITY IDEAS



Fibromyalgia Awareness Week is an opportunity for us to raise awareness of fibromyalgia across the country, and around the world. It's also a chance for us to educate and empower people to be aware of the condition, the importance of early diagnosis, and the urgency in receiving timely access to treatment and support.

The way in which you want to celebrate Fibromyalgia Awareness Week is entirely up to you! You could create an event in your local area, or host an online activity. You could speak to your local newspaper, or simply tell friends and family about fibromyalgia. Whatever you choose to do, every action is a step forward in the right direction for the fibromyalgia community.

We've included some examples on the next page which you may want to think about, but we are sure you've got plenty of other great ideas!

COFFEE & NATTER



What's more British than sitting down for a chat with a nice cup of tea or coffee? Each day, people up and down the country come together to catch up in this way - so why don't you hold one for fibromyalgia?




You could hold a coffee (or tea) morning at your home, in a community venue or even in your local coffee shop! It's a simple and effective way to bring people together to talk and listen in a relaxed environment.

ARTS AND CRAFTS



Arts and crafts are a great way to start conversations in an informal and fun atmosphere. Lots of other support groups use art and craft activities as a part of their regular group meetings, so why not use this approach for awareness week too?

Here are some activities you may want to try:

-  **Card making:** Whether it be a greetings card, or a postcard, people can get creative - they could even have a butterfly theme to share the message about fibromyalgia!
-  **Bracelet making:** Using beads and thread, people could make bracelets for themselves and other people - these could include alphabetical beads spelling out fibromyalgia, or some of the ways fibromyalgia affects people. You could even make them to raise funds for your group too!
-  **Knitting:** It's the latest trend to be re-energised, so why don't people grab their knitting needles and wool, and create something beautiful! You could even make it competitive by introducing a knit-a-thon!

FIBRO PLEDGE WALL

Why don't you create a space for a 'Fibro Pledge Wall' in your local community, for people to write down what they will do to raise awareness and support people with fibromyalgia. It could be a notice board, or something as simple as a sheet of paper with post-in notes. You could host this where your group meets, or even approach other locations in the community.

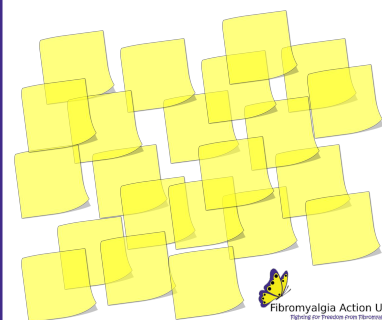
PUB QUIZ



Who doesn't love a good quiz? Adding a fibromyalgia round into an existing quiz is a great way to encourage people to think and learn about fibromyalgia in a fun and slightly competitive way. If you also felt comfortable, you could give a small talk during the quiz break to the audience, to tell them a little bit about your experience.

If an existing quiz isn't possible, create your own quiz night!

FIBRO PLEDGES



MATERIALS TO DOWNLOAD AND PRINT

There are a range of materials available to download and print from the Fibromyalgia Action UK website, that you can use to promote your activity, or to encourage people to talk about fibromyalgia.

You can access all of the materials in this pack by visiting: www.fmauk.org/campaigns

If you would like to order printed resources (for example, our standard posters, leaflets and information booklets), please visit: www.fmauk.org/resources

AWARENESS POSTER



FIBROMYALGIA AWARENESS WEEK 2018
DON'T DELAY, CONNECT TODAY

**FIBROMYALGIA REMAINS
UNDIAGNOSED IN AS
MANY AS 3 OUT OF 4
PEOPLE.**


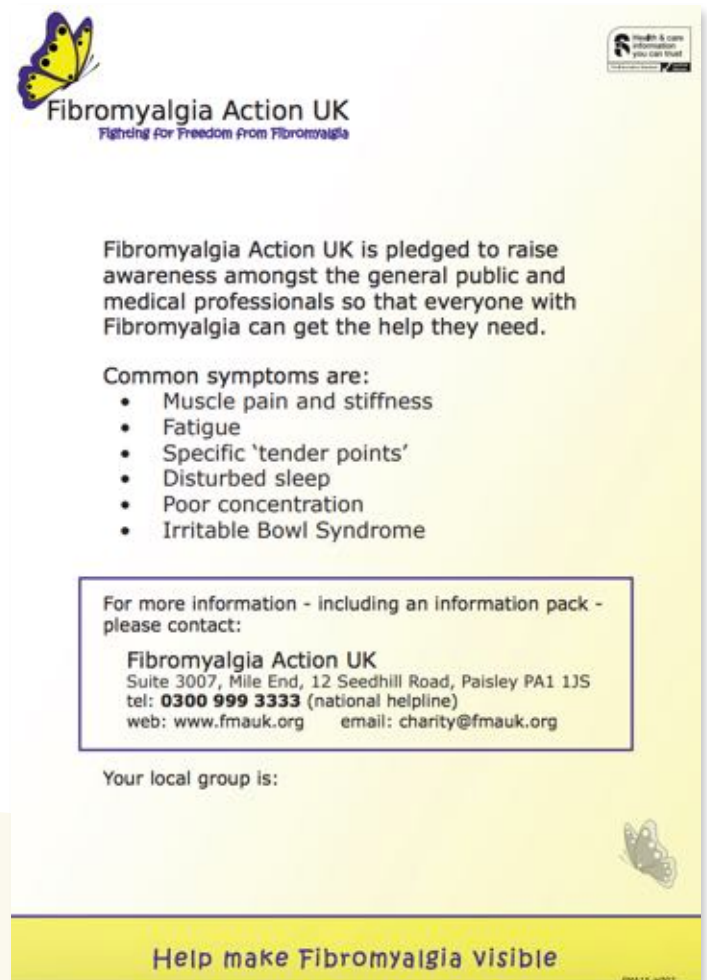
Help us to highlight that early recognition and diagnosis, along with timely access to treatment and support, are essential for the long-term health and wellbeing of those living with fibromyalgia.

#Fibro2018
02-09 September 2018



Fibromyalgia Action UK
Fighting for Freedom from Fibromyalgia

LEAFLET



Fibromyalgia Action UK
Fighting for Freedom from Fibromyalgia

Fibromyalgia Action UK is pledged to raise awareness amongst the general public and medical professionals so that everyone with Fibromyalgia can get the help they need.


Common symptoms are:

- Muscle pain and stiffness
- Fatigue
- Specific 'tender points'
- Disturbed sleep
- Poor concentration
- Irritable Bowl Syndrome

For more information - including an information pack - please contact:

Fibromyalgia Action UK
Suite 3007, Mile End, 12 Seedhill Road, Paisley PA1 1JS
tel: **0300 999 3333** (national helpline)
web: www.fmauk.org email: charity@fmauk.org

Your local group is:



Help make Fibromyalgia visible

FMAUK 0202

FIBRO FACTS

MYTH: FIBROMYALGIA IS RARE.

FACT: FIBROMYALGIA IS ONE OF THE MOST COMMON PAIN CONDITIONS, ESTIMATED TO AFFECT AT LEAST 2 MILLION PEOPLE IN THE UK.

#Fibro2018



MYTH: FIBROMYALGIA ONLY AFFECTS WOMEN.

FACT: ANYONE CAN DEVELOP FIBROMYALGIA, ALTHOUGH IT APPEARS TO AFFECT AROUND 7 TIMES AS MANY WOMEN AS MEN.

#Fibro2018



MYTH: FIBROMYALGIA ONLY AFFECTS PEOPLE OVER 50.

FACT: FIBROMYALGIA DOES NOT DISCRIMINATE BY AGE! ALTHOUGH IT TYPICALLY DEVELOPS BETWEEN THE AGES OF 30 AND 50, IT CAN DEVELOP IN CHILDREN, YOUNG PEOPLE AND THE ELDERLY.

#Fibro2018



MYTH: THERE'S NOTHING THAT CAN BE DONE TO TREAT FIBROMYALGIA.

FACT: ALTHOUGH FIBROMYALGIA CANNOT BE CURED, FOR MANY PEOPLE, A DIAGNOSIS CAN BE VALIDATING. IT CAN MARK THE BEGINNING OF A NEW JOURNEY TOWARDS RELIEF OF SOME SYMPTOMS. MANY PEOPLE ARE ABLE TO BETTER MANAGE THEIR SYMPTOMS THROUGH LIFESTYLE CHANGES, TREATMENT AND PEER SUPPORT.

#Fibro2018



MYTH: THE SYMPTOMS OF FIBROMYALGIA ARE MILD.

FACT: THE CONDITION AFFECTS EVERYONE DIFFERENTLY. FOR SOME, SYMPTOMS CAN BE MILD; HOWEVER, FOR MANY, IT CAN BE SEVERE, HAVING A SIGNIFICANT IMPACT ON QUALITY OF LIFE.

#Fibro2018



MYTH: FIBROMYALGIA JUST CAUSES PAIN.

FACT: WHILE PAIN IS A SYMPTOM OF FIBROMYALGIA, THERE ARE A VARIETY OF OTHER SYMPTOMS TOO, INCLUDING: FATIGUE, COGNITIVE DISTURBANCES (BRAIN FOG), HEADACHES, CLUMSINESS, DIZZINESS, IRRITABLE BOWEL SYNDROME (IBS), AND SENSITIVITY TO CHANGES IN THE WEATHER AND OTHER ENVIRONMENTAL FACTORS.

#Fibro2018



GETTING INVOLVED ONLINE

Don't worry if you can't hold a physical event! Raising awareness online can be a fantastic way to share the message about fibromyalgia. If you use social media, we'd love you to join the conversation, and hopefully create some excitement in the run up to and during Fibromyalgia Awareness Week.

We will be tracking the buzz on on social media using the hashtag **#Fibro2018**. Whenever you share anything on social media, don't forget to include the hashtag - we will be looking out for your posts throughout the week on Facebook and Twitter!

EMAIL SIGNATURE BANNER

Use our email signature on your messages if you wish to do so - help to share the message about fibromyalgia among those you speak to!

FIBROMYALGIA AFFECTS AROUND 1 IN 20 IN THE UK

Early diagnosis and access to treatment and support is essential.
Don't Delay, Connect Today.
2nd-9th September 2018



Fibromyalgia Action UK
Fighting for Freedom from Fibromyalgia

FIBROMYALGIA AWARENESS WEEK 2018

#FIBRO2018

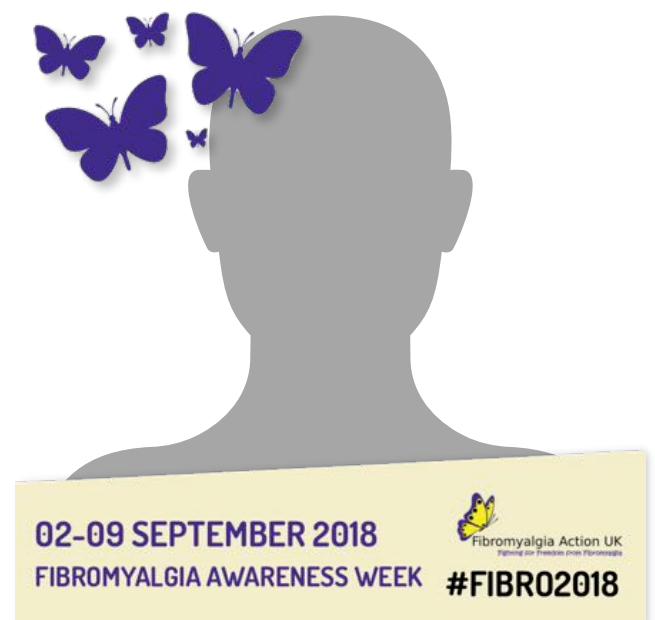
FACEBOOK AND TWITTER COVER IMAGES

Update your personal and/or page profiles on Facebook and Twitter using these images, to show that you are supporting Fibromyalgia Awareness Week.



PROFILE PICTURE FRAME

Add a frame (also known as a Twibbon) over your existing profile picture on Facebook and Twitter to show that you are supporting Fibromyalgia Awareness Week! Simply visit:
www.twibbon.com/support/fibro2018
to add yours!



TEMPLATE SOCIAL MEDIA POSTS

Have you got writers block, and are stuck as to what to write for awareness week? Don't worry - use these templates to get started, and check out our top tips for blogging and using social media effectively!

- “ “ We are calling on you to help raise awareness of the importance of early diagnosis of fibromyalgia. Share this post to show your support! #Fibro2018
- “ “ Early diagnosis and access to treatment and support are essential in reducing further impact of fibromyalgia on people's quality of life. #Fibro2018
- “ “ Fibromyalgia remains undiagnosed in as many as 3 out of 4 people with the condition, with diagnosis times averaging 5 years. #Fibro2018
- “ “ It's Fibromyalgia Awareness Week from Sunday 2nd to Sunday 9th September 2018 - join us in placing the spotlight on fibromyalgia! #Fibro2018





TOP TIPS FOR BLOGGING AND USING SOCIAL MEDIA

- 🦋 Use photographs and videos to make your posts stand out.
- 🦋 Use our awareness week hashtag **#Fibro2018** in all of your social media posts so that other people can more easily find what you are saying. You could also include other hashtags like **#FightFibro** to attract a greater reach!
- 🦋 Include a 'call to action' in your social media posts. For example, 'get involved', 'find out more here' and so on.
- 🦋 Posts are more interesting when people can relate to them - so focus on people in your posts.
- 🦋 Post regular, consistent updates during and leading up to awareness week to keep the momentum going!


WOULD YOU LIKE TO SHARE YOUR STORY WITH US?

We love to read and share personal experiences from people living with fibromyalgia. Personal stories can be a powerful way to change attitudes, offering a different perspective to people who are unaware of the realities of fibromyalgia.

If you'd like to share your story, please email head.office@fmauk.org - following the guidance below:

-  Maximum 600 words;
-  Include your name;
-  Attach a photograph of yourself (if you wish to do so);
-  Include a link to your blog (if you have one).

Once you've sent your blog, we may edit it for clarity or to remove content which may cause significant distress to other people, but we will always share any edits with you before we publish.



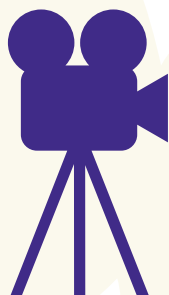
My story
I was diagnosed with fibromyalgia in 2012, after several years of coping with horrendous symptoms. I had just brushed off the fatigue and cognitive lapses as a sign of getting older...

SPEAKING WITH THE MEDIA

If you are holding an event, are wanting to promote the work of your local group, or would like to share your story about living with fibromyalgia, contacting your local media is a good way to do this.

Securing media coverage is a great medium to communicate the importance of early diagnosis and timely access to evidence-based treatment of fibromyalgia. For any type of event you are hosting, media support can play a vital role in generating awareness of the event and its aims. We encourage you to use a combination of traditional and social media activity to raise awareness of your local activities.

On the next few pages, we've included some things to think about, along with some tips when speaking to journalists, and a template press release that you may want to use. If you'd like to include somebody from Fibromyalgia Action UK, please contact Head Office: head.office@fmauk.org



Whether you phone or email a journalist, you need to be clear about what you want to speak about, since they'll have lots of people contacting them. Are you wanting to tell them about the event that you're organising? Or would you be happy to share your personal experiences? These are the questions you need to have answered yourself before contacting a journalist.

Regardless of your rationale for contacting a journalist, you need to remember that you are speaking as an individual, and not as a representative of all people with fibromyalgia, or Fibromyalgia Action UK. This means that you don't need to remember lots of information about the campaign, or what Fibromyalgia Action UK does. If a journalist wants to know more about us, or wants a quote directly from the charity, please ask them to contact Head Office by email: head.office@fmauk.org or by telephone: **0141 255 1570**.

Think about the level of detail you want to give to journalists. For example, are you happy for your full name to be used? Can they include where you are from and the condition(s) that you have been diagnosed with? How much detail do you want to share about your experiences? It's a good idea to think about such questions before you approach journalists, so that you can be upfront, since they will need to know whether or not there is enough to cover in print.

CONTACTING A JOURNALIST BY PHONE OR EMAIL

- 🦋 Introduce yourself clearly, explaining who you are, and what you are calling or emailing about. Make it simple and clear.
- 🦋 Explain what you want them to do. For example, ask them if they would be interested in covering the story, or attending the event, and whether they would like to film or photograph the event.
- 🦋 If you don't receive a reply that day, chase them up the next day to check that they have received your voicemail or email, or to see if they are looking to cover the activity.
- 🦋 Attach your completed press release to the email, and copy it into the body of the email, attaching any pictures you may wish to use.

SCHEDULES FOR CONTACTING THE MEDIA

BEFORE THE EVENT

If you are hosting a public-facing event, get in touch with as many local news outlets as possible to invite them to the event, including print, online and broadcast/television.

For a policy meeting, you may wish to invite policy and health journalists.

Send an email, and follow up with another call to see whether they want to attend.

ON THE DAY OF THE EVENT

Send a press release and some photographs to your media list (including media that attend and those that cannot attend the actual event).

Don't forget, if any photos or videos feature other people, you should have their permission before sharing and publishing them. Likewise, if your photos or videos feature children, you will need to seek parental permission before sharing.

FINDING PEOPLE TO BE CASE STUDIES

Personal stories are fantastic for bringing a campaign to life. You could offer journalists the opportunity to interview somebody that is living with fibromyalgia, and has a story about the importance of early diagnosis and access to treatment and support. Personal stories are much more likely to get press coverage compared to simply stating facts about an activity or event. If a journalist does wish to conduct an interview, it is important that you brief your interviewees thoroughly beforehand. Ask them to provide answers with a positive 'call to action' alongside their personal experience. To help make the experience pleasant, it's important that you ask them if they are happy to take part in an interview, and provide them with some examples of the questions that they could be asked, such as:

- 🦋 When did you begin to notice symptoms of fibromyalgia?
- 🦋 When were you diagnosed with fibromyalgia?
- 🦋 How did the timing of your diagnosis impact your life?
- 🦋 How does fibromyalgia affect your quality of life?
- 🦋 How do awareness campaigns like this help people with fibromyalgia?
- 🦋 How do you believe early diagnosis benefits people with fibromyalgia?
- 🦋 What action would you like to see the public take in terms of fibromyalgia diagnosis, awareness and management?
- 🦋 What action would you like to see politicians take in terms of promoting the early diagnosis of fibromyalgia and its management?
- 🦋 What's your hope for the future?

SHARING YOUR STORY WITH JOURNALISTS

If the interview goes ahead, it may happen face-to-face, or over the phone. It's a good idea to find out whether the interview will be live (radio or television) or pre-recorded. If it's pre-recorded, they will probably use a short segment of what you say, whereas a live interview will go straight out onto the radio or television.

An interview for a newspaper or magazine is likely to be done over the phone, and may take longer as there may be more in-depth questions. The journalist will write this up as either a first person piece or as a story including quotes from your conversation. If you would like them to repeat something you have said to make sure you are happy with it, just ask.

BE YOURSELF

The most important thing to remember is to be yourself - the journalist is interested in your story and what you have to say.

PRACTICE, PRACTICE, PRACTICE

Practice your interview with a friend or relative - it's good to feel at ease with talking, and responding to questions on the spot.





PREPARE WHAT YOU WANT TO SAY

Preparation is key to a good interview. Have prompts ready, and note down key messages that you need to get across.

SPEAK WITH STYLE

Try to be clear and concise with what you say, since this will help to get your message across. Remember to take some deep breaths too if you're nervous!

SOME USEFUL TIPS FOR WORKING WITH THE MEDIA

-  You can usually find contact details for your local newspaper, radio station and television channel on their website.
-  You can try to phone or email the appropriate media contact, but remember that they receive hundreds of calls and emails each day, so they may not respond immediately, or at all if they are particularly busy, so try not to take this personally.
-  News desks are looking precisely for news, so if you contact them, think about why they will write or feature your story at that point in time - for example, the event or activity you are hosting.
-  If you need public participation in your event or activity, speak to the media at least two weeks before the day of your event or activity.

TEMPLATE PRESS RELEASE

FIBROMYALGIA AWARENESS WEEK 2018

DON'T DELAY, CONNECT TODAY



Fibromyalgia Action UK
Fighting for Freedom from Fibromyalgia

For immediate release

[insert date]

[Name of group] holds [insert event title] to support Fibromyalgia Awareness Week 2018

[Name of group] will be holding an event on [insert date of event], as part of a national effort to raise awareness of fibromyalgia. Fibromyalgia Awareness Week, from 2nd to 9th September 2018, was established by Fibromyalgia Action UK to raise awareness of fibromyalgia. The awareness campaign now takes place every year during the first full week of September.

Fibromyalgia is a chronic, long-term condition involving widespread pain, a heightened pain response, and overwhelming fatigue, among a variety of other symptoms. These include: un-refreshing sleep, waking up tired and stiff; cognitive disturbances, including a lack of concentration, temporary memory impairment and mixing up words, more commonly known as 'brain fog'; clumsiness and dizziness; headaches; irritable bowel syndrome; and a heightened sensitivity to changes in environmental stimuli, such as light and touch.

Fibromyalgia Awareness Week aims to get as many people as possible talking about fibromyalgia, and for the first time in 2018, Fibromyalgia Action UK have decided to use a theme to co-ordinate events throughout awareness week, building upon the theme launched for International Fibromyalgia Awareness Day on May 12th 2018. The theme, 'Don't Delay, Connect Today' is being used to emphasise the importance of early diagnosis and recognition of fibromyalgia, in addition to timely access to evidence-based treatment and peer support for those living with fibromyalgia. This theme has been inspired by the European League Against Rheumatism's ongoing 'Don't Delay, Connect Today' campaign.

[Name of group, location] will join hundreds of other groups, organisations and individuals, who will all be talking about fibromyalgia and the impact of this condition on the lives of those living with the condition, as well as their family and friends. The activity planned for awareness week by [name of group] will include [include a sentence or short paragraph here about what your group is doing to celebrate awareness week].

To the surprise of many, fibromyalgia is a relatively common condition, though few people are aware of it. A European survey of five countries estimated that 2.9% to 4.7% of Europeans were living with fibromyalgia. Using the lowest estimate, this means around two million people in the UK are likely to be directly affected by fibromyalgia.

[Name of representative, role at group] said [“include a quote about why you are taking part in awareness week.”]

Des Quinn, Chair of Fibromyalgia Action UK, said: “Fibromyalgia is an all too common condition that affects potentially 1 in 20 people. Yet too often, we find that people are not aware of the condition. Publicity in the last year with Lady Gaga and other efforts have helped this, but there is still some way to go. Fibromyalgia is not just being a bit sore; it is a condition that can ruin people’s working and personal lives, leaving them to grieve for the people that they once were. Fibromyalgia Action UK continues to fight for freedom from fibromyalgia and with our supporters, we will continue to raise awareness generally and fight to improve treatment options within the National Health Service (NHS).”

For more information about fibromyalgia awareness week and how you can get involved, please visit: www.fmauk.org/campaigns

Notes to Editor

For more information about Fibromyalgia Action UK, please email head.office@fmauk.org or call 0141 255 1570.



Fibromyalgia Action UK
Fighting for Freedom from Fibromyalgia

DON'T DELAY, CONNECT TODAY
FIBROMYALGIA AWARENESS WEEK 2018

SIGNPOSTS TO SUPPORT

Fibromyalgia Awareness Week is a great way to start and focus conversations about fibromyalgia, and we hope that these materials and ideas will help us to collectively engage more people. However, given the nature of fibromyalgia, individuals may need additional support to help them to cope with the condition. There are lots of places you can go to for help - whether you are living with fibromyalgia, or caring for someone with fibromyalgia. We've included a couple below. Our national helpline is also given at the bottom of this page.

SAMARITANS

Telephone: 116 123 (Free 24 hours a day)

Email: jo@samaritans.org

Website: www.samaritans.org

Samaritans provide confidential, non-judgmental emotional support for people experiencing feelings of distress or despair, including those that could lead to suicide.

CARERS DIRECT

Telephone: 0300 123 1053 (9 am to 8 pm weekdays, 11 am to 4pm weekends)

Website: www.nhs.uk/conditions/social-care-and-support/carers-direct-helpline/

The Carers Direct helpline advisers can help give you information such as taking time off work and benefits for carers. They can also put you in touch with specialist national and local sources of help.

MORE INFORMATION

INFORMATION BOOKLETS

Take a look at our information booklets, and share them with people who may find them useful: www.fmauk.org/booklets

MEDICAL PACK

Send a medical pack to your general practitioner (GP) or other healthcare professionals if they need some further information about fibromyalgia:

www.fmauk.org/GP-Request

USEFUL CONTACT INFORMATION

Below are some useful contacts at Fibromyalgia Action UK. Please do reach out to us if you have any queries when planning and delivering your activity for awareness week, and please let us know about any local or regional media coverage!

HEAD OFFICE

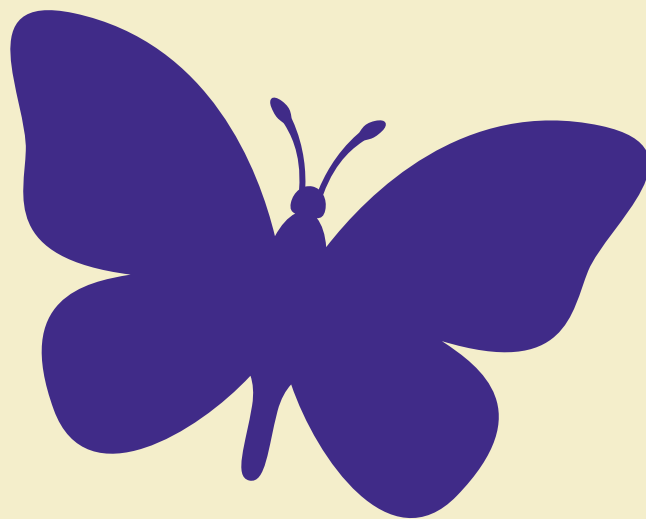
Email: Head.Office@fmauk.org

Telephone: 0141 255 1570

NATIONAL HELPLINE

Telephone: 0300 999 3333 (10 am to 4 pm weekdays)

#Fibro2018



FOR MORE INFORMATION



@ukfibro



@fmauk



www.fmauk.org



Fibromyalgia Action UK
Fighting for Freedom from Fibromyalgia

Registered Charity Number: 1042582
Company Number: SC492045