

I really hope you have found this booklet useful and now realise you are not alone or going mad!

Fibromyalgia can be so debilitating and has no doubt changed your life completely but managing is feasible with lifestyle change along with a little self-belief and a sense of empowerment. Do not be afraid to adapt, with the right mind set anything is possible.

Useful Resources

I have found the following resources useful.

- Chronic Pain. The Pain Management Plan: How People Living with Pain Found a Better Life: The Things That Helped Them and the Things That Set Them Back by Robert Lewin.
- Fibromyalgia Action UK (<http://www.fmauk.org/>)

Fibromyalgia & Central Sensitisation

A personal account from
one patient to another

Introduction

Hello. My name is Charlotte Goodwin and I suffer from Fibromyalgia.

I have created this booklet to share my journey living with Fibromyalgia; from the long process of being diagnosed, to how it initially affected me and relationships with others, my symptoms, how I have adapted with home life and work, and that I am now able to manage 3 years down the road from diagnosis.

I'm hoping this booklet will help you and give you something to relate to, whether you have just been diagnosed or have suffered for years.

This booklet isn't to tell you what to do but to let you know you are not alone and hopefully help you re-adjust to this horrid condition (I would like to call it something else but that would be highly inappropriate!)

Pre Diagnosis

My symptoms started around 12 years before I was diagnosed. I had a severe episode of fatigue where I couldn't grip a tissue, but because it was a one off I didn't feel the need to go to my GP so I ignored it. From the age of 18, I suffered from IBS and migraines which I self-managed. At 21, my hairdresser noticed I had bald patches (alopecia areata) which would come and go.

Then I hit 30. I found I could hardly walk first thing in the morning and I was getting more fatigued in the afternoons. My feet and legs seized and my back sore.

This is unintentional from most. Sadly, your close ones can be just like your colleagues where they do not see your pain therefore they don't think you have any. They don't understand how one minute you can be crying in pain and the next feel ok again.

Unfortunately this is just typical human behaviour but that is not what you want to hear as a sufferer.

It is difficult but try to see it from their point of view. Maybe your family and partner are actually scared because they have never heard of this condition before and don't understand how it will affect you in the long term. You could inform your partner that you understand it must be upsetting for them to feel so helpless. For example if you wake up in the middle of the night rolling in pain crying and there is nothing physically they can do to help but actually all you need is for them to hold you and let you know that they are there for you.

For your own sanity, and theirs, you need to communicate and make them aware that you need emotional support. Arm yourself with information about fibro and give it to them, they may take their time before they are ready to read but they will.

What I have realised is I do not want sympathy or for anyone to do everything for me. All I need is acknowledgment that I do have a chronic pain condition and love and support when I am in pain.

When you tell close ones this then they may actually feel relieved that something so simple could help you so much.

but with plans in place I am now able to work through them knowing they will pass after a couple of hours.

I have also worked with my employer to input reasonable adjustments. Fibro is classed as a disability and therefore your employer has a duty of care.

I have reduced my hours which were a big change for me as I used to work full time but what's more important - Your health or an extra couple of hundred a month?

I now work day on day off so I can rest between shifts and I no longer do night shifts due to the fatigue.

Don't be scared to communicate and tell others how you feel, if anything it's an eye opener for them especially as they cannot see your pain.

Relationships with Others

If you've been suffering for years, or suffered for only a few months and have just been diagnosed, there's no doubt your condition has had an impact of your relationships with family, friends, partners and colleagues.

From the start of your journey, unintentionally, these people may have had quite a negative impact on how you think about yourself and condition; whether it be they are dismissive, frustrated, angry with you when you are in pain, or don't talk about it what-so-ever and tend to act like there is nothing wrong with you making you feel like you are attention seeking or over exaggerating.

It would take me 10 minutes to walk to the bathroom (sometimes crawling!) and getting up off the loo was another feat in itself. I put this down to working too hard.

Within 18 months more symptoms materialised which included:

- Waking up in the night in pain
- Waking up feeling 'hung-over'
- Spasms and twitching in my face, arms and legs
- Struggling to climb the stairs
- A feeling like my bones were being scraped with a knife in my arms and legs
- Severe itching
- Nausea
- Hot flushes
- Feeling cold easily
- A feeling of deep bruising when gently pressed on my body
- Severe loss of use of my arm (you can imagine how fun that was whilst at work!)
- Hands ceasing
- Irritable Bowel Syndrome

These symptoms would come and go. I could have a few at the same time which would last for a few days or sometimes weeks.

I only went to my GP when I developed pain in my coccyx and had been suffering with this for around 6 months (I was ready to go insane by this stage!). I had explained some of the other symptoms but my GP put

me on pain medication, amitriptyline and the likes of but nothing worked.

A couple of months later I was told to look at the NHS website by a nurse practitioner as it didn't look like I suffered from back pain. I left the appointment in tears feeling ignored and helpless.

I then made another appointment to see my GP who diagnosed coccydynia (pain in my coccyx). I was baffled as I hadn't injured it. I was then referred to a physiotherapist who gave me exercises and trialled acupuncture. I must say I felt like a fool with needles in my backside! But to no avail.

It wasn't until I was towards the end of my course of treatment that I started suffering from severe pain in the side of my ribs. Some days it hurt to breathe and move - on one particular appointment with my Physiotherapist I sat in tears through the pain and he couldn't do any exercises with me. The physio explained I had become hypersensitive and should go back to my GP and be referred to the pain team. I thought "not again, he's going to think I'm a hypochondriac"! My GP then diagnosed costochondritis (inflammation of the cartilage in the rib cage).

Diagnosis

After waiting a few months to see my Pain Consultant, the day came and I was diagnosed with Fibromyalgia. The following months I found really difficult. I call this time my 'grieving process'. I went from being in denial to anger and frustration. I was becoming frustrated with

I wouldn't ask anybody for help as I didn't want to admit defeat to fibro and I didn't want to look like I was being lazy or being a burden.

I expected people to offer to help me as they were aware that I had a condition but unfortunately it doesn't work like that in the workplace!

When I was at the acceptance and wanting to help myself stage, work became easier.

After undertaking the pain management programme as part of the pain service at Plymouth Hospitals NHS Trust, I came to the realisation that I could work through my pain at work. I created a work flare up plan which detailed how I could help myself and how my colleagues could help me which I emailed to everyone. It's imperative to communicate with others, if you don't tell them than how can they help?!

On my plan I asked my colleagues to be patient with me and to understand that one day I may look fine and the next be in horrendous pain. What you tell your colleagues will be dependent on what you struggle with in the work place.

My work plan is very similar to my home one, breathing exercises etc. What I tend to do is rock from side to side and sing or hum! People think I may be a little crackers but for me it works.

Working through your flares saves your sickness records from increasing and actually gives you a real sense of achievement. I didn't think that it was possible

doing and not be able to resist; my brain telling me to do it but my body shouting NO!

Listening to your pain is key.

- **supplements/pain relief and diet.**

I found taking pain relief for months on end didn't work for me and did not take away my pain - I only take Paracetamol and Ibuprofen when my pain is at its worse which I find works better.

I take Vitamin D and Magnesium daily. I also have a Magnesium flake bath to soak in 3 times a week as these really help with my muscle spasms and cramps. (Flakes can be bought online or in health shops).

I've changed my diet considerably and I try and eat as healthy as possible but do have the odd treat.

It's all trial and error to determine what suits you best.

Managing at Work

Being in pain whilst at work made me feel judged, isolated, frustrated, angry, upset, misunderstood, depressed, resentful of others and a general nuisance.

Every time I became flared at work I would go home 'sick' because I thought I should and because my colleagues would be telling me to. This would affect my sickness record which triggered meetings which would cause stress and flare me up further!

everyone around me. I didn't think anybody cared or wanted to understand and this lasted for a few months.

The next stage for me was acceptance. I realised I had to try and started by educating myself and others around me. I found this task difficult as I came to realise that people around me were also in denial and no matter how much I tried to inform them about my condition, I still didn't feel like they wanted to listen. Some were dismissive and others impatient. I just wanted and needed acknowledgement.

It wasn't until I attended my local Pain Management Programme that it changed for me.

Finally. I now understood that with Fibro or Central Sensitisation there isn't one cure but there are ways to manage that help me live my life as 'normal' as possible. It is this knowledge that I would like to pass to you.

How I Manage at Home

- **relaxation/mindfulness**

With fibro the only way your body can truly rest is through relaxation. You may not think that this would be something helpful to you initially but give it a try, it really does help! There are plenty of ways to relax for pain which you can find on YouTube. Try searching for word repetition, guided and non-guided meditation, body scanning, self-guided imagery and visualisation to see what works for you. I practice meditation daily - especially when I flare up with pain as being

mindfulness helps me concentrate on anything other than pain.

- **flare up plan**

For me this is essential. I have written up my personal 'flare up plan'. This plan is for me to look at when the pain is at its worse. It's a list of what I can do to help me with my pain like walking around, breathing exercises/relaxation, taking pain relief and having a hot magnesium bath. It also includes what my partner can do to help me. It's so handy because when you are in pain it's hard to focus on anything but the pain, whereas a plan reminds you to concentrate on something else and how you can do this.

- **exercise**

Initially I found this really tricky but it is another essential routine which I find helps preventing my body seizing up as much. Light exercise such as tai chi, yoga and pilates can help with sleep.

I also find walking and swimming helpful but it is about finding what is right for you.

If you can find a hydro pool or jacuzzi these are AMAZING for pain! The most difficult part of this routine is learning your limitations. Start slow and set yourself goals. I started by sitting down and standing up from a chair and achieving more each time. This may sound simple but you will be surprised by how much energy you use.

For me it's important to not sit down for long periods so I switch and try and sit for no longer than an hour then I make an effort to get up and walk around as this saves me from taking 10 minutes to straighten up.

- **housework**

Some days the last thing I want to do is the washing! I wake up and feel bruised all over my body hobbling around but I still want to be able to do the general chores. I'm a person who is always on the go wanting to 'get things done' but I've had to slow down and adapt.

I tend to do two trips when carrying washing upstairs or I use a cordless vacuum with a hand held attachment so I can do the stairs. For gardening, I used to do it all in one go but now I do it in stages. Being able to do the things I used to keeps me sane!

There are ways and means, it's about taking control, planning and helping yourself. I still have my 'down days' but they are much less frequent than when I wallowed in self-pity. It's not about feeling like a failure anymore or feeling like I'm giving in and letting people down - if I need help I now ask for it. When you are used to being so self-sufficient you do initially feel like a 'burden' to everyone but you will find they want to help, especially if they can see you are trying to help yourself. I've now learnt to listen to my body - when my hands start to feel sore I stop.

If I am really flared on a particular day I've taught myself that I need to rest today. Initially I found this difficult as, being a perfectionist, I would look at jobs that needed