

A hidden condition

Ten people living with fibromyalgia tell their story

June 2016

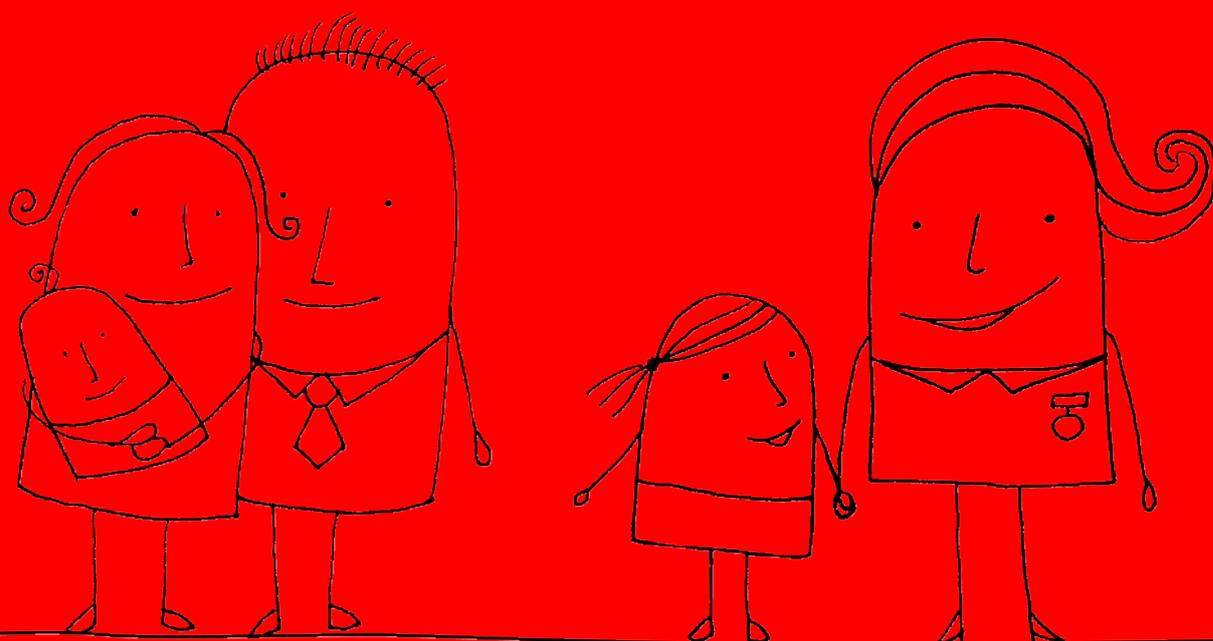


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Foreword

Dear Reader,

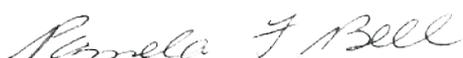
I am delighted to have been asked to contribute the Foreword to this publication by the Patient and Client Council. Over the past three years their work with those who live with long term pain, in particular 'The Painful Truth' project, has made considerable progress in engaging people and their families in highlighting the burden of pain on their lives and their concerns about the provision of adequate health and social care services to those who shape and deliver them.

One group of people who were involved in the project, and who continue to contribute to the conversation about service provision through the Chronic Pain Forum of the Health and Social Care Board, are those with fibromyalgia.

This condition is so much more than just widespread pain, as this publication attests. The stories of the contributors tell of the impact that the condition has on their health, family life, work and hopes. Most telling, is their frustration with the time taken to get a diagnosis, the lack of understanding of the condition on the part of many healthcare professionals and society, and the lack of effective medication and support for self-management.

Please take time to read these stories and appreciate the perpetual difficulties of the lives of their authors; they are to be commended for their willingness to share them. If fibromyalgia seems a puzzling disease, the introduction should clarify matters for the lay and professional reader alike.

I have been privileged to be part of the Patient and Client Council's work with this group of people, witnessing the efforts that they make to attend meetings, engage in email conversations and direct our deliberations. I know that the Patient and Client Council will continue this work to ensure that those with fibromyalgia are not disadvantaged, forgotten or 'hidden'.



Dr Pamela F Bell

Chair, The Pain Alliance of Northern Ireland

Introduction

What is fibromyalgia?

Fibromyalgia, also called fibromyalgia syndrome (FMS), is a long-term condition that causes pain all over the body.¹ The pain does not reflect any specific identified problems with joints, muscles or bones.²

It can impact every part of a person's life. Relationships with spouses/ partners, children and friends can be affected and people living with the condition can experience loneliness, isolation, self-doubt and guilt.³ It has been shown to have a significant cost in terms of absence and loss of productivity for employers.⁴ It is also associated with higher risk of death through suicide or accidents.⁵

What are the symptoms?

People with the condition report how they ache all over and experience profound fatigue. Their muscles may feel like they have been pulled or overworked. The pain tends to be felt as diffuse aching or burning. It may be worse at certain times and can change location, usually becoming more severe in parts of the body that are used the most. In terms of fatigue this can range from feeling tired, to the exhaustion of a flu-like illness. It may come and go and people can suddenly feel drained of all energy as if someone just "pulled the plug".⁶ Other symptoms include sleep disorders, problems with cognitive functioning, irritable bowel syndrome, headaches/ migraines, tingling and numbness, anxiety and depression and problems with mental processes such as memory and concentration (sometimes referred to as "fibro-fog").^{1,7} This is an overview of the main symptoms as many other symptoms are associated with the condition (between 60 – 100 different symptoms).^{8,9}

Figure 1.1 highlights some symptoms of fibromyalgia.

Figure 1.1: Example of some symptoms of fibromyalgia



Symptoms can vary for different individuals and are generally classed as mild, moderate and severe fibromyalgia.¹⁰ People with mild to moderate cases of fibromyalgia are usually able to live a normal life given the right treatment. On the other hand, if symptoms are severe people may not be able to hold down a permanent job or enjoy a full social life.⁶

There are no outward signs of the condition, so many fibromyalgia sufferers go unnoticed. This makes it hard for outsiders to understand how bad someone is feeling, which can be depressing or frustrating for those with the condition.²

What is the cause?

There is no known cause of fibromyalgia; however it is suggested that a number of factors are associated with its development, such as a particular physical or emotionally stressful or traumatic event.^{1,11-13} This can include events such as; a fall, car accident, viral infection, childbirth, operation or emotional event.⁶ For others it can occur spontaneously.¹⁴ Some studies have noted that there may be a genetic component to fibromyalgia and it could therefore run in families.¹⁵ Other research is on-going seeking to understand other factors which may be involved, including problems with how the central nervous system processes pain.¹⁶

The condition can occur in isolation, but more often it co-occurs with other conditions now being shown to have a similar underlying physiological process (e.g. irritable bowel syndrome, interstitial cystitis, and tension headache) or as an additional disorder in individuals with diseases characterised by on-going peripheral damage or inflammation (e.g. autoimmune disorders and osteoarthritis).¹⁷

Prevalence of fibromyalgia

Fibromyalgia is a common condition and anyone can develop it.¹⁸ However, it can be difficult to diagnose, which makes it more problematic to get a true reflection of how many people are affected.¹

Epidemiological studies report a fibromyalgia prevalence of between 2 and 7% (roughly affecting 1 in every 25) in most nations.¹⁹ It is reported that fibromyalgia accounts for 2% of patients seen in a general practice setting and 5% of those attending a general medical outpatient clinic.¹⁸ It has also been demonstrated that a diagnosis of fibromyalgia is more common in Northern Ireland than in other areas of the UK.²⁰

The condition typically develops between the ages of 30 and 50, but can occur in people of any age, including children and the elderly.¹ It has also been found that fibromyalgia is more prevalent in females than males (3.4% versus 0.5%).²¹

Diagnosis

Diagnosis is very important for people living with fibromyalgia so that they have an understanding of their pain and can be subsequently treated and/ or referred to other services to help them manage their condition. A definitive diagnosis may reassure patients that their symptoms do not reflect another underlying condition. It can allow them to feel more in control, which thereby fosters acceptance and allows symptoms to be appropriately treated. Simply "being believed" may have a significant influence on patient health and well-being.²⁰

However, diagnosing the condition can be difficult and there is no specific test that can be used to diagnose it as it does not show up on blood tests, x-rays or scans.² Until recently the diagnosis of fibromyalgia was based on a 'tender point examination' and people with the condition are often very tender on gentle pressure in these areas.²²

The most recent classification criteria for fibromyalgia recommend that, in addition to pain, health care professionals also include fatigue, sleeplessness and cognitive problems (fibro fog) when making a diagnosis of fibromyalgia. The full symptom profile of patients is also included in the diagnostic criteria.²³

The symptoms of fibromyalgia can vary and can be similar to those of several other conditions. However, fibromyalgia has unique clinical characteristics and GPs can make a diagnosis based on the disorder's clinical presentation. Fibromyalgia is not a disorder of exclusion.²⁴ Fibromyalgia symptoms can mimic other conditions (e.g. hypothyroidism and inflammatory rheumatic diseases, myalgic encephalomyelitis (ME) / chronic fatigue syndrome (CFS), rheumatoid arthritis, osteoarthritis, systemic lupus erythematosus, spinal stenosis, neuropathies, sleep disorders such as sleep apnea). It is important that these conditions are identified if present. The presence of these conditions does not preclude a diagnosis of fibromyalgia.²⁴

As is often the case for those with fibromyalgia, people in Northern Ireland have reported that their fibromyalgia diagnosis has taken too long and that some GPs do not have the knowledge or experience to quickly diagnose the condition.²⁵

Treatment

There is no cure for fibromyalgia; however there is evidence that treatment can ease some of the symptoms and improve quality of life.¹ At present, learning to manage the condition seems to be the most successful way of dealing with fibromyalgia.⁶

A number of international guidelines have also emphasised the importance of physical activity in the management of fibromyalgia²⁶⁻²⁸ and there is some evidence of improvement in quality of life with physical activity^{29,30} but people with fibromyalgia report that exercise can often exacerbate their symptoms.³¹ One of the major challenges in managing fibromyalgia is striking a balance between gently increasing physical activity and controlling symptoms.

Patients require support through therapies in a coordinated way to ensure symptoms are controlled as much as possible to enable them to manage their lives as well as possible.

Fibromyalgia has numerous symptoms, meaning no single treatment will work for all. Treatments that work for some people will not necessarily work for others.¹ Due to the complexity of fibromyalgia it requires a multidisciplinary approach to treatment based around patient self-management.³² In general, treatments for fibromyalgia tend to be a combination of:

- ▶ Talking therapies;
- ▶ Lifestyle changes such as gently increasing physical activity; and/or
- ▶ Medication.

Talking therapies

Talking therapies such as cognitive behavioural therapy (CBT) and counselling can help fibromyalgia sufferers cope with changes in their life and help them manage and come to terms with the changes they have to implement in their lifestyle.³³

Lifestyle changes

It has been found that the best way to cope with fibromyalgia is to use a number of techniques that ease the symptoms as much as possible, as shown in **Figure 1.2** below.

Figure 1.2: Suggested techniques to cope with fibromyalgia



Relaxation

It reduces tension in the mind and body to calm the symptoms, especially pain



Heat

Obtained through a hot water bottle or showers can help reduce pain and stiff joints



Exercise

Research has shown exercise can reduce pain and tiredness



Diet

Excess weight has been said to exacerbate some of the symptoms

People with fibromyalgia will often use complementary and alternative medicines, but further evidence-based trials using complementary treatments are required to determine the true scientific value of these.^{32, 34}

People with fibromyalgia can have good and bad days. Whilst it can be tempting for individuals to overdo it on a good day, it is important that they pace themselves and rest to avoid exacerbating the symptoms in forthcoming days.⁶

Medication

A variety of medications can be used to treat fibromyalgia, and this generally benefits half of those with the condition. Medicines that can alleviate some of the symptoms can include:

- ▶ Painkillers, such as paracetamol, codeine or tramadol to alleviate the pain;
- ▶ Neuromodulatory drugs that work on the nervous system to change how pain is processed in the brain and spine. Whilst developed for other purposes, they have been shown to help many people with fibromyalgia;
- ▶ Amitriptyline and nortriptyline taken in the evening can help sleep and reduce pain. These are also used to treat depression, but the doses effective in fibromyalgia are usually much lower; and
- ▶ Other medications used in fibromyalgia include gabapentin, pregabalin, fluoxetine and duloxetine.²

Social impacts

Depending upon the severity of fibromyalgia, those who have it can experience difficulties in performing normal activities of daily living.

Strenuous activities such as walking, climbing stairs and shopping can be challenging for patients. However, it is important that, when able, people with fibromyalgia try to do even a little physical activity. Some patients have found it beneficial to use a heart rate monitor to control their exercise intensity.³⁰ This way patients can engage in physical activity in a controlled way that will not exacerbate their symptoms.

Some people with fibromyalgia may have to reduce the amount of work they do and some may have to give up work altogether, which can cause a strain both mentally and financially. People with fibromyalgia can feel disempowered and unable to support themselves and their family. Therefore if they are unable to work, that puts a large monetary strain on them.

Some fibromyalgia sufferers are able to maintain employment. However, whilst they can maintain their employment many find their symptoms compromise their ability to be productive due to frequent absences and reduced work hours,¹⁹ as well as draining them of energy needed to participate in family and social life.

Service provision in Northern Ireland

As part of the background research for this project, contact was made with the five different Health and Social Care Trusts, the Health and Social Care Board and the Department of Health, Social Services and Public Safety (DHSSPS). As part of these enquires, we asked each Trust to provide a list of services which were available in their area. We also asked the DHSSPS for a copy of the departmental policy and to clarify if there is a defined care pathway for this condition. Information was also requested from the HSC Board around what services have been commissioned and to detail any plans for service development or changes in the future.

Overall, the responses highlight that there are no specific services available for patients with fibromyalgia in Northern Ireland. Correspondence indicated that patients presenting to their GP are referred for further investigation and a range of hospital specialties including rheumatology, neurology, psychiatry, gastroenterology, endocrinology and primary care (GPs). A summary of the responses received are provided in **Appendix 1**.

Aims and objectives

This project was developed with the assistance of people living with fibromyalgia who wished to highlight issues relating to their condition. A steering group was subsequently established with a view to reporting and raising awareness of the condition. The project aim is to understand the experience of a small number of people living with fibromyalgia. It also seeks to raise awareness of people's experiences in relation to:

- ▶ Getting a diagnosis;
- ▶ Living with the condition; and

► Experience of Health and Social Care in Northern Ireland.

Through listening to people's experiences, this report seeks to provide an understanding of what the challenges are for people living with fibromyalgia and highlight potential gaps in their health and social care services.

Note to reader

The stories recorded in this document outline what people told us in their own words. However, the names used in this report are not the actual names of those who we spoke to. The project steering group guided us in identifying people who wished to tell their story.

When people discuss the 'NHS' throughout this document, they are referring to the Health and Social Care system in Northern Ireland.



**Patient
stories**

Janet's story

“

It all started when I had a car accident back in 1997, after which I had terrible pains in my legs and lower back trouble. I have never fully recovered since the accident.

”

(Female, 35-44 years old)

I lived alone for many years and was very independent. I loved gardening, a little bit of DIY and was generally very active. After the accident, I had constant pains in my legs and lower back and frequently visited my GP where I was referred to different physiotherapy programmes and pain clinics, none of which improved my situation. This was a worrying time as I never felt any closer to getting a diagnosis, wondering what the diagnosis would be and, all the while, my health was deteriorating. As each year passed I was able to do less and less. I had been working up until 2001 and had periods of sickness with lower back pain and pains in my legs until, eventually, I just couldn't sit or stand for the full eight hours. I tried cutting my hours but it didn't work and I have been out of employment since then.

“

I had never heard of fibromyalgia until I was diagnosed...I wasn't given any information on how to manage the condition.

”

My biggest breakthrough was, when after eight years of failed treatments and no improvements in my health, I attended the pain clinic where the doctor thought I had inflammatory arthritis and, as a result, I was referred to a rheumatologist.

Whilst waiting for my appointment with the rheumatologist I made an appointment with a private rheumatologist who gave me an injection in my hip. I later received an appointment with the same consultant through the NHS where he then did an MRI scan and, within three weeks, I was called back to the

hospital and diagnosed with fibromyalgia.

I had never heard of fibromyalgia until I was diagnosed, I had to look it up on the internet and find out as much information as I could about it as I was not given any information on how to manage the condition.

Over the years my condition has deteriorated and since my diagnosis in 2005, it has got dramatically worse. I depend a lot more on people, especially my sister who helps me around the house and garden, as well as walking the dog. I lived quite a distance away from my sister and my parents and found I was travelling home more frequently for moral and emotional support. After a number of years, I moved back home within two miles of my mum, dad and sister. Even though I still live on my own, I wouldn't describe my life as independent as I completely rely on my family. I do not get any support at home other than from my family and I also have my support group which provides me with a social aspect to my illness. I find having someone who really understands the illness can help you when you are at your lowest point. Professionals will advise that exercise is key but sometimes this is just not possible when you have hit a low or your energy is just non-existent. Sometimes all you need is someone who knows you and knows how you are feeling and what you are capable of to be there for you and help you through the rough times.

I get benefits to help me out financially as I can't work but it's a difficult process and I had to go to a solicitor who specialises in filling in forms and they helped me with the forms to access benefits. As fibromyalgia is an unpredictable illness it is difficult to record on a form how you

are feeling from day to day, making it more difficult to get benefits. This added to my worry as I was no longer in full time employment and I wanted to maintain my independence but had very little money to live on.

I currently do not receive any treatment for fibromyalgia other than painkillers, amitriptyline, propranolol and venlafaxine. I usually visit the GP every three months to review my situation and my medication will either be increased or decreased depending on what I need. My GP has been very good the whole way through my journey. He stands out as being the most knowledgeable about my condition and has played a key part in my care since 1997 and, particularly after diagnosis, he really helped me through it and explained things to me. My experience with other professionals I have been referred to varies, some may not have heard of the illness, others don't take it seriously or think it's all in my head. I would say I got the most help and support about my illness from my local GP practice.

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My GP was willing to refer me to anything he felt would help my chances of getting a diagnosis, although I had to wait for the referrals. For example, it took six to eight weeks to be referred onto physiotherapy programmes and it was four years before I was sent to a pain clinic. I was never denied access to any services but, for both fibromyalgia and ME (which I was also diagnosed with), there is no provision of services at all to meet my needs. Any treatment I have received has never lasted any longer than maybe a few days or a week.

“ You are not dictating your life anymore, your illness is dictating your life and what you are able to do and it's very restricting. ”

I have been living with fibromyalgia now for ten years and have had to move closer to my family so they can look after me. My sleeping pattern is so bad I sometimes sleep for 12-14 hours but when I waken I still don't have any energy or feel like I've had a brilliant sleep. Or I go to bed and can't sleep at all; sometimes it could be another four hours before I actually get to sleep. I don't cook for myself, I had a wet room installed as I couldn't manage the bath and I live in a bungalow as I couldn't manage stairs. My only mobility at the moment is driving, walking is terrible and my sister supports me 90% of the time. I get very little housework done as I would do one room and then I would have to sit down, so my sister helps with the housework and the shopping. My parents are elderly and I feel I should be looking after them but I can't. All I can do is drive them about and then they have to look out for me.

I have a lot of involvement in a fibromyalgia support group which keeps me focused, it's nice to meet people who are going through the same thing as you and you can share pieces of advice about what has worked for you. But living like this can be very frustrating and it can drag you down emotionally. You are not dictating your life anymore, your illness is dictating your life and what you are able to do and it's very restricting.

When I was first diagnosed with fibromyalgia I felt very alone and didn't know where to turn. Other people do not fully understand that there is a lot of pain involved and they don't see the debilitating lack of sleep and the fatigue during the day. Unless someone cares for you or sees every minute of your life, then I don't think people fully understand it. If you make a really big effort one day and shower and dress and do your make-up, you can look the best, but that is not the true picture of how you are feeling. You lose a lot of people who you thought were friends. This is not a glamorous lifestyle to have.

Carol's story

“ I was taken into hospital with extreme pain down my side and around my diaphragm and neck and I collapsed a couple of times. They removed my gall bladder and I woke up in intensive care. When I woke I couldn't move and that was the start of what I now know is chronic fibromyalgia. ”

(Female)

I had been having pains before I went into hospital. I was scanned and it was discovered that I had one gall stone. I thought the operation was to remove the gall stone but they removed the gall bladder as well. The operation took place in January 1999 and I have been living with the pain since then, nearly 17 years.

In my journey to get a diagnosis I saw at least seven health care professionals, including my GP and private consultants. One consultant told me it was constipation whilst another said he had never seen anyone in so much pain and did not know what was wrong with me. Some doctors I have come into contact with think it's all in my head and I have had a lot of trouble trying to convince clinicians that fibromyalgia actually exists. The one and only time I saw a pain consultant I had a horrendous experience, he did not treat me like a human being, he pressed along the vertebrae of my back and when I got up, I was screaming in pain. He said "for goodness sake it can't be that sore, I won't be giving you a spinal injection anyhow". When I got home my whole spine was black and blue, he left me worse and the pain down my spine went on for nine months solid.

“ ...some doctors I have come into contact with think it's all in my head and I have a lot of trouble trying to convince clinicians that fibromyalgia exists. ”

After going to a number of different consultants

the doctor referred me to a rheumatologist but it would be 18 months before I would be seen. I couldn't wait that long so I lifted the phone and made an appointment with a private consultant rheumatologist and he diagnosed me quite quickly. Going privately I got the diagnosis in eight days but I had waited one and a half years on the NHS and was no further on. I paid to see this consultant and he diagnosed me after five minutes, he said "I have seen you walk and I think you have fibromyalgia and you will have to live with it" and I didn't have time to question it. I would have liked him to talk to me about how I was feeling and provide me with some sort of support to manage it, especially because I was paying to see him.

Throughout my diagnosis journey I had great support from the two girls that I share a house with. One girl in particular really understood and was there for me when I needed her. I wouldn't wish this on anyone, sometimes I feel that life just isn't worth living. I was a social worker and was always out and about and now, when I'm feeling low, I don't want to see people or I feel inferior or humiliated about how I look and how I'm feeling. I used to hold lots of dinner parties and went out and socialised but that has become totally non-existent. Before my diagnosis, subconsciously, I thought I had cancer and I think my family thought that too but we never discussed it. When I was told I had fibromyalgia and it was a muscle pain condition I thought "thank God I don't have cancer". That was the one positive thing to come out of my diagnosis, I wasn't going to die.

When it came to sorting out how I was going to survive financially I knew a man who worked in the Citizens Advice Bureau, he was a good family friend, and he said to me that I wouldn't be able to go back to work and asked had I thought about the finances. That got the ball rolling and the Disability Living Allowance doctor came out to see me. He was able to see exactly what was wrong with me and told me I would get benefits indefinitely because of my diagnosis.

I have never been offered any treatment for my fibromyalgia; I'm on anti-depressants and tablets for diabetes and high blood pressure. To make matters worse, I have problems with my stomach as well and if I took a painkiller today I would be in extreme pain in my tummy, so I have to weigh up the worst of two evils. The GP reviews my medication only when I go to have them reviewed. I usually go when I feel I'm in that dark place that we sufferers go to and I would ask for my medication to be changed.

The GP works with me; he is the best GP in my area. Throughout my fibromyalgia journey I didn't really get any care from health and social care services apart from my GP, he did his best for me. There are no suitable services available for fibromyalgia sufferers. GPs need to have knowledge of fibromyalgia and ME to know to refer patients to the right place.

“ The GP works with me; he is the best GP in my area. Throughout my fibromyalgia journey I didn't really get any care from health and social care services apart from my GP, he did his best for me. There are no suitable services available for fibromyalgia sufferers. GPs need to have knowledge of fibromyalgia to know to refer patients to the right place. ”

Living with fibromyalgia is awful; I have to sleep downstairs as there is no way my legs would

take me up the stairs. To give you an idea of what it feels like to be me, imagine walking with breeze blocks on the sides of your legs and your legs are covered in open sores and someone scratches down your legs, you can start to get an idea of what the pain feels like for me. When I go out I can't walk very far and need to make sure I can park close to where I'm going and I won't have to climb any stairs. I used to need help with personal care but now I have a shower downstairs which I can sit in by myself, it is fantastic.

My mood is also affected. If you can imagine going into a dark place, a dark room with no light, that's how I feel. I sometimes have a cry day, I just cry very easily, I don't like feeling that way, I am just not in control.

Like any other condition, people who don't have it don't take time to understand it and understand what you might be going through. I long for the day when there are clinics for people with fibromyalgia and ME where they can get some sort of solace and help and not be given the run around or told "it's all in your head, take a pill and go home." We need people to understand and help.

Mary's story

“ I had been going to the doctors feeling exhausted and very sore and a lot of other problems as well. The GP did tests and it came back as an underactive thyroid, which I was treated for and didn't feel any better even though my thyroid was back to normal. ”

(Female, 45-54 years old)

After being treated for an underactive thyroid, I went back to the doctor as I was in so much pain and so tired and she said to me “OK, we are going to have to give you something for your fibromyalgia.” That was the first time it was ever mentioned to me that I might have fibromyalgia, although I had suspected myself for years that I had it, ME or chronic fatigue.

“ ...it was a relief to be diagnosed as opposed to just snapped at and told to take ibuprofen. ”

I've had symptoms now for ten years but it was only four years ago that fibromyalgia was provided as a diagnosis by my GP. I had been to see another GP in the same practice and told her that I was in so much pain, and she looked at me and just said, “well you are going to have to just take some ibuprofen”, she didn't do blood tests or anything. When my usual GP diagnosed me, it was a relief to be diagnosed as opposed to just snapped at and told to take ibuprofen.

The GP referred me to a rheumatologist and I waited eight/ nine months and still hadn't heard anything. I went back to the GP and she had sent the letter but there must have been some sort of error because rheumatology had not received it. The GP sent it through again as urgent but I still had to wait another few months. In total, I had to wait over a year to see the rheumatologist who sent me for a scan and x-ray and diagnosed me with fibromyalgia, early

stage osteoarthritis and she also thought that I might have rheumatoid arthritis as well. The consultant then sent a letter to my GP basically discharging me back to my GP's care, so I only saw the consultant once.

When I first presented with symptoms at least ten years ago, the hypothyroidism masked the fibromyalgia as it has similar symptoms, but when I was treated for the underactive thyroid and it didn't improve it occurred to the GP it might be something else.

After my diagnosis from the rheumatologist, my GP referred me for physiotherapy and they were very nice but, on certain days, the physiotherapist could see I was fatigued. She did some research and advised me to attend a class for fibromyalgia patients. I went to one class but it was during the day which was difficult for me as I work. There were six or seven people there and the physiotherapist basically told us that we wouldn't get better, it will only get worse. I found it really depressing so I didn't go back to the other three classes. That is the only support and help I have had, nothing else has been offered and I was very angry that the rheumatologist signed me off and put me back into the care of the GP. There needs to be some consistency because some people would be constantly kept on with a rheumatologist whereas I was signed off. There is no specialist consultant care which is very very frustrating, if I had another illness I would be under the care of a consultant and sent for reviews periodically but there is nothing, you are sent home to rot.

“ I feel I am lucky that I have a GP that believes the condition exists. ”

I was devastated when I got my diagnosis, I was working two part time jobs and I felt gutted that there was no help whatsoever. I feel I am lucky that I have a GP that believes the condition exists because I know from my experience that people are dealing with GPs that say it doesn't exist so, from that perspective, I am lucky but all she can do for me is give me medication to deal with symptoms, there is nothing that can actually make me feel better. I am currently on sleeping tablets, anti-depressants, beta blockers, thyroid medication, vitamin D and calcium tablets. I was also given amitriptyline and Lyrica, which is specific medication for fibromyalgia patients, but after doing some research I came off them as it seems to make people worse. Now I just manage with ibuprofen, paracetamol and migraine tablets and, to be honest, they don't really work. Sometimes I feel the pain is so great that the medication doesn't really ease it. Nothing really makes you feel better because you have the side effects from the medication as well. I have not been offered any other treatment and the only review of medication I get is for the thyroid medication every six months, no other medication is really reviewed.

I had been working two part time jobs but I had to give up one. I work in a family business every afternoon when I am well enough which is easier than working two full days, which I had been doing in my other job. The business is at my house and that is the only reason I can work. If I wasn't working at home I wouldn't be able to work as no other employer would put up with the days that I am not able to go into work so I haven't applied for benefits yet.

I have found other health professionals have absolutely no understanding of or acknowledgement of the condition. When I was in hospital they asked if I had any other conditions, when I said fibromyalgia I might as well have said toothache as they didn't understand or didn't know what fibromyalgia was. There is a need for a greater understanding

of fibromyalgia amongst health professionals and there also needs to be specialist services or someone who specialises in the area which people could be referred to, for example, a consultant in charge of fibromyalgia.

Living with fibromyalgia I find my life is really limited. When you wake up each morning, you wake up absolutely exhausted like you haven't had a proper night's sleep. You can't organise anything as you don't know if you are going to be well enough to go and if you do feel well enough you know that over the next few days you will be really really tired and sore all over or spend the next few days in bed. It is very very limiting on your quality of life.

You find you lose a lot of friends because you let people down as you are not well enough to go to something or you just can't keep up with them. It's tough on family too because if you have a really bad day, they are the ones who have to go and make your dinner and look after you. If a family member has something on, they are never sure if I will be well enough to go with them. They have to be very, very understanding and, thankfully, mine are, but it has a big impact on their life too.

I can't do housework anymore; I can't Hoover, wash floors or do any heavy work. On a good day I could maybe do some light work and cook but on a bad day I would be in bed.

“ Even if I do the hoovering on a good day I could be in bed for a week afterwards and it isn't worth it so someone else has to do that for me. ”

Thinking about my condition, I feel like part of my life is over, unless something miraculous happens and a cure is found then my life is just going to go down; and most people don't understand this illness so it does make you despair. The problem with fibromyalgia is that you look ok physically and I only go out when I'm feeling a little better and have my makeup on. The reason this illness is called the invisible

illness is because when you are not well you can't go out so no-one sees that. I think that most people just think you are lazy and are faking it. Also, there is so much misdiagnosis because there is no proper test and it is so frustrating because you feel like, not only do you have to fight the illness, but you have to fight to be believed that you have an illness as well.

“ Not only do you have to fight the illness, you have to fight to be believed that you have an illness. ”

I am involved in a support group and that's the only thing that keeps me sane. There is nowhere else for people to go and everyone supports each other. The group are also on Facebook and we can chat to each other and keep each other going.

Olive's story

“ I fell and hurt my back while out walking in 2009, I was off work for many months and the pain continued long after the doctors felt it should. It wasn't until three years later that I was diagnosed with fibromyalgia. ”

(Female, 45-54 years old)

Over the years I've had episodes in hospital with pain and medical investigations carried out. At one point I was told I would have to have my kidney removed but when they did further tests, they couldn't find anything wrong. I had really bad gynaecology problems for many years and had a hysterectomy just before my 40th birthday, I didn't realise until after I was diagnosed with fibromyalgia that this can be one of the symptoms.

After I fell and hurt my back, I was sent for physiotherapy and I went myself to the chiropractor and to someone who dealt with pain management but, while some things helped for a little while, nothing permanently helped.

It wasn't until 2012, after three years of being told there was nothing wrong with me, I went to a new GP within my practice. She looked at my file and asked me a few questions and said "I think you've got fibromyalgia." She referred me to a rheumatologist but I was told I would have to wait a year. I had a private health policy with work so I went private and was seen in April 2012 and he confirmed the diagnosis of fibromyalgia. Later, when I had my appointment with the rheumatologist on the NHS, he also confirmed the diagnosis. In both instances when I saw the rheumatologist (NHS and private), I was with them for five minutes, there were no blood tests taken, no x-rays, nothing, it was a case of being poked in a few certain spots and told I had the trigger points and had fibromyalgia. I had one appointment with the rheumatologist on the NHS and one private appointment and then I was discharged.

Both rheumatologists wrote to my GP and recommended lyrica (used in the treatment of fibromyalgia) and various other pain medication.

“ I was with the rheumatologist for five minutes, it was a case of being poked in a few certain spots and told I had the trigger points and had fibromyalgia. ”

The GP prescribes my medication but these are not reviewed on a regular basis. If it is reviewed it's because my condition has changed, possibly due to a flare up, and I go to see the GP because I need something else to help with the pain. It is very difficult to establish a good pain management regime. Generally I find the medication helps in that I am not in agony but I'm not living a normal life with it. I'm not working, I've no social life and I spend a lot of time in bed. I can't do a lot of things that my family would want to do.

As part of my medication I have also been given a morphine patch, it never takes the pain away but it helps, it numbs it a little. I've been to the NHS pain management clinic where I was given facet joint injections, which seem to help for a while, but my last injection didn't last very long. I was told there was nothing they could do for me and was discharged back to the care of my GP. While at the Pain Management Clinic I was however offered a pain management course and I've received a couple of letters asking was I still interested and I replied to say I was, but this was over a year ago and I haven't heard any more about it.

I asked the consultant at the pain management clinic if I could get a lidocaine infusion as I'd read on some of the fibromyalgia forums that people in other parts of the UK are getting these, but I was told that the pain clinic I attended did not offer them for fibromyalgia. I found a pain consultant who offers lidocaine infusions privately and I had four to six weeks of very good pain relief from that.

I did try swimming to help keep my muscles supple but the water in the pool was too cold and it made my condition flare up. I also did an Expert Patient course with Arthritis Care in my local leisure centre and it taught me how to make the most of my appointments with the GP, as well as some relaxation exercises and learning to live with a chronic health problem. Through this course I also got to meet other people like me who had a chronic illness.

I had quite an active job before I hurt my back and, after a few periods of being on and off sick, I had to leave the job I had been in for over 20 years. Whilst I was still working I was able to get Disability Living Allowance (DLA). I had to look into this myself; no-one provided me with any information on how to go about getting benefits. I found a website which costs £20 a year for membership and they have good guides on there about filling in forms for benefits. I found this really useful as I had never claimed a benefit before and found the forms very tricky. When I left work I used this website again to help with my application for Employment and Support Allowance (ESA) and the online support groups I dip in and out of also helped with this.

“ I've all these questions but there is nobody to talk to, no-one is really knowledgeable enough to help. ”

There is not enough support in place to help people like me manage this condition. I get more help from a Facebook page of a fibromyalgia support group than I do from anywhere else. What would really help would be to have someone to talk to about it. I've all these questions but there is nobody to talk

to, no-one is really knowledgeable enough to help. My friend has multiple sclerosis (MS) and she can contact an NHS MS nurse if she has any queries or if she is worried about her medication or how things are going. There's no-one like that for people with fibromyalgia to go to. The only person I can go to is my GP and sometimes I feel like a hypochondriac and that I'm wasting their time. My GP has been very nice but there is another GP in the surgery who I would not go back to. I find them dismissive, as if they don't believe in me or my illness. If they had a nurse who was a specialist in fibromyalgia in the GP setting that would be more helpful.

The services available to fibromyalgia patients do not meet our needs and I don't know what other services are available. I have been offered pain medication but there is no-one to sit down with me and explain the basic symptoms and how the fatigue and other symptoms may affect me. Anything I have found out about fibromyalgia I have found out myself.

People don't understand what it's like to have fibromyalgia. They tend to think it's what the doctor diagnoses you with when they don't know what's wrong with you. Even within the family it's very difficult for people to understand as one day I can manage to help make dinner and then the next day I can't even get out of bed.

I had to leave work and I felt very guilty that I had wrecked the plans for the family. I was the key wage earner and now our whole financial setup has gone pear shaped. It puts a lot of pressure and strain on me; I had a lot of guilt and was very depressed not knowing how we were going to cope and how I would cope with the pain. One of our children found it particularly hard to cope with and understand. They would call me lazy and give me that sort of verbal abuse. It affects everyone in the family, not just me.

I had a lot of friends in work but we haven't really kept in touch. There is one girl who still keeps in contact with me and we would meet once a month for coffee. I have another friend who

has ME and once a fortnight I would call round to her house as she's not well enough to go out. You feel so isolated and you just feel people don't care, or they just don't know how to cope with you. Initially people would have invited me to come out with them to a Christmas dinner, for example, and then it gets to that date and I'm not well or I go but then have to leave straight after the meal as it takes too much out of me.

“ You feel so isolated and you just feel people don't care, or they just don't know how to cope with you. ”

There is also this mentality among some people that everybody who says they are disabled is a cheat and a fraud and are only out to fleece the government. Every time I put a form in, I'm stressing out, "will they believe me, will I get the money, what happens if I don't get it this time, will they believe me if the medical appointment happens to be on a good day?" I have all those extra stresses, people don't view an invisible illness as a disability.

I feel that having this condition I have to fight for everything. It's a fight to get diagnosed, a fight to make sure you are on the right medication, a fight to get to see somebody and having the fight to wait a year and a bit to get onto a pain management course which no-one has even told me what it's about.

I don't know if my story will help anybody but, hopefully, it will show that you can go from being a relatively normal person in society to living in your own wee world quite quickly.

“ I feel that having this condition I have to fight for everything. It's a fight to get diagnosed, a fight to make sure you are on the right medication, a fight to get to see somebody. ”

John's story

“ My fibromyalgia goes right back to my childhood. When I was younger I had no energy, had headaches and pains which were perceived as growing pains. I am now in my 50's and have only been diagnosed in the past ten years. ”

(Male, 45-54 years old)

I've always had symptoms of fibromyalgia but I was always told to shake myself and get myself to school or work, but my worst flare up came in 2005/ 06. This is what put me down and stopped me working. My father also had the condition since 1977 but only got diagnosed a few years before me and because we have the same doctor then that's how I got my diagnosis also. The actual diagnosis process was very quick. I went to the doctor in 2005/ 06, he examined me and said, "I think you have fibromyalgia" and I think my appointment with the consultant rheumatologist was six months later.

After my appointment with the consultant I was put on medication, went to pain clinics, and had psychiatric treatment. My main problem was going to the doctors and explaining how much pain I was in and that I needed stronger painkillers, I had to fight to get them. One doctor would give me painkillers that worked, then I'd go back to another doctor who wouldn't give me the same painkillers as they were too strong. I eventually left that surgery and went to another surgery where I was sent back through the whole process again - back to the consultant as there were a lot of things the first doctor hadn't done, for example, simple blood tests. I also received a diagnosis for myalgic encephalopathy (ME) last month. I knew I had fibromyalgia but I knew I had something more. I had to go private to get that diagnosis.

There is no treatment for fibromyalgia in Northern Ireland on the NHS. There is nowhere to be sent, it's not the doctor's fault, it's not the

specialist's fault, there's just nothing. There is a complete lack of services and a complete lack of education on it. I went to the doctor, a specialist and pain clinics, but was told there was nothing more they can do for me, so I tried alternatives such as hydrotherapy, acupuncture and acupressure. I found the hydrotherapy was brilliant when you are actually in the water but then I have to get out and get dried, get dressed and get back to the car and, by the time I get home, whatever benefit you had got is gone. I would like to be able to receive lidocaine infusions which seems to help a lot of people. Anyone I have spoken to that has received it said they felt great for the first few weeks before it wears off again, but when you are talking about somebody who had pain for 10 years plus, offering them a fortnight off is a God send. Some Trusts in England, Scotland and Wales provide the lidocaine infusions on the NHS yet, in Northern Ireland, we have to go private if we want them.

“ There is a complete lack of services and a complete lack of education on it. ”

I am in phone contact with my doctor about four times a year and have a yearly MOT where I would go and get my blood taken and whatever other checks need done. It is easier for me to go once a year than four or five times a year. I don't find my current medication very effective, but if I don't take my medication, then I basically just descend into hell.

I used to work in the construction industry and

they were going to train me up for different machines but I took ill with pneumonia and a collapsed lung and it took me a long time to recover from that. I wasn't able to go back to work after that and my partner and I had an awful lot of stress trying to get benefits. We had so many tribunals that, in the end, we went to the Ombudsman. There was nobody to help us, we did it all ourselves and that pushed me further and further down. In order to get benefits I had to convince them, one, that I had this illness and two, that it was a genuine illness. There are so many people out there who don't believe it.

I have no energy, right now I am living in a two bedroom flat on the first floor of a building which has a set of steps down to the ground. So I'm living in a flat which I can hardly get out of and I have rarely been out this past four - five years. I need help with my fight for suitable accommodation.

“ I had to convince them that I had this illness and that it was a genuine illness, there are so many people out there who don't believe it. ”

Our kids are grown up and away but the condition has had a huge impact on my life and on my partner's life. Every day I wake up with what feels like the worst hangover of my life even though I haven't touched alcohol. I have to take painkillers to get out of bed.

We've stopped going out and my partner doesn't like going out by herself and she is staying in more to care for me, so it's very difficult for her as well. I think it is harder for her; she has to watch me, help me and do things that she shouldn't be doing, she's my partner and she shouldn't have to do those things. I can't even share a bed with her, I can't cuddle her or she can't cuddle me. Everything we knew about life has gone. She always has had anxiety and depression but having to deal with me and this illness is making it worse for her. She has had to take over a lot of things that I did around the house. I have to rely on her for about 98% of

what has to be done around the house.

Socially, I have not been out in about seven years. We occasionally get out to my mum and dads, they just live across the park from us, but my energy levels go very quickly so, if I do get out it's usually an hour and an hour is pushing it. It's usually half an hour and if I get to an hour I'm going to regret it. I'll then have to spend a week in a darkened room to recover. Normally, by the time I am out of the flat, I am wrecked because I've had to walk down the steps from the flat – I've already used 75% of my energy just to get to the car.

The person that I once was is gone. I have gone through a grieving process, it's exactly the same as if you were grieving for a family that died but it is you that has died. I used to love swimming, canoeing, walking, going to the disco and playing darts but now I'm confined to the same four walls watching TV with the sound down and sub-titles on as I'm both light and sound sensitive. If I get one of my better days and think I can go to a shop, go for a walk then you know there will be payback and, if it doesn't happen immediately, it will be the next day and the day after.

Friends dropped away very, very quickly. Quicker than I thought. I can honestly say, this year alone I have had a friend knock on my door about three times. It is mainly family that comes to visit. I can't blame my friends for dropping away because most of them I have known through different things, whether it be swimming, cycling or canoeing. I can't do those things anymore so the thing I had in common with these people is no longer there.

“ Most of the frontline staff of all the different departments I have been to have all been absolutely brilliant. The problem is that a lot of them have no education of the illness so they don't know how to treat you. ”

I am involved with a community and voluntary group; although I can't get to the meetings the Facebook group is fantastic. It is a closed group which means we can talk together about our condition and everyone understands.

Most of the frontline staff of all the different departments I have been to e.g. rheumatology, neurology, occupational therapy and psychology have all been absolutely brilliant. The problem is that a lot of them have no education of the illness so they don't know how to treat you. When you go to people for help you presume they have training and then you find out they haven't had any. Some staff believe you but don't know what to do about it and then you have others who don't believe you.

There is a small percentage of the population, I would say 5 – 10%, that fully understand fibromyalgia. The reason they understand it is that they know someone that has it or they have it themselves. The other 90%, most of them look at you and think there's nothing wrong with you because you don't have a broken arm, or you aren't permanently in a wheelchair. It is an invisible illness, there are people that look at me and say, "you're looking great today." In response I say, "thank you very much, it's the drugs." If it wasn't the drugs I wouldn't be out in the first place for them to see me.

Laura's story

“ If I had not been going for orthopaedic referrals, if they hadn't been good and side-lined me into rheumatology, I would say that I could still be beating my head against the wall as my GP never mentioned fibromyalgia. ”

(Female, 45-54 years old)

I finally got my fibromyalgia diagnosis six years ago, but have been living with the condition a lot longer. My diagnosis was a long drawn out process; I had been going to the doctor with a pain in my back, then pains here, there and everywhere. I kept getting fobbed off, so I went and got an MRI scan done privately then went back to the doctor and told him there was a problem with my back. I had arthritis in my hand and at one of my orthopaedic appointments I had time to talk to the consultant and told him I was not sleeping and the different problems I had. He started poking me in different places and then told me that I had fibromyalgia. A couple of my friends had been telling me I had all the signs but I didn't believe them. Overall, it took about a year and a half to get my diagnosis.

I went back to the doctor and asked to be referred to the pain clinic but he said no, he could deal with it. He said I had chronic pain in my back but didn't mention fibromyalgia. I had another orthopaedic appointment and was talking to the consultant and he asked had I ever seen a rheumatologist. I told him my doctor wouldn't refer me to the pain clinic, so there was little point in asking for an appointment with rheumatology. Orthopaedics put it in their report and I ended up going to a rheumatologist who confirmed that I had fibromyalgia. It was good in a way as someone had confirmed I wasn't a mental case, but I was no further on as the advice I was given for fibromyalgia contradicts the advice I was given for my arthritis.

“ I went back to the doctor and asked to be referred to the pain clinic but he said, no, he could deal with it. ”

Eventually, I got an appointment at the pain clinic and it happened to fall on one of my bad days so they took me off the medication I was on and put me on stronger medication. They also asked would I be interested in attending a pain management programme that they run, so I have my name down to go to that as well.

I've gone back to my GP several times with aches and pains or just feeling really down and depressed and have just been fobbed off with "oh it's just your fibro." On one particular occasion I went to the GP and told him the pain was getting much worse. He talked about giving me injections but told me I would have to lose weight first, as there was no point in referring me for injections as they may not work due to my weight. This was the first time I had met this doctor and I was very upset. I did not need to go in there and be told "you're too fat, you need to lose weight", because I was already feeling rotten that day. I came away from the doctor feeling worse off. It's a vicious circle, I can't exercise because of my back and my knees and, because I can't get out, then I sit in and comfort eat.

I'm on a lot of medication for the pain/ nerves and also to help me sleep. It's difficult to say how effective my medication is because I don't know until I stop taking it. At the minute it appears to be working as I'm not having many flare ups so I would be reluctant to

change. Having fibromyalgia can also make you depressed so through my job I also see a psychologist. I find counselling really helps me, he understands or listens and I'm happy going and talking with him, I'm not in that dark place anymore. The doctor sometimes doesn't understand, if they see you and you look OK, they think "oh you look OK, you've got here OK, why do you need that medication?" The doctor also sent me for physiotherapy on my back and I'm getting exercises to do which is difficult but I go and, if it works, it works and if it doesn't, it doesn't. I have nothing to lose by going.

I would love to work part-time, but I don't know what I could do without being a burden on other employees. I retired early from work because of the pains and, because I'm retired, I have a pension, but as my pension is over a certain amount it means I can't claim any benefits. I worked for 29 years and I'm entitled to nothing. The only thing I could apply for would be DLA but there are so many horror stories from others who have tried to claim it that the thought of applying terrifies me. I think you have to get a GP to back you as well but whenever I go to my GP, I have to wait two weeks for an appointment, and if you want to see a specific doctor, you have to wait longer, so every time I go, it's someone different I see.

I get the impression with some GP's that fibromyalgia doesn't appear on their radar, it's like if you don't have a plaster cast on it, it doesn't exist. The GP will tell you, you need to exercise, but there's no plan or guidance for what to do. There needs to be a nurse specialist who deals with pain where people with fibromyalgia could go to and ask for professional help. There needs to be more awareness of the condition with health professionals and the public.

“ There needs to be more awareness of the condition with health professionals and the public. ”

I live on my own but I have animals, and I'm glad I do have them because some days, if it

wasn't for them, you know, I wouldn't make it out of bed. I don't really socialise, if you were to phone and ask me to go out next Friday night, I would have to say "No, I'll let you know nearer the time." I find I can't cope in a group of people with everyone talking and sometimes, even the noise in a shopping centre I find hard to deal with and have to go home. I tend to shrug the fibromyalgia off but it is hard trying to keep it tucked away. I have two friends that I would see, one of them is really good, but the other just doesn't understand.

“ If I find I have a good day...I try to do too much and I can do nothing for the next couple of days. ”

I find if I have a good day I try to do things around the house and then I try to do too much and I can do nothing for the next couple of days. I know I have to pace myself but when you feel OK I think to myself, well I have to do that today, because I might not feel good tomorrow. My mother is in her 80's, so with regards to family I don't have any support, it's really me on my own. I take the attitude that I'm OK, I can manage, but in some ways that goes against me as I would rather do without than go and ask for help. One of the things about having fibromyalgia is that it's like going through a grieving process because I've lost my life; I've lost the life I had, to be able to go out, to take the dog out, and just to be able to do normal things. It's like I'm grieving for all the things I can't do now.

Kelly's story

“

My fibromyalgia was triggered through pregnancy with my daughter. I was told at the time it was post-natal depression but I didn't feel depressed and I had pain in my joints. It has taken nearly four years to be diagnosed with fibromyalgia.

”

(Female, 25-34 years old)

I was fine until I got pregnant, but the pregnancy must have triggered something off. I've always had bouts of exhaustion and always recovered, but not after pregnancy, I've never recovered so that's just over four years now I've been living with this.

I was exhausted and had severe joint pain during my pregnancy; I was diagnosed with pelvic girdle pain and was sent for physiotherapy at the end of my pregnancy. It got really bad when I took what is called 'brain fog', which I had never heard of or experienced in my life. After the birth of my daughter I couldn't pick myself up again and reasonable things were a real chore so I went to the GP. As I was struggling with my memory I was sent to a neurologist and had a brain scan, which was fine, so the doctor then diagnosed me with postnatal depression. I told the doctor I didn't feel depressed, it was more that I wasn't able to do things I wanted to do, but he insisted it was postnatal depression and put me on medication.

“ ***I told the doctor I didn't feel depressed, it was more that I wasn't able to do things I wanted to do, but he insisted it was postnatal depression.*** ”

I moved house and, as a result, changed GP practices. I made an appointment with my new doctor and explained everything, telling her how exhausted I was, how much pain I was in and how numb I feel with it now and that it was making me anxious. Her response was to wear

an elastic band around my wrist and snap it when I felt anxious! Again, I was diagnosed as having post-natal depression and was offered a course of counselling and cognitive behavioural therapy (CBT).

I was still having the pain and spasms and struggling to keep going so I paid privately to see a chiropractor for my back. She was very good and asked about my family history and, when I told her about my father dying at 45 with rheumatoid arthritis in his internal organs, she asked had I ever been checked by a rheumatologist. I went back to the doctor again with that dread thinking that they would think of me as a hypochondriac. I explained about my dad and what the chiropractor had said and the doctor said "you don't need that." I insisted that, because my father died at 45 and I'm only 30, I would like to get checked. They checked me over and the results came back positive. The doctor then told me "this may not necessarily all be in your head after all, so we're going to change your medication and we suspect you may have arthritis." An urgent referral was made for me with the rheumatologist, but it still took six months. The rheumatologist did an x-ray and MRI scan and said there's no sign of arthritis but diagnosed me with fibromyalgia and Hypermobility Type 3. I asked for someone to explain to me what I had been diagnosed with but was told I would see the specialist in a few weeks and I was just left with a diagnosis. I was given no information and nobody could tell me anything about it.

“ I was given no information and nobody could tell me anything about it. ”

Recently I've taken the decision to detox and come off all my medication. I was on a lot of medication for pain, rheumatoid arthritis, inflammation, sleeping anxiety and depression. Now I'm taking nothing as I would like to have another child. The GP thinks I'm mad but I want my little girl to have a brother or sister. If I get pregnant again, I would go back on the medication after the baby was born. I got no support coming off the medication after three and a half years on it, I thought I couldn't live without it and I was told I couldn't live without it. I want to be as strong as possible so I came off the medication and the past four weeks have been horrendous, without the meds I feel more pain but you find a way to deal with it and block it out as I've accepted it is never going to go away. I miss the pain relief at night but I might try some herbal medicine for that. There is no one size fits all with medication and, especially with fibromyalgia, no-one really understands it and there's not enough known about it.

I've given up on the GP, I'm sick of running back and forth saying the same thing. They take the attitude, "you've got your diagnosis, deal with it, you're not dying. We've sicker patients to deal with than you." The one thing I do find helpful is the counselling which I was referred to when I was diagnosed with post-natal depression. The counsellor has ME so he understands and gives me lots of advice and coping mechanisms. I also pay for the chiropractor and acupuncture, it's expensive but it really does help me.

A lot more research needs to be done into the condition and awareness raised. Professionals need to be taught how to deal with the condition, GPs don't seem to have enough knowledge or awareness of fibromyalgia and the associated conditions. I am doing my own research, but nobody is here to help me, to tell me if it's OK to do things or try things. It's very difficult. There needs to be more services available on the NHS, for example chiropractor and acupuncture. People also need something to motivate them and work towards but there is

nothing. I wake up in pain, I go to bed in pain, it would be nice to see other methods to cope with it other than just being handed painkillers. Each case is different and each person's treatment plan should be specific to them and should be reviewed every six months to a year.

“ I wake up in pain, I go to bed in pain, it would be nice to see other methods to cope with it other than just being handed painkillers. ”

When the pain started I had just turned 30, I did hair and make-up and was always on the go. I'm not one of these people that lies about and is really lazy, I would really push myself. I tried to go back to work part time a year and a half after my daughter was born and kept pushing myself to keep going. I want to do things but I can't, it's not that I don't want to go to work, I can't. I'm getting there, but I think half the battle is focusing my mind to tell myself that it's never going to go away and it's something I have to live with for the rest of my life. I've now accepted that and pace myself on a daily basis.

I wasn't raised to live on benefits but I was advised by a fibromyalgia support group to apply for DLA, which I did, but I was turned down. I don't work because I can't work, I tried to work part-time but couldn't, so the only thing I can get is working tax credits.

No matter how awful I feel, I make sure I am still looking good on the outside. One way of coping for me, even when I'm really bad, is to get up, get dressed, put my make-up on and do my hair so I don't look like death warmed up. My life has been turned upside down; I'm not the person I used to be. I can't make plans as I don't know how I'm going to be feeling that day and you lose a lot of friends. I do my best to explain to people but they just don't understand what's wrong with you. I feel so isolated. Everything has been taken from me, my career, my family, my social life and my relationship with my partner, and nobody seems to care.

Paul's story

“ My work involved a lot of walking which caused me a lot of pain. I was sent for x-rays which showed wear and tear in my spine. I was then sent to physiotherapy and given medication which did not control the pain. Three years later the doctor diagnosed me with fibromyalgia. ”

(Male, 65 years old or over)

I had x-rays back in 1996 which showed wear and tear on my spine and I was sent for physiotherapy and given medication. The physiotherapy helped a bit but the medication never seemed to kill the pain. Three years later the doctor diagnosed me with fibromyalgia. After my diagnosis in 1999 I made a private appointment with a rheumatologist. I told him I wasn't sleeping well and was taking painkillers to go out and do a farm walk for work. He confirmed that I had fibromyalgia.

“ Not only was the medication upsetting my stomach, but it was making me extremely tired. ”

I didn't keep going to the doctor as I soon realised the tablets weren't doing me any good but I did go back to tell him the tablets weren't working and ask should I go off them as they were affecting my stomach. Instead of going off the medication the doctor gave me further medication that was to protect my stomach, but it didn't help either. Not only was the medication upsetting my stomach but it was making me extremely tired – in fact, worse than I would have been with the fibromyalgia.

At the moment I'm not getting any treatment or taking any medication, I take a few drops of St Johns Wort a few times a month, a vitamin C drink a couple of times a week and a banana every morning. I have a very good osteopath who I have been going to for nearly 20 years but I pay for this myself. I stopped attending the pain clinic a long time ago as the medication

wasn't agreeing with me and I didn't want to take it anymore. I attend the GP once or twice a year, I don't like giving people bother and I always think to myself there are people in worse situations than me. There doesn't seem to be enough information for doctors, and no doctor will have time to sit and listen to you.

When I got my diagnosis I continued to work as long as I could but, in 2001, I gave up my job as I couldn't sit long enough to do my paperwork and I was afraid with all the pain that I'd make a mistake which would have repercussions on my health and other people as well. Since then I've had to fend the best I can. I got my pension and a lump sum from work as I had been there 38 years. If I didn't have my pension then I would have been in a serious situation.

I can't cope with sitting about doing nothing. I have learned to pace myself and whenever I find myself getting tired I tend to come in and rest for a while. Sitting too much would be counterproductive for me as I get extremely sore when I sit for long periods of time. I have to accept the situation I'm in and the possibility that I may never get better. I try to make the best of it and do some woodwork and work on cars, but I have to use specially adapted equipment. I also changed my lawnmower to one which makes it easier for me; otherwise I wouldn't be able to cut my own grass. My quality of sleep is very poor and I never get a full night's sleep. I am constantly exhausted and even having a conversation with someone can exhaust me.

I get the impression that there's not that much known about fibromyalgia. The good thing about my GP was that he realised medication wasn't going to solve the problem. The consultant rheumatologist did not prescribe medication but asked about my physical activity and he recommended I keep doing what I was already doing. A lot of people with fibromyalgia are keen to talk about medication but I don't believe it's all about medication, I try my best to fight it and diet is very important in doing that, if you don't have a good diet then your body can't function properly. I think having a massage to loosen the muscles helps, and having the proper seats at home to sit in to support me. Having a comfortable seat has made a big difference to me for wanting to sit and watch television. I find that my fibromyalgia gets worse between November and March because of the cold and damp weather.

“ I get the impression that there's not that much known about fibromyalgia. The good thing about my GP was that he realised medication wasn't going to solve the problem. ”

One of the big problems with fibromyalgia is that it's a mystery disease and people don't see there is anything wrong with you, they look at you and say "you are looking great, just the same as ten years ago." If I had a broken leg it would be a different story. The thing with fibromyalgia is that there is physical pain, but there is also mental pain and frustration that I'm not able to do what I used to do. You need to have a coping strategy, I walk a little every morning to get myself loosened up and I try to keep my brain occupied so I don't feel the pain as badly but it is much harder to concentrate with the pain. I have my good days and bad and if I can't do something one day then I will leave it until I'm having a better day. I have to keep going, I had an uncle who had bad rheumatism and when he got bad he sat in the armchair by the fire and it ended up he was fit to do virtually nothing and I often have that view of him when I'm getting it a bit difficult.

Karen's story

“

It all started last summer when we were on holiday in Cornwall. My daughter wouldn't go out, she didn't want to do anything, she just wanted to stay in bed. I thought she was depressed but it escalated and she just gave up, she's very into drama and was a film extra, but she gave up everything.

”

(Female, 35-44 years old)

My daughter (13 years old) has been having symptoms now for over a year and we have been back and forward to the doctor about ten or eleven times but every time we went they would say it was post viral fatigue and wouldn't elaborate on what it was. I asked a number of times if it was ME but was told by the doctors that "we don't like to label children." She was referred to a rheumatologist and they couldn't find anything wrong with her. They referred her to physiotherapy but they didn't do anything with her, we went every week and for 45 minutes and they just talked to her, asking her if it was all in her head.

I have fibromyalgia myself and she's exactly the same as me, same symptoms, depression, pain, fatigue. I took her privately to see another rheumatologist and he said "you're right, she has fibromyalgia." My daughter was bullied very badly in primary school and I think the fibromyalgia was brought on through that.

“ ***The doctor said it was all in her head and she was bringing it on herself as she was depressed.*** ”

Nobody would listen to me and when I kept bringing it up I was told I was being silly and to stop labelling my child. We saw all three doctors in our health centre and one of them said it was all in her head and she was depressed and was bringing it on herself through her depression. It made me angry as my daughter is the sort of

child that would rather know what was wrong with her so she can deal with it rather than being told it's all in her head. It was hard as she always had to leave class and go to the sick bay in school as she didn't feel well, and I was constantly getting phone calls and I think the teachers were getting fed up with her. It was very hard when she didn't have a diagnosis.

I was trying to get her help in school as she was finding it very difficult carrying her schoolbag as her school doesn't have lockers. I was ringing up the school asking for a locker for her or double books so she didn't have to carry as many and the school would say there's nothing wrong with her. Once she got the diagnosis I was able to get her on the Special Educational Needs (SEN) register and she has a locker now and they are being more helpful.

I hated that it took so long to get a diagnosis because she was so down. I think her teachers and classmates thought she was attention seeking and she did become quite depressed. I was very worried about her and worried about what was going on. My daughter said she was delighted to have an actual diagnosis and to know that she wasn't going crazy because everybody was telling her it was all in her head and she was starting to believe it.

She doesn't receive any treatment as she can't swallow tablets. The consultant who diagnosed her said if she was going to be put on medication it would be amitriptyline but

she's too young so, at the moment, we're using a TENS machine and ice. She hasn't been given the option to attend the pain clinic but I will be looking into that, which will probably be another lengthy process unless I go private again. I took her privately for physiotherapy but because it was stimulating her muscles, the next day she hurt even more.

I don't know that there is any support available on the NHS to help manage the condition. When she was diagnosed we weren't given a leaflet or anything, the consultant talked to her about it and said she needed to exercise but that was it. I got a copy of the letter that was sent to her school and it basically said she had fibromyalgia and it was very important for her to do exercise but it didn't specify what type of exercise. I think the consultant meant graded exercise, like pacing yourself, but that needs to be made clearer on the letter.

Our experience of the NHS has been absolutely horrendous and it has all been very vague. There is very little understanding about the condition. We've had to go private for everything, which is absolutely ridiculous. If we didn't have private health insurance we would still be hanging on wondering what was happening.

“ Our experience of the NHS has been absolutely horrendous... there is very little understanding about the condition. ”

Before last summer my daughter was very active, going to drama classes twice a week and would always have been out, but that has all stopped as she is too tired. She sees her friends but they would come over here, she's not very active at all now, she rests more. It's hard as I blamed myself at the start as I thought it was hereditary and my husband was upset. We have a nine year old son as well and they would play fight and he has a habit of poking or nipping her and we have to tell him not to do that as it really hurts her. I think he thought it was a load of nonsense and we had to try and explain to him and get him to understand. The condition affects her concentration and

her exam marks have gone down a lot and the teachers are telling her off, saying she could do better. We, as parents, are being told we need to push her and that she can't have too much time off school but, when you know what she's going through, it's very difficult. Her friends don't understand her condition and she feels that people think she is making it up or that she's attention seeking. They don't understand it and are not willing to listen, so they're going to continue to not understand it.

It's a hidden illness, you look perfectly fine and you know if you're standing with a smile on your face but you feel like absolute utter hell, nobody knows, nobody can see it as there is nothing there for them to physically see. Therefore, a lot of her friends think there is nothing wrong with her and she is attention seeking. It's very difficult.

“ It's a hidden illness, you look perfectly fine...nobody can see it as there is nothing there for them to physically see. ”

I would like to know where I can get leaflets / books / brochures as I can't get them anywhere and I would like to be able to give these to her teachers so they understand a bit more about the condition. I would like my daughter to be involved with other children who have fibromyalgia but there doesn't appear to be any groups for her age. It's such a lonely condition. It would be nice if she could get involved with others who were the same as her but there's nothing, absolutely nothing.

Jessica's story

“

When my symptoms started we were in the process of organising our wedding. I was struggling to stay in work and had to reduce my hours which meant reduced pay and financial struggles. My husband is also disabled and doesn't work so it put a lot of strain on our relationship and there was a lot of stress and arguing. We were arguing so much that we nearly didn't get married at all, but we did in 2007 and I was diagnosed with fibromyalgia in May 2008.

”

(Female)

It's been approximately ten years since the pain started and, back then, I was at the GP a few times and they did a lot of blood tests and checked my thyroid etc. to find out what was causing the fatigue and pain. Everything came back clear so I was sent to the hospital to see a rheumatologist. He bent me forwards, backwards, sideways, everywhere and poked at me and pressed on my back and knees and told me it was fibromyalgia. I had heard the word before but didn't know anything about it, I had it grouped with MS and thought that it was going to get really really bad and would, eventually, be fatal. The consultant reassured me that the worst day I have had will be the worst it will get, but it did get worse than that, it got a hell of a lot worse. They say it doesn't progress as such but it progresses to where your symptoms get more intense and sort of take over.

“ ***Every time I see a new doctor I have to explain everything and the appointment only lasts ten minutes.*** ”

My diagnosis took approximately two to three years, which is ridiculous. Although, from what I have heard, that is faster than some other people. To be honest, I didn't expect to get diagnosed quickly as I had been through the

same process previously and it took ten years before I was diagnosed with endometriosis. It's difficult as I am registered with one GP but every time I go I rarely see the same GP. In my GP practice there are about six or seven GPs and to get an appointment with my registered GP I would have to wait three or four weeks. Every time you see a new doctor, whether a GP or in hospital, I have to explain everything and a doctor's appointment only lasts ten minutes, it's no good.

At the beginning, I was working full-time and had to reduce my hours which was a big strain as I was trying to pay a mortgage and pay bills. It's even more stressful when you don't know why you are tired and in pain. I had dizzy spells, memory loss and hadn't a clue what was going on. I started to withdraw a bit from society, I stopped going out, so I was literally going to work and coming home and going to bed. That was my life then and has basically been my life since.

When I was first diagnosed I was given Lyrica (a drug for fibromyalgia), but now I am also on painkillers, beta-blockers, tablets for IBS, anti-depressants and tablets for the acid reflux in my stomach, which is caused by all the other tablets I take. I have also had hydrotherapy, which was

quite good, but it completely exhausts me for the day - the effort that it takes to get up and dressed, get down there, then get undressed and into the pool for physiotherapy. Afterwards, I have to get dried and dressed and home, I do get very tired and even the day afterwards I'm still tired but after that it does help, it eases the pain. I received this once a week for 8-10 weeks, but then that was it. You have to get re-referred back into the system and wait for the appointments. I once tried reflexology but I was really ill for a week afterwards with it. I also tried laughter yoga, which is all about breathing exercises. I enjoyed it as my mood was better and it seemed to help the pain. I wasn't as bad for four or five days, or even up to a week.

I have just been referred to a pain clinic and had an appointment with the pain nurse and he just went through a list of symptoms and told me about different options and things. I was given a mini tens machine to try, it does help to a certain extent but I know other people have tried it and said it doesn't help them.

After a number of years, I was referred back to the rheumatologist as I was having more pain during the day than I had been but when I went to see him, he wanted to reduce my medication from 400mg of tramadol a day to 100mg. Afterwards, the pain got much worse and I went back to the GP and he increased them and referred me for a pain management course but there is a year's waiting list. That was last September and I still haven't heard anything, so my manager in work referred me to occupational health, which is how I ended up going to the pain clinic. I struggled on with the reduced medication and tried to stay on in work but I had a full flare up in May this year and have been off work since. My medication has been upped to 300mg a day, but I spend most of my time in bed. If I do go out for a couple of hours to see my friends or mum then I am in bed for a couple of days after as those few hours completely exhaust me.

Before this lapse I had been doing well and was back at work full-time, although I was redeployed to a desk job as I wasn't able to do

my original job. I enjoy my job and would like to get back to work again.

“ My GP referred me on a pain management course a year past in September and I still haven't heard anything. ”

I find the Facebook forums are very good, as I get information from them and they invite people to come and speak, for example, pain nurses. However, some people attending the group can be unsupportive. At one group, I said about working full time and someone behind me said, "well you can't have a proper diagnosis of fibromyalgia because anyone with a proper diagnosis of fibro can't work". I do work and I do have a diagnosis of fibromyalgia, however, I am very fortunate as occupational health in work have been very good. It was through them I was referred to the pain clinic and also the hydrotherapy. They also have had physiotherapists out to my office to assess my workplace.

“ My own GP is very good but not all the GPs in the practice are great, some of them take the attitude that all I need to do is exercise and are not very supportive at all. ”

My experience with health and social care staff varies. My own GP is very good but not all the GPs in the practice are great, some of them take the attitude that all I need to do is exercise and are not very supportive at all. When I saw the consultant last year the nurse that was with him was quite surprised when I said I worked full time and said "how do you manage that?" but I said it was only because of the medication I was able to manage. The rheumatologist diagnosed me, wrote a letter for my GP and said "I don't need to see you again, you are back to the care of your GP". You don't see him again unless your GP refers you back. If you are referred back again then there is another lengthy waiting period.

Prior to having symptoms of fibromyalgia I was very active, we would have went to the gym, camping, fishing, dancing, cycling and walking the dogs etc. I was in a motorbike club and involved in animal rescue, but I had to give it all up. I was so physical; now I get up, deal with the pets and then back into bed.

“ I don't think people understand the condition unless they have it themselves or knew me before I had it. ”

I don't see a lot of my friends that I used to be in contact with. I withdrew myself from socialising and, because of that, I sort of got forgotten about. Eventually people stop asking you to go places as I would always say I have to see how I feel on the day and sometimes it's the afternoon before I can let them know. I can't commit to anything and I constantly feel like I'm letting people down. People stop asking as I keep declining or can't go. I don't think people understand the condition unless they have it themselves or knew me before I had it. I think a lot of my friends think that I'm making excuses.

I think my husband understands the pain, but I don't think he understands the fatigue side and he gets a little frustrated. He was diagnosed with muscle-wastage down one side and he also gets very tired as well so we have both sort of withdrawn from our social lives. We don't go out together anymore as it takes too much effort to get ready, never mind go out, so we just stay in. He sometimes goes out with friends or on his own to family things and I will stay at home.

Key issues and recommendations

Key issues

The stories in this report include a number of common themes and experiences. For many, their journey for help and support started at primary care. Understanding their condition and being diagnosed was important to them. GPs played a key role in this process, however a lack of understanding and awareness of the condition sometimes contributed to delays in diagnosis.

Specialist services for fibromyalgia are not available in Northern Ireland. Typically, help and support was provided by GPs, pain clinics and rheumatologists. Those who shared their stories had variable experiences in the services available to them and the support offered. The most positive experiences were reported by people who felt that those who provided help had a good understanding of their condition and their needs.

The importance of good information and advice was a consistent theme emerging from the experiences of the people that we talked to. This can not only help people to understand their condition, but provide the knowledge of how they can manage to live with it. However, often people reported that they needed to source information about fibromyalgia themselves, either online or through support groups. Support groups were also reported as being a useful source of advice on applying for benefits, such as Disability Living Allowance (DLA).

A wider lack of awareness among the public contributed to reported difficulties in living with fibromyalgia. For many, it was described as a 'hidden' or 'invisible' illness which the wider public do not recognise. For some, it was felt that the lack of awareness and recognition of the condition had wider daily consequences, such as difficulties in applying for entitled benefits and allowances.

Recommendations

Recommendations have been developed based on consistent themes emerging from this report and in guidance from service users on our steering group.

1. The recent scoping exercise by the Public Health Agency (PHA), which identified opportunities to provide more effective care for patients living with chronic pain, should be reviewed in light of the specific issues raised by people in this report. A needs assessment should be produced by Health and Social Care commissioners to understand how many people live with fibromyalgia and what services need to be developed for them. It should also identify a coordinated care pathway to support people living with the condition.
2. Health and Social Care in Northern Ireland should recognise the lack of awareness of fibromyalgia that exists across primary and secondary care. Education and training resources for Health and Social Care professionals should be developed, guided by people who live with the condition. These training resources should also be developed so that they can be used by other public services staff who would benefit from an increased understanding of the condition.

Appendix 1: Service provision for fibromyalgia in NI

Service Area	Service provision for fibromyalgia patients
Department of Health, Social Services and Public Safety	<ul style="list-style-type: none"> ▶ Patients initially present with symptoms to their GP. ▶ GPs will refer the patients on for appropriate investigations. ▶ Once diagnosed, support and information is available to GPs and patients from national organisations. ▶ The HSC Board works closely with these organisations to signpost patients to relevant advice and support. ▶ Due to the diverse nature of fibromyalgia symptoms, training in its recognition and management will occur in a number of different specialties including rheumatology, neurology, psychiatry, gastroenterology, endocrinology and GP.
Health and Social Care Board	<ul style="list-style-type: none"> ▶ The Board and PHA have established a chronic pain forum which is taking forward the recommendations from the PCC report "The Painful Truth".
Belfast HSC Trust	<ul style="list-style-type: none"> ▶ No response at time of publication.
Northern HSC Trust	<ul style="list-style-type: none"> ▶ There are no specific services for persons who have a diagnosis of fibromyalgia. ▶ A social work service is provided for those aged 18-65 who have a physical or sensory disability that has a substantial and long lasting effect on their ability to manage daily life. ▶ The team will assess the person's needs to see if they are eligible. The service provides access to services at home, day care opportunities, respite for the person and their carer, and help to identify options for long term care. They can also provide advice and counselling to help identify coping mechanisms, manage the effects of the disability and refer to other professionals/ organisations that could offer support.
Southern HSC Trust	<ul style="list-style-type: none"> ▶ There are no specific services for fibromyalgia. ▶ Fibromyalgia patients are referred to the Physical Disability Team. ▶ There is no specific pathway but the normal Care Pathway would apply i.e. assessment, discussion with the individual and relevant carers about options and develop an agreed care plan which would be implemented in partnership with all stakeholders. ▶ There are currently no plans for specific service development for this group.

Service Area**Service provision for fibromyalgia patients**

South Eastern HSC Trust

- ▶ There are currently no specific services for fibromyalgia.
- ▶ GPs refer patients they suspect may have this condition to a range of hospital specialties including rheumatology, neurology and the pain clinic.
- ▶ Consultants help patients manage their symptoms through the use of medication or through referrals to psychology for cognitive behavioural therapy or physiotherapy for exercise classes. They may also refer to the Pain Service if required.
- ▶ Current waiting times for initial GP referrals for routine appointments are 40+ weeks depending, on the specialty.

Western HSC Trust

- ▶ No dedicated fibromyalgia clinics or a dedicated Consultant with a special interest in fibromyalgia, or a Specialist Nurse
- ▶ Patients are referred to rheumatology consultants.
- ▶ The services provided are limited to a diagnostic service, and patients would be referred on, as appropriate, to a Pain Clinic or physiotherapy.
- ▶ Unaware if commissioners are planning to develop fibromyalgia services.

Appendix 2: Glossary of clinical terminology

Acupressure: Acupressure uses the fingers to gradually press key healing points, which releases tension, increases circulation, reduces pain, and develops spirituality and vibrant health.³⁵

Acupuncture: Acupuncture is a treatment in which fine needles are inserted at certain sites in the body for therapeutic or preventative purposes. It is often seen as a form of complementary or alternative medicine (CAM), although it is used in many NHS general practices, as well as the majority of pain clinics and hospices in the UK.³⁶

Amitriptyline: Amitriptyline is a tricyclic antidepressant. It affects chemicals in the brain that may become unbalanced. Amitriptyline is used to treat symptoms of depression. It can also be used for other purposes and is not specifically for depression.³⁷

Chiropractor: Chiropractors use their hands to treat disorders of the bones, muscles and joints. Chiropractors use a range of techniques, with an emphasis on manipulation of the spine. They may also offer advice on diet, exercise and lifestyle, and rehabilitation programmes that involve exercises to do in your own time.³⁸

Cognitive behavioural therapy (CBT): Cognitive behavioural therapy (CBT) is a talking therapy that can help manage problems by changing the way people think and behave. It is most commonly used to treat anxiety and depression, but can be useful for other mental and physical health problems.³⁹

Hypermobility type: Generalised joint hypermobility that affects large (elbows, knees) and small (fingers, toes) joints is evident in the Hypermobility Type. Recurring joint dislocations are common occurrences. Certain joints, such as the shoulder, patella and temporomandibular joint dislocate frequently. The skin is also more liable to bruising.⁴⁰

Hypothyroidism: An underactive thyroid gland (hypothyroidism) is where your thyroid gland doesn't produce enough hormones. Common signs of an underactive thyroid are tiredness, weight gain and feeling depressed. An underactive thyroid can often be successfully treated by taking daily hormone tablets to replace the hormones your thyroid isn't making.⁴¹

Hydrotherapy: Hydrotherapy is the use of water in the treatment of different conditions, including arthritis and related rheumatic complaints. Hydrotherapy differs from swimming because it involves special exercises that you do in a warm water pool (33-36 °C) with the assistance of a physiotherapist.⁴²

Laughter yoga: A combination of deep yogic breathing and playful laughter exercises. It is usually practiced in groups where you can make eye contact and connect with your sense of childlike fun.⁴³

Lidocaine infusion: Lidocaine is a common anaesthetic (painkiller). The medicine is delivered by intravenous (IV) infusion. It works by blocking pain receptors in the brain and spinal cord. This may help decrease chronic pain, especially for patients with neuropathic pain.⁴⁴

Lyrica: Lyrica (pregabalin) is an anti-epileptic drug, also called an anticonvulsant. It works by slowing down impulses in the brain that cause seizures. Lyrica also affects chemicals in the brain that send

pain signals across the nervous system. Lyrica is used to control seizures and to treat fibromyalgia. It is also used to treat pain caused by nerve damage in people with diabetes (diabetic neuropathy), herpes zoster (post-herpetic neuralgia, or neuropathic pain associated with spinal cord injury).⁴⁵

Neurologist: A neurologist is a doctor who specialises in treating diseases of the nervous system including the spinal cord and the brain.⁴⁶

Osteopathy: Osteopathy is a way of detecting, treating and preventing health problems by moving, stretching and massaging a person's muscles and joints.⁴⁷

Propranolol: Propranolol is used to treat tremors, angina (chest pain), hypertension (high blood pressure), heart rhythm disorders, and other heart or circulatory conditions. It is also used to treat or prevent heart attack, and to reduce the severity and frequency of migraine headaches.⁴⁸

Rheumatologist: A rheumatologist has received further training in the diagnosis (detection) and treatment of musculoskeletal disease and systemic autoimmune conditions commonly referred to as rheumatic diseases. These diseases can affect the joints, muscles and bones causing pain, swelling, stiffness and deformity.⁴⁹

TENS: Transcutaneous electrical nerve stimulation (TENS) is a method of pain relief involving the use of a mild electrical current. A TENS machine is a small, battery-operated device that has leads connected to sticky pads called electrodes. These pads are attached directly to your skin. When the machine is switched on, small electrical impulses are delivered to the affected area of your body, which you feel as a tingling sensation. The electrical impulses can reduce the pain signals going to the spinal cord and brain, which may help relieve pain and relax muscles.⁵⁰

Tramadol: Tramadol is a narcotic-like pain reliever. Tramadol is used to treat moderate to severe pain.⁵¹

Venlafaxine: Venlafaxine is an antidepressant which affects chemicals in the brain that may be unbalanced in people with depression. It is used to treat major depressive disorder, anxiety, and panic disorder.⁵²

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