

## Learning outcomes

By the end of Module 4 the learner should be able to:

- Know the commonly used diagnostic criteria for fibromyalgia (FM)
- Describe the clinical presentation of fibromyalgia and its differential diagnosis
- Understand the initial management of FM
- Have an overview of a psychological model based pain management programme (PMP)
- Appreciate the importance of the multi-disciplinary team in the management of FM
- Summarise the recommendations on the use of drugs commonly used in persistent pain in pregnancy

## Trainer information

Module 4 uses a fictional fibromyalgia pain management programme, attended by five participants and lead by a specialist pain psychologist and physiotherapist, to introduce some important concepts to the learner. The module allows interactive progression of the case with several alternative outcomes. The alternative narratives provide equivalent learning opportunities to the learner.

## Case study

The background is introduced including a summary of current evidence on the diagnosis and management of FM.

The learner spends the module participating in the first day of a eight day, weekly, PMP. They are signposted to the Arthritis UK FM patient information booklet. A timetable for the day showing key element of a psychologically based PMP is included and further information on each component is offered including:

- An example of an acceptance commitment therapy formulation
- The concept of windup in persistent pain
- Mindfulness
- Sleep hygiene
- Creative hopelessness
- Pacing

The learner is given an audio recording of the PMP group introducing themselves and describing their experiences of FM. The learner is then prompted to discuss the key points with their Faculty Tutor (Pain) or Clinical Supervisor if possible.

The group continues with a physiotherapist lead mindfulness group and a second audio recording of a psychologist lead session on creative hopelessness. At this point the subject of the use of pharmacotherapy in persistent pain and pregnancy is introduced and a summary of the RCOG guidance and surrounding evidence is offered.

## **Trainer information - discussion**

Discussion of the case should develop naturally according to the individual's learning needs in a similar fashion to a CbD in a clinical setting. The learner should be encouraged to develop their own professional judgment according to required curriculum competence areas. The learner should be aware of these as they are stated at the start and on completion of each Module.

Other points for discussion could include:

- The clinical diagnostic criteria for FM
- The differential diagnosis of FM and targeted investigation
- The initial management of FM
- The role of the multi-disciplinary team in the management of FM
- Components of a psychological model based PMP
- Management of persistent pain pharmacotherapy during pregnancy

## **Appendix 1: Module 4 transcript 1 - PMP group introductions**

**Paul (psychologist):** *Good morning everyone and welcome to the first day of the fibromyalgia pain management program. I'm Paul the clinical psychologist, I've got lots of experience in helping people manage fibro and you are going to be seeing a lot of me over the next eight weeks. What I'd like is if everyone in the room could introduce themselves and if you're comfortable just tell us a little bit about how your fibro affects you and what has brought you to the PMP today?*

**Helen (participant):** *I'm Helen, I was diagnosed with fibro seven years ago but to be honest I've probably had it since I was a teenager. I remember always having aching legs and my parents putting it down to growing pains. As I got older I'd be so tired when I got in from work that I'd hardly be able to keep my eyes open. My GP said it was post viral fatigue but when it didn't go away, said it might be chronic fatigue. I had a whole lot of tests and saw a rheumatologist who told me I had fibro and that I just had to learn to live with it. I feel once you've been labelled people assume you're either making it up or are on the scrap heap. I've got so much to do that I can't just live with it. I've got three kids, my husband works away, I have to do everything. Most of the time it really is all down to me. That's why I'm here, I'm sick of a life where I feel like I'm carrying a backpack of rocks, up a mountain, in the fog.*

**Sandra (participant):** *Hi I'm Sandra, and I can really identify with some of what Helen is saying. I'm a carer for my dad and actually, I need to be well to look after him, but it feels like all the time I'm getting more and more ground down with the constant pain. Even my skin hurts sometimes and really gets me down that I'm failing in life because of having to cope with all this stuff. It took eight years*

*of constant back and forth to the doctors to get a diagnosis. And it's not just fibro, I suffer from migraines, dry eyes, endo, I have OA and IBS. I want to be seen as a whole person, who gets joined up care, not all these disjointed problems. I spend so much of my life sort of self-checking for how I am and whether something else has gone wrong, it's exhausting, and I really want things to better.*

**Elin (participant):** *Hello, I'm Elin, I've had a similar experience to the others. I've had the constant stress of not having a diagnosis and being told it might be this thing or that thing. It was such a relief to have a name for all the things I was suffering. And all the time I'm trying to live with a yo-yo of symptoms, I have a good couple of weeks and then I'm on my knees. Because I look fine people assume that it's nothing or that I'm exaggerating when I say I'm in so much pain. I have what feels like toothache but in every part of my body and on top of that there are trigger points in my neck and shoulders that send pain down my arms and back, that's awful, but my worst things is the fibro fog, it's so frustrating, I can't leave the house without forgetting something. I can't concentrate, I have to write everything down and sometimes making the simplest decision is too hard. It caused me big problems at work and that's why I left. I want to be able to enjoy my retirement and that's why I'm here.*

**Rhiannon (participant):** *I'm Rhiannon. My fibro is mostly pain, that, and bone crushing tiredness. It started after I gave birth five years ago. I put it down to just being normal, I'd just gone through a hellish labour and are hardly sleeping because of a new-born. But then six months in and I still wasn't better and I knew something wasn't right. The pain can be awful, my fingers, hands, back, neck, shoulders, legs, even my jaw feels bruised all over. I'm like Megan, my sleep is*

*terrible. I get restless legs and that's miserable at night when I can't sleep. I have sciatica too and when that's bad I know I'm in for a rough time. My GP doesn't take me seriously, they won't give me stronger painkillers when I need them because they say they don't work for fibro. But I've got little kids and need them to be able to function. It's so frustrating when people don't understand. I've had injections in my back before which helped and I'm here because I want to try them again, and they said I had to try this first.*

**Megan (participant):** *Hi, I'm Megan. Like everyone else I was back and forth to the doctors and the hospital for countless tests and scans. Dealing with that process and living with that uncertainty for years was exhausting even before you factor in the fibro. For me, the insomnia and tiredness is horrendous. Ironically, when I'm having a flair though, I can sleep 15 hours and still wake-up tired. It's so limiting to constantly compromise on what I can do because the energy just drains out of me. It started with pain across my back and shoulders, now I'm always in pain and that's miserable. I turn to food for comfort and I don't have the energy to exercise because of my fibro. I've also had problems with my thyroid and so I've pilled on the weight in the last few years. I hate it because people always put my pain down to my weight and it's like they're blaming me for causing this myself. I have a busy job and a long commute into work, and I feel like I'm just going through the motions in my life the whole time.*

**Paul:** *Thanks everyone. I'm sure everyone can see there are some common themes that you are all talking about and it's really helpful to bring them up at this stage so we know what's important to you and what you want to get out of the course. This PMP is to support you in finding new ways of coping with the*

*things you are identifying as problems. Right, now the next session is with our physio Graham on mindfulness.*

## Module 4 transcript 2 - Creative hopelessness group

**Paul (psychologist):** *Is everyone ready to start again? Yes? Great. So now we are going to have a bit of a think about what you do now to try and get on top of your condition and how that's working for you. We briefly touched on it earlier, so can anyone expand on that and describe some of the thoughts, emotions and sensations that come with having fibro?*

**Rhiannon:** *for me, the obvious one is physical pain? And being sick to death of being like this which honestly makes me feel quite hopeless.*

**Paul:** *Thanks Rhiannon, so you're talking about being in pain and how hopeless that makes you feel?*

**Rhiannon:** *Yes exactly, and sad, sad that it's like this now.*

**Paul:** *What about you Sandra?*

**Sandra:** *I feel anxious half the time waiting for the next problem I have to deal with. If it's not me it's dad or one of the kids.*

**Paul:** *So you're on high alert because you're worried what's going to happen and that makes you anxious?*

**Sandra:** *Yes, and that I'm not going to be up to coping with the next thing, that it will be too hard, I guess I feel sort of inadequate. I live in a constant state of*

*fear that everything is going to fall apart. It means everything in my life has narrowed down and I've forgotten who I am.*

**Elin:** *I complexly get that Sandra. After I took early retirement, I lost part of my identity and that made me feel like a failure, that I just wasn't good enough anymore to keep everything going.*

**Paul:** *So what you're both describing is some loss of self because of your condition, and the restrictions it causes?*

**Megan:** *So much of fibro is like that though, it's like my weight gain, I can't help it, but I feel sort of guilty and ashamed about it and I hate it went people judge me, they think I'm fat and lazy but I'm fighting the whole time to keep going, they don't have a clue.*

**Paul:** *That must be really frustrating Megan. How does it make you feel when you think people are judging you?*

**Megan:** *Well...I guess...I feel angry I suppose. That they are judging me when they have no idea.*

**Helen:** *I feel angry sometimes about how unfair it is that I have to deal with this. I feel angry with myself that I'm not being a good enough mum, that I'm not doing well enough at work, that I haven't got the same perfect life that my friends do. Then I feel guilty for the kids and my husband because they have to live with the rubbish version of me.*

**Paul:** And what do you do to try and manage those feelings Helen?

**Helen:** Well I guess I push myself even though I know I'll pay for it later, then it's like a vicious circle because I'm so exhausted that I can't do stuff with the kids or do well at work anyway and that makes me feel worse.

**Sandra:** I'm guilty of that too. I push myself but that has the knock-on effect that I haven't got any energy left to play with the kids or do other things I used to enjoy.

**Paul:** So you're sacrificing self-care to try and keep up with things?

**Sandra:** Yes, because if I don't do these things, I feel guilty and like a failure and that's worse.

**Paul:** You feel like there isn't an alternative?

**Sandra:** Well there isn't really, no one else is going to look after dad and the kids.

**Paul:** It sound like you all put a lot of energy into keeping up a front and carrying on like everything's fine?

**Rhiannon:** But that's the way it is, that's why I need the pain killers, I'm like Sandra, no one else is going to do this stuff, so I need them to keep going.

**Paul:** And do they work for you? Do they let you keep going the way you want?

**Rhiannon:** *That's not the point, it's all I've got and they're better than nothing. No one else has offered any real solutions.*

**Paul:** *Why do you think your GP doesn't want to give you stronger pain killers?*

**Rhiannon:** *Because he doesn't get it. He doesn't understand how much pain I'm in.*

**Paul:** *You feel misunderstood? Could there be another reason?*

**Rhiannon:** *He says they're dangerous, have side effects and don't work in the long term.*

**Paul:** *He says that? What do you think?*

**Rhiannon:** *I've got to the point where I don't care. I get that they have side effects, but I need them to function. I just want to feel like I'm doing something.*

**Paul:** *So you feel more in control?*

**Rhiannon:** *Yes! Just a tiny bit in control of this rubbish situation.*

**Paul:** *And do you think that's working? Do they give you control?*

**Rhiannon:** *Well no, obviously not, that's why I'm here, I need something else.*

**Sandra:** How are they dangerous? The drugs I mean? I thought they were safe. I'm on tramadol and amitriptyline. They wouldn't give them to you if they weren't safe. Surly?

**Paul:** I think it's dangerous in so far as all drugs come with the risk of side effects. And there's no point in having the risk of side effects if they aren't helping.

**Elin:** But I was reading in the paper the other day that there's a crisis in some countries because of these sorts of meds and loads of people have got addicted to them and can't get off them. They've been dishing them out for years and now realise there's a huge problem.

**Sandra:** [Rushes out and slams the door]