Condition Insight Report (CIR)

Fibromyalgia

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Completed in collaboration with
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Overview

What is the condition usually called / any abbreviations used?

Fibromyalgia or fibromyalgia syndrome (FMS)

Brief overview of the condition

Fibromyalgia is a long-term condition that causes pain all over the body. The exact cause of fibromyalgia is unknown, but it's thought to be related to abnormal levels of certain chemicals in the brain and changes in the way the central nervous system (the brain, spinal cord and nerves) processes pain messages carried around the body.

It's also suggested that some people are more likely to develop fibromyalgia because of genes inherited from their parents.

In many cases, the condition appears to be triggered by a physically or emotionally stressful event, such as:

- an injury or infection
- giving birth
- having an operation
- the breakdown of a relationship
- the death of a loved one

What is the generally preferred term for someone with this condition?

An individual living with fibromyalgia.

Presenting Symptoms

Can include, but not limited to:

- Pain: constant dull body pain that lasts for more than 3 months, increased sensitivity to pain
- Muscle stiffness upon waking or after staying in one position for too long
- Sleep problems
- Cognitive difficulty: it is usually referred to as ‘fibro fog’, difficulties in focusing or paying attention
- Fatigue: people with this condition often feel tired and weak, sleep for longer periods and wake up with pain
- Insomnia or waking up feeling just as tired as when you went to sleep
- Abdominal pain, bloating, nausea, and constipation alternating with diarrhoea (irritable bowel syndrome)
- Tension or migraine headaches
- Jaw and facial tenderness
- Sensitivity to one or more of the following: odours, noise, bright lights, medications, certain foods, and cold
- Feeling anxious or depressed
- Numbness or tingling in the face, arms, hands, legs, or feet
- Increase in urinary urgency or frequency (irritable bladder)
- Reduced tolerance for exercise and muscle pain after exercise

Fluctuations

Variability of their condition, are there any triggers such as hot/cold that makes things worse, do they have flare ups? If so how often and how long do they last for? Explore good days and bad days, what makes a good day and what makes a bad day. What can they do on a good day they would not be able to on a bad day, and what effect does that have on them?

Think about exploring things like:

- **How has the condition been over the past 12 months?**
  What changes have they seen, over what period of time did they experience any deterioration, what has this meant for their functional ability now compared to previous?
- **What level of pain/fatigue?**
  Can they quantify this, do they use a scale and can they describe it? Can they share what a ‘typical’ day might be for them? What are their triggers? Whilst exertion is a main trigger, what amount of exertion is enough to cause further limitation? How are triggers managed?
- **For any impaired cognitive function**
  How consistent is their presentation, how do they manage their memory deterioration, are they orientated, can they plan tasks as they used to?

Reliability

What specific areas should be covered to ensure a complete, reflective report?

SAFETY	TIMELY	ACCEPTABLE STANDARD	REPEATEDLY
Do they have any symptoms which could cause a safety consideration?	For any activities where restriction is reported how long does it take them to complete these activities? Has how long it takes them changed over time?	How have they adapted to completing tasks over time – is this different to what might be considered ‘normal’?	Are they able to repeat a task as often as required? Is this the same every day?
Safety considerations can result from physical and psychological symptoms. Cover how any risks are mitigated and if there is a history of incidents within activities 1, 2, 3, 4, 5, 9, 11 and 12 to ensure you have addressed the needs of the individual claimant.	People may have impaired cognitive function. They will experience difficulty with concentration, or in processing information, which will become more profound, as will their short-term memory. Tasks which require exertion physically and even mentally are likely to take longer, so it is critical this is fully explored.	Exploring <u>**HOW**</u> they complete the task in depth can help to draw out any compensation strategies which can then be explored further. Exploring the extent of symptoms during an activity will help your consideration of whether this is acceptable whilst completing activities and the impact on daily life.	Due to fluctuation of the condition for the claimant, sometimes hour to hour, it may prove difficult to ascertain the level of functionality of the claimant for more than 50% of the time, and what they are able to achieve reliably, therefore more expansive questions may be needed about ability/functionality, along with talking to the carer, to ascertain overall impact.

Sensitivities

What areas might they find difficult to mention or perhaps understate the impact of?

- The fatigue and pain of Fibromyalgia can affect memory and cognitive function (especially when under stress) therefore sufferers may need prompting about all aspects of their daily lives
- They may find it difficult to relay that whilst they can do some of their daily activities, it causes them pain/fatigue during & afterwards and/or they couldn't do it repeatedly
- The pain from Fibromyalgia can be excruciating & the fatigue profound at times, it's hard to get this across to an assessor when sufferers often look so well

Watch **Jo** talk about her experience of living with Fibromyalgia **HERE**.

Customer Care

How is it best to ask about any sensitive topics and what are the common courtesies?

In general

- Do not ask too many questions at once
- Give time for a response before asking another question
- Involve any companions
- Be clear you are going to assess how their condition impacts on their daily lives, not the condition itself
- Try and recognise, if possible, when the claimant is deteriorating and becoming more physically and cognitively distressed – ask if they want to stop, take a break etc.

During face to face interactions

- Signpost individuals to toilets and exits
- Support by holding open any heavy doors
- Confirm they can get up and move around should they need to
- Access to a comfortable chair where possible

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 1: Preparing food

Fibromyalgia sufferers may experience fatigue during or after an activity making it difficult to complete it as often as required. Also, consider that they may suffer from poor concentration impacting their ability to cook.

Remember in PIP…

They need to be able to complete this activity within the realms of STAR. Can they cook safely or have they had any incidents in the kitchen? How do they feel after cooking? How long does it take them/ and do they have to have regular breaks

Activity 2: Taking nutrition

Someone who has Fibromyalgia may find this task tiring or experience a loss of appetite secondary to their symptoms.

Remember in PIP…

You will need to establish if someone is able to reliably take nutrition. Can they eat without prompting throughout the duration of a meal? Have they choked before? Can they cut their food and bring it to their mouth?

Activity 3: Managing therapy and monitoring a health condition

Individuals may have physiotherapy, talking therapies, alternative therapies, and be prescribed analgesia, mostly for neuropathic pain but may struggle to remember to take it or complete the activities given to them.

Remember in PIP...

If they are having any therapy in the home, do they require assistance with it? If so, why is this and how long is it required for?
Ensure to explore how any medication is managed including if they remember to take it and can get it out of the packet.

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 4: Washing and bathing

Muscle pain may lead to difficulty washing and combing hair due to limitation in raising arms and washing their body. Episodes of tiredness can come on suddenly. Levels of tiredness can also be highly variable. Some may use aids or have reduced the number of times they bathe.

Remember in PIP…

Explore what management strategies are used to manage the effects of symptoms and consider whether aids would help or whether the action would still be unreliable due to one or more aspect of STAR. How long does this task take and how do they feel after?

Activity 5: Managing toileting needs and incontinence

Pain may make it difficult to sit and stand from the toilet and cause difficulties with cleaning after the toilet. They may also suffer from incontinence.

Remember in PIP…

If the claimant is incontinent, how frequent is it and how is it managed? Can this be managed with pads independently or do they need assistance to maintain hygiene? How do they transfer on/off the toilet and clean themselves?

Activity 6: Dressing and undressing

Muscle pain may lead to limitation in movement of upper and lower limbs. They may struggle to put a top over their head or bend to dress lower body.

Remember in PIP…

Ensure to probe how they overcome any restrictions with this activity. How long does it take them and how do they feel after? Do they need assistance? Can they dress their entire body?

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 7: Communicating Verbally

When communicating, some may find they become more cognitively fatigued and speech may slow or they may have difficulties absorbing information.

Remember in PIP...

That there are specific boundaries for what is considered basic and complex. How their emotions impact on their ability to manage relationships and respond to individuals is likely to be managed in A9. Ensure to explore for specifics where a restriction is reported to determine if simple and/or complex criteria is met.

Activity 8: Reading and understanding signs and symbols

Consider any impact of their cognitive changes on reading.

Remember in PIP…

Remember to explore examples of what they can read. Can they manage more than one sentence? Can they understand and absorb what they have read?

Activity 9: Engaging with others face to face

Many have associated mental health conditions and may find it difficult to engage socially and either avoid them or rely on others for support.

Remember in PIP…

Cover where specific restrictions are reported how they manage this. Detail of any support provided and whether this support can be provided by anyone or only specific individuals. Who can they engage with? How do they feel meeting new people?

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 10: Budgeting

Consider any impact of their cognitive changes and any associated mental health.

Remember in PIP…

Remember to explore how they manage budgeting. Do they manage their own finances? Do they remember to pay bills? Could they understand change in a shop?

Activity 11: Planning and following a journey

Consider any impact of their cognitive changes and many have associated mental health conditions.

Remember in PIP…

Where there are associated conditions you must explore the 4 stages to a journey 1. Frequency and type of outings 2. before a journey 3. during a journey and 4. post a journey.

Any social anxiety and/or anxiety related to change? If so to what extent, how and when does this manifest, how it is managed, is it present on all journeys or just unfamiliar ones? Are there any cognitive changes which could affect their ability to plan and follow a route? How would they plan a route to get to an appointment at a specific time? How would they manage any changes that occurred?

Activity 12: Moving around

Their condition may cause profound fatigue such that the individual reports inability to walk more than a few metres without having to stop due to pain and fatigue. The impact of doing any physical activity will mean that they will be unlikely to be able to repeat the task, and may be unable to do so for many days after.

Remember in PIP...

Explore the impact of pain and fatigue on their ability to reliably complete this activity. If they report they can walk a distance, is this timely? Could they repeat this distance at the same pace or do they slow? How do they feel after walking? Have they had any falls?

Additional reading or other resources

EXTERNAL

- www.fmauk.org
- For further information see NHS Conditions and Treatments: https://www.nhs.uk/conditions/fibromyalgia/

INTERNAL

- Desktop Aid – Fatigue, Activity 12, Activity 6
- CPD on Fibromyalgia and Chronic Fatigue Syndrome

Version control

Version	Date	Signed off by	Comments
1.0	07/10/2021	Dr Shah Faisal and *Fibromyalgia Action UK*	New re-banded document
1.1	Signed off 31/01/2022 Reviewed 15/03/2023	*Rebecca Simmons CGL- Stakeholder engagement*	Amendments made to functional impact and Remember in PIP sections