

**TABLE S3.** Additional Supporting Quotations From the Sessions

Theme/ subtheme	From the transcripts	From the field notes
(1) MS fatigue is not formally screened	<p><b>Focus group with physiotherapist 4, private:</b> “Having those engaged MS nurses and people that are knowledgeable on fatigue, it means that the patient journey is probably a lot smoother because they can get referred into a specialist service relatively early rather than grappling with fatigue for many years before anyone thinks to do something about it. It’s kind of potluck of who you see as a patient and what they know, I suppose, and who they might refer on to.”</p> <p><b>Interview with service manager 1, NHS:</b> “...and not just physical impairment and cognitive impairment and fatigue, but talking about sexual dysfunction and bladder problems and spasticity and pain and roles and relationships and tissue viability and end-of-life stuff. Can you do all of that? And we can just about probably ask all those things, but then can you do outcome measures for tissue viability and cognition and fatigue and walking and balance? No. So, you’ve kind of got to pick the priority area in those clinics to either focus on 1 thing but knowing that that review may be the only review that they get in a year, maybe 6 months if we’re lucky, so making sure that you’re reviewing everything and checking on everything proactively so that people can manage it, referring to the right place, giving self-management advice at that same time.”</p>	<p><b>In-clinic consultation with neurologist 1:</b> [Explaining the study preappointment] “The person living with MS said that his partner always says he has ‘borderline narcolepsy’ and that he can ‘go really quickly’ when he gets fatigue. He mentioned that sometimes he could be reading a bedtime story for his kids and then suddenly fall asleep and not realize. He mentioned getting the train home and starting to feel fatigued so he would stand up so as not to ‘miss a stop’.” [After neurology appointment] “MS fatigue was quite a big problem but not raised during the appointment with the neurologist.”</p> <p><b>Online consultation with nurse 4:</b> MS nurse: “Any background symptoms, pain, muscles spasms, bladder, fatigue?” Person with MS: Fatigue is the top one. “Is that down to the MS? Down to me getting older?”</p>
(2) Promoting self-management for MS fatigue	<p><b>Focus group with occupational therapist (OT) 3, NHS:</b> “I think it [fatigue] is just put down to the bottom of the pile because it’s seemed that nothing can be done to help you manage it. And often they always come into the clinic thinking ‘I need a pill, I need something.’ Whereas if we said, ‘Here’s a pill: It’s called rest; take it 4 times a day,’ they’d do it, but because it’s not fun, it’s not exciting, it’s exhausting trying to plan and pace your activity and prioritize things.”</p> <p><b>Focus group with OT 10, NHS:</b> “And I know when we’ve looked at the diaries and things and people themselves, encouraging rather than us again analyzing and telling them what we think, you know, a lot of the homework we’ll give them is like, ‘Do that and then have a look. Have you noticed anything about this? What are your thoughts?’ And actually, they come prepared, and it’s again about setting that expectation. Is that what we want? We’re not going to tell you the answers.”</p> <p><b>Interview with physiotherapist 2, MS therapy center:</b> “He and I sat down and we talked about his fatigue, and he just said, ‘I know, I know what I’ve got to do. I know what I’ve got to do, I just can’t do it,’” and trying to get him to make that shift from knowing what to do to actually doing it is, that for me is the tricky thing.”</p> <p><b>Interview with nurse 3, NHS:</b> “I think I was saying some of the challenges that you don’t always feel like you’ve got the tools to help them. So despite the fatigue management, I can send out a booklet, but that’s not going to be a magic wand that waves, that takes away their fatigue anyway, so that’s a challenge in itself, isn’t it? There’s nothing that’s going to totally cure it and, I suppose people need to have realistic expectations that what we’re doing is helping them manage their fatigue, not really taking it away, maybe improving it slightly, maybe making them feel they’re more in control of things.”</p>	<p><b>Online consultation with nurse 4:</b> MS nurse: “Can you have a good rest in the day/throughout the day? Do something that’s not overstimulating, having a cup of tea to take time out.” Person with MS: Can often go to the van or whatever. MS nurse: “Do you do that to manage or do you push yourself through?” Person with MS: <i>Nods.</i> MS nurse: “Do your colleagues know about your diagnosis?” Person with MS: <i>Nods.</i> MS nurse: “Might be worth explaining to your senior site manager... oh, is that you?” Person with MS: “Yes.” <i>Laughs.</i> MS nurse: “Telling yourself!” <i>Laughs.</i></p> <p><b>Home visit consultation with OT 17:</b> “The OT asked the person with MS if he ‘were to do the day again, what would you do differently?’ which allowed the person with MS to lead on what they thought could be reasonable adjustments. The person with MS said they could ‘get a taxi instead’ and they discussed spreading out high energy activities so they weren’t all in 1 day. For example, that day he had been to the shop and back, but he was also out in the evening so he was extra tired.”</p>

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<p>(2.1) Conserving, redistributing, or increasing energy</p>	<p><b>Interview with nurse 3, NHS:</b>          “I do say gentle exercise can reward you with energy. I tell them that they need to pace themselves and I think of them as having, like, a bucket of energy and they need to sort of divide it up throughout the day doing things that give them pleasure and not always just things that drain them from energy. So, for example, some people enjoy housework but if it’s something that just drains you, then you’re going to waste a lot of that bucket on energy that’s even more depleting, but if you go out for a gentle walk then it may be that it rewards you with more energy.”</p> <p><b>Focus group with Pilates instructor 1, MS therapy center:</b>          “To give an example, there is a member here who goes downstairs and gives a small group core class. This member is probably around or over an EDSS 6.5, so they don’t walk very well and they only walk with a rollator.... You would think that, to a degree, they’re tired, but actually, when they come in to see me only half an hour later, they actually move better. Now, that being said, I could think of numerous other examples where actually, you know, I had another member the other day who had done too much in their week, not necessarily exercise, but potentially exercise, and then they came in to see me and they just couldn’t do anything. So there is a conflict of knowing what is exercise, again, that’s going into that boom or bust cycle, or what is exercise that is actually helping you inch, what is that envelope that you can push before it becomes problematic, and what is the envelope that you can manage and start progressing in?”</p> <p><b>Interview with service manager 1, NHS:</b>          “I think there’s such a fine balance because often what we might find on an initial interview when we’re talking to someone about fatigue is that their main, neurological fatigue impairment is that they’re so sedentary and that they’re not engaging in any activity, and then I suppose there’s 2 arms, really. The opposite of that is someone who’s really busy and is constantly on the go and doesn’t rest, which then we would be talking about rest breaks. But for those patients who have more of a sedentary lifestyle and are less active, our focus would be on returning to activity and exercise. So we’d be talking about moderate to light resistance exercise to support with fatigue levels.”</p> <p><b>Interview with OT 9, NHS:</b>          “What we talk about is thinking about how we might reframe thoughts and how our automatic thoughts really influence our behaviors and influence our routines and our thought patterns, but we spend a lot of time thinking about how they can be quite deep-rooted into current routines, and then, therefore, how can we challenge them. And we would spend time, maybe using thought diaries to analyze what this might look like, thinking about the emotions that they feel, the evidence that’s for and against.”</p>	<p><b>Home visit consultation with OT 17:</b>          “He had been asked to fill out a fatigue diary between 5 AM and 10 PM every day for a week and HCP went through this to note down what was taking a low, medium, or high amount of energy. She noted, ‘What takes all your energy and what wipes you out?’ She explained about noticing patterns and said the reason was to help him try things differently, plan or organize his time better, prepare for a high-energy task or how to ‘recharge his batteries.’ It was clear going through this what was tiring for him and it seemed to be a really helpful way to demonstrate to him what areas could be adapted to help him with his fatigue. They had obviously discussed previously about his daily activities tiring him out as he mentioned that he had just hired a cleaner to help him keep on top of things.... When talking about adaptations to his routine, the HCP suggested he get dressed later in the day, as he seemed to be more tired if he got dressed very early or suggested he do some activities, such as a puzzle, that would ‘prompt him to rest’ in between other activities.”</p> <p><b>Online group fatigue management session with OTs 14 &amp; 15:</b>          “Negative thinking styles can be really easy to fall into, can’t manage what you used to manage before, can creep in.... Rest a bit before you’re getting frustrated, trying to learn your body, learn when you’re getting fatigue, before getting to that point of frustration that you can’t do something.... Reminder of their fatigue management toolbox—delegation, pacing, prioritization, grading, organization, sleep hygiene, energy conservation, relaxation, exercise, and diet.”</p>
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(2.2) Helping people with MS communicate about fatigue	<p><b>Focus group with physiotherapist 1, MS therapy center:</b>          “It’s giving people a language or some way of communicating how fatigue is relevant for them or how it impacts them. Sometimes it’s an analogy. One of the favorites that people tell me about is the phone charger, you know, if you plug it in before it runs out of battery completely, it’s quicker to charge. People generally really like that analogy and tend to use it quite a lot with friends and family.... I think it opens up conversations for people with their support networks about what people can do to help, whether that’s encouraging the rest breaks, or for other people, it might be about encouraging the activity.”</p>	<p><b>Online group fatigue management session with OTs 14 and 15:</b>          “‘You can’t sometimes see what’s going on on the inside with fatigue, not like a cast on your leg.’ Occupational therapists talked about people living with MS understanding more about their own fatigue so they can hopefully be more confident to talk about it.”</p>
	<p><b>Focus group with occupational therapist 4, NHS:</b>          “We always say to individuals, ‘Be aware of what triggers you,’ but actually, you might be displaying some symptoms prior to your sheer exhaustion, where you can identify where your battery is running down, and somebody outside can actually identify that to you. For instance, we had an individual patient who, when she was sheerly exhausted, had really bad headaches and migraines, her eyes became much worse, but she wasn’t aware, probably a while before that occurred, she actually started to adjust her glasses, so almost her brain was telling her, ‘You can’t see properly’ so she started to adjust her glasses, but actually her husband noticed that and actually said, ‘That is a preexisting symptom. If I tell her that, look, you know, you’re starting to adjust your glasses now, just take a break.’ So, actually allowing them to give permission to their carers to actually enable them to pace and prioritize as well.”</p>	<p><b>In-clinic consultation with neurologist 2:</b>          “The neurologist asked the person with MS about who supports her. It seems her partner lives 25 miles away and her 4 children are adults and don’t live at home. The person with MS mentioned that she had spoken to her children about supporting her more but they didn’t seem keen so she didn’t push it.”</p>
	<p><b>Focus group with OT 10, NHS:</b>          “A relative saying, ‘You’re just not doing enough; you’re lazy,’ it just feeds into that negative experience for that person, and they’re less likely to take on strategies because they’re just perceived to be lazy.”</p>	<p><b>Online consultation with nurse 4:</b>          MS nurse: “Is there anyone else that can walk the dog?”          Person with MS: Partner walks dog in the morning and evening, “unless I feel up to it.”          MS nurse: “Great, so you don’t feel the pressure, you’ve got that backup there.”</p>

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<p>(2.3) Making self-management meaningful</p>	<p><b>Focus group with physiotherapist 4, private:</b>          “When you get to know people better, you can often delve a bit deeper into, well, ‘You’ve got grandchildren, what do you like doing with them? Do you like to play with them?’ I suppose reframing it, so maybe not talking about it in a fatigue management way, but in a ‘What are we trying to achieve?’ What do we need to be able to get there? I suppose fatigue management as a concept to your average Joe doesn’t mean much, maybe.”</p> <p><b>Focus group with physiotherapist 2, MS therapy center:</b>          “No, I definitely agree with that, with the goal setting, because it’s like you say, we can improve the fatigue levels, but what does that actually mean? It means that you’ve got a different number on a bit of paper. It needs to actually relate to everyday life. ‘I want to improve this because it means I can take the kids to school 3 days out 5’ or whatever or I can do and actually then you’ve got something objective to measure.”</p> <p><b>Interview with service manager 1, NHS:</b>          “I think people are quite reluctant with exercise when they’re that tired, and it’s quite a hard sell. I guess as a physio, I’m quite used to having a hard sell on people doing exercises and activity, but I guess in the physio world, there was a big push a couple of years ago that actually telling people to do exercises isn’t particularly useful and, actually, if you frame it as activity and that different things can be done as exercise, things like maybe parking a few roads away from your kid’s school and walking to and from and those kinds of things and the housework and the gardening and it’s those things that aren’t, you know, running on a treadmill or doing weights or whatever in the gym. So it’s for people who aren’t naturally people who like exercising, framing it differently, but it is a hard sell with fatigue because when you’re that tired, they say ‘Oh, I haven’t got, I haven’t got the energy for anything else let alone exercise,’ but we talk about the research a little bit and we talk about, actually, ‘I know it sounds strange, but just trust us with this, give it a go and see how it goes and some do and some don’t, but some do.’”</p> <p><b>Focus group with occupational therapist 10, NHS:</b>          “It’s the Canadian Occupational Performance Measure.... So, for example, a lady who has MS was saying that she really wanted to be able to play with her grandchildren more, and that was something that was really important to her and she said that her level of satisfaction at the moment is only a 2, it was really bad, she wanted it to be much better, so we did a piece of work with her on fatigue and giving her ideas and grading her activities, etc, and then you repeat it at the end and she rescored and anything above an increase in 2 is deemed clinically significant.”</p>	<p><b>Home visit consultation with OT 17:</b>          “He said he would ‘walk a bit, rest a bit’ and that the rollator helped him with pacing, so he could just sit whenever and ‘watch the traffic,’ but it was also very tiring. The HCP asked if he ‘were to do the day again, what would you do differently?’ which allowed the [person with MS] to lead on what they thought could be reasonable adjustments. The [person with MS] said they could ‘get a taxi instead’ and they discussed spreading out high energy activities so they weren’t all in 1 day. For example, that day he had been to the shop and back, he was also out in the evening so was extra tired.”</p>
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<p>(3) MS fatigue cannot be treated in isolation</p>	<p><b>Focus group with OT 5, NHS:</b>                  “For quite a while, I’ve felt like a counselor. So, someone would be referred for fatigue, but actually, there’s a lot more going on than just the fatigue. It impacts on their relationships; there’s the whole adjustment process, a grieving process. So, yeah, a lot of what I was doing, particularly on a one-to-one is, was around counseling, and other members of the team as well, before we even got to the strategies, the pacing, the planning, and all, and all that kind of thing. It’s massive. Like you said, specialist input is rare, isn’t it? Even though it’s such a big part of...of living with MS.”</p>	<p><b>In-clinic consultation with OT 16 (patient 1):</b>                  “When discussing secondary fatigue, the OT said ‘medication might cause tiredness’ or infections. The therapist asked the person with MS about her sleep, ‘not very good’ but ‘a bit better recently.’ ‘Listens to the radio’ and has ‘bad sleep hygiene.’ She wakes up a couple of times a night to go to the loo, and the therapist picked up on this, ‘sleep is a really big one’ and asked if the neurologist had referred the person with MS about her bladder urgency and suggested this. The person with MS said that she ‘feels like I need to go now, which I don’t’ and this was discussed a little more.”</p> <p><b>In-clinic consultation with OT 16 (patient 2):</b>                  “When discussing medication, the person with MS gave a long list of medications, which caused the OT clear concern. These medications can cause drowsiness, and the therapist spoke about these side effects and suggested that the person with MS spoke with their MS nurse or neurologist about whether all the medications were needed. They discussed what times of the day these medicines were being taken, and they discussed a medication review.”</p>
<p>(3.1) MS health care professionals trickle-down fatigue management</p>	<p><b>Focus group with OT 1, NHS:</b>                  “I think it’s a little bit different in occupational therapy than it is probably with the nursing and elsewhere, so if that’s the goal that they [person with MS] want to work with, I can spend as much or as little time. If they’re willing, obviously, I give more time, isn’t it? I will make sure that I rebook them more often. There are limitations because the caseload is big and you have to be mindful of it, but you make it work.”</p> <p><b>Interview with physiotherapist 2, MS therapy center:</b>                  “I mean, I say if they have identified that [fatigue] in that as one of their key problems, then, you know, after my initial assessment, we would always have a discussion about, right, this is what.... These are your priorities, this is what we can help you with, where shall we start? So, it’s always a discussion.”</p> <p><b>Interview with service manager 1, NHS:</b>                  “And everyone’s area is a priority area, and fatigue is a huge area, don’t get me wrong, but the physios will think that balance and spasticity are, and, obviously, mental health services think that we ought to be doing that on everybody, and you can see the importance of everything. But how much can you actually do?”</p> <p><b>Interview with service manager 1, NHS:</b>                  “I think it’s all very different. So, some nurses will offer basic advice or more thorough advice. In some areas, the nurses have been doing the FACETS courses themselves, so you know, this is just from my knowledge from networking and may not be wholly accurate, but to get a general feeling.... Some people I know, they’ll maybe ask about it [fatigue], but haven’t got that much knowledge on it and so it will be basic advice only and referral on if there’s someone to refer to, but we know that in community services, in terms of fatigue and OT advice or other professionals who do it, there aren’t any. So it’s basic advice only. It varies quite a lot, I think.”</p>	<p><b>In-clinic consultation with physiotherapist 8:</b>                  “They talked about the effort required to push yourself in a wheelchair and how it was much better with the motorized version. The physiotherapist asked about how adjustable the wheelchair was and whether the arms could be moved out of the way to get in and out of the chair.”</p> <p><b>Video consultation with nurse 4:</b>                  MS nurse: “Yes, do something you’re looking forward to,” following a routine.                  MS nurse followed up with: “Are you finding that you’re getting tired by the end of the day?”                  Person with MS: “Still struggling to sleep if getting up...”                  MS nurse: “Are you on antidepressants at the moment with your mood being low?”                  Person with MS: “Yes, been on citalopram for quite a long time.” Takes duloxetine as well, not as an antidepressant but for pain.                  MS nurse: “Citalopram can sometimes help with fatigue. Do you find benefit with that drug?”</p> <p><b>In-clinic consultation with neurologist 2:</b>                  “The person with MS mentioned fatigue multiple times, but this was not picked up on by the neurologist.”</p> <p><b>In-clinic consultation with neurologist 3:</b>                  “The neurologist discusses topics including family, work, the patient’s culture, and background. He also asks about their interests or profession, which he uses to spur conversation, relax the patient, assess patient lifestyle choices regarding their conditions, and often to make analogies from, to explain medical terms in their area of expertise. He is interested in the patient’s career, life events, or general lifestyle, while accessing medical information on the computer, often leaving pause for silence where a patient may interject, but mainly, the conversation flows, and things are addressed as they come up. His initial topics regarding function are bowel, bladder, mobility, spasticity, speech and swallowing. Neurologist: ‘How’s life, apart from the bloody MS?’”</p>

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