

Hart R, Hackett K, Newton J, Ng WF, Thompson B.

[The F-Word: Why Is Talking about Fatigue so Hard?](#)

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Title: The F-Word: Why is Talking About Fatigue so Hard?

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Background: Fatigue is a common symptom for people with inflammatory arthritis and associated auto-immune conditions. Its impact is wide-ranging and significantly reduces health-related quality of life. Research evidence, however, suggests that neither clinicians nor patients consistently raise the issue in clinic. In-depth discussion of fatigue and support from professionals to manage its impacts are rare. Arthritis Research UK developed a booklet, 'Fatigue and Arthritis', intended to help patients help themselves. Our study has explored patients' approaches to managing fatigue and the impact this booklet has upon them.

Methods: Twelve patients from a rheumatology outpatient service in north-east England took part in in-depth, qualitative interviews before and after being given the 'Fatigue and Arthritis' booklet. Patients were recruited purposively to ensure variation in diagnosis (rheumatoid arthritis (RA), ankylosing spondylitis (AS), and primary Sjögren's Syndrome (pSS)), fatigue severity, and demographic characteristics. Data, in the form of transcripts, was analysed thematically using coding, mapping and memoing techniques.

Results: This study confirms both the impact of fatigue and evidence that neither clinicians nor patients routinely raise the matter in consultations. Our data suggests patients face significant barriers to communicating their fatigue, including: reliance on a diverse, colloquial vocabulary to define the problem; uncertainty how it relates to their condition; doubts to its place on the consultation agenda; and a belief that nothing can be done about it. These barriers affect both if and how patients raise their concerns and are reinforced where clinicians' responses do not invite elaboration.

None of our participants, even those who had discussed fatigue with a clinician, reported having seen the 'Fatigue and Arthritis' booklet before. Not all found it of practical help in improving their day-to-day management and experience of fatigue (criticisms including the familiarity and/or unsuitability of advice). However, most reported gaining something from the booklet. Benefits included: improved understanding of a distressing symptom; validation of their concerns; and a sense that things could be done to manage fatigue. These gains made it easier to discuss fatigue and its impacts with clinicians and with family, friends and colleagues.

Conclusion: Our research adds to the limited evidence on barriers to fatigue communication in the rheumatology clinic. In detailing patients' difficulties, it reinforces prior recommendations that clinicians need to be prepared both to initiate discussions and respond sensitively to concerns about fatigue. It suggests that information materials such as the booklet featuring in this study may be a useful tool for improving communication. We encourage clinicians to give this booklet (or a similar resource) to patients reporting fatigue, and to commit to discussing it at future appointments. More effective communication about fatigue would improve clinicians' understanding of the burden of disease individual patients bear and facilitate improved (shared) decision-making about management options.