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**Article:**

Aggarwal, VR [orcid.org/0000-0003-0838-9682](https://orcid.org/0000-0003-0838-9682), Wu, J [orcid.org/0000-0001-6093-599X](https://orcid.org/0000-0001-6093-599X), Fox, F et al. (3 more authors) (2021) Implementation of biopsychosocial supported self-management for chronic primary oro-facial pain including temporomandibular disorders: A theory, person and evidence-based approach. *Journal of Oral Rehabilitation*, 48 (10). pp. 1118-1128. ISSN 0305-182X

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**Table 1: Patient Feedback from 3 PPI user group meetings identifying key themes related to personal experiences of current care pathways and benefits of using supported self-management.**

Domains	Corresponding feedback
Personal Experiences (AF, BF, CF, DF, EF,)	<ul style="list-style-type: none"> <li>• We have been grinding and clenching our teeth both during the day and night since we were at least 15yrs of age (over 30 years ago). We have suffered from quite intense pain and at times have been left unable to eat solid foods at all. Hard or crunchy foods have been a challenge for many years as the repetitive chewing can be extremely painful in the jaw so we have tended to avoid these.</li> <li>• We have had quite severe sleeping difficulties, waking up multiple times throughout the night and feeling fatigued most days, even after an apparent 8-10 hours sleep!</li> <li>• The inside of our mouth is often sore and bleeding where we have bitten it with our grinding and this leads us to bite it again aggravating the unusual jaw movement.</li> <li>• No one can 'see' our pain so no one understands it and we have to put up with it.</li> </ul>
Experiences of the current healthcare system	<ul style="list-style-type: none"> <li>• Being "passed from pillar to post" within primary and secondary care in search for a diagnosis and not receiving the appropriate care for their personal condition quickly enough, when the appropriate resources are actually available.</li> <li>• Often patients are not referred by their primary care practitioner (GP or dentist) for pain management at time of diagnosis</li> <li>• (BF) Receiving the wrong medication i.e. given medication for epilepsy which can have side effects.</li> <li>• (CF) In her experience some drugs prescribed can lead to reliance e.g. Antidepressants, strong painkillers.</li> <li>• Irreversible, invasive treatment still ongoing, ie teeth extraction in some cases, where there is nothing wrong with the patient's teeth but are being extracted due to the pain. This may also cause long term damage (AF, CF, BF)</li> <li>• BF stated that after 30 years of great discomfort at dental appointments, an appointment was finally made for the hospital. The hospital health professional, advised not to use her splint as it was not working.</li> <li>• Cost implications - These should not be underestimated for patients, they are paying out for years of treatment (both NHS and private), that doesn't necessary help (ALL).</li> </ul>
Experiences with the supported self-management intervention	<ul style="list-style-type: none"> <li>• Members use it any stage of pain. CF when she has flare ups considers it a 'constant companion' more so during the Covid lockdown.</li> <li>• BF has distributed it to friends and employers who, having read it have understood her pain issues and shown empathy.</li> <li>• Four members of the group, who have used the guidance would like to see it available to patients who are in pain now. They recognise that the guide is not a one-off solution and patients will use the techniques that work for them.</li> <li>• CF had seen doctors and dentists interchangeably on a regular basis, but</li> </ul>

	<p>found the guide was the most effective information for her condition. She also shared how she went for a routine dental check-up recently and the dentist said she has many patients with the same problem; so CF shared the guide. The dentist said she had problems with time allocation with patients but CF suggested she give it to them and call them back at a later date.</p>
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