

Long COVID: supporting people through the quagmire

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Opinion

Long COVID – supporting people through the quagmire

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Long COVID, the post-acute sequelae of SARS-CoV-2 infection, is seen in growing numbers of people and has been highlighted as the only illness to be initially identified by individuals coming together on social media [1]. Each reports a constellation of symptoms that are debilitating, persistent and unexplained, often limiting day-to-day activities [2]. These include headaches, fatigue, breathlessness, mood changes, dizziness, insomnia, joint aches and pain. While some are reported as persistent and others may be more 'sporadic', triggered by e.g., exercise, all such symptomology is underpinned by feelings of fear, uncertainty, anxiety and depression, especially when many patients identify that their '*quest to be seen and cared for*' [1] by health care practitioners has failed.

While searches for causes, mechanisms, and treatments are underway, it is crucial that the patient narrative is understood across the health care environment, with urgent attention paid to supporting those with long COVID to manage and mitigate their symptoms, moving towards recovery. This poses challenges because symptoms of long COVID vary between individuals, many of whom are at increased risk of developing a psychiatric disorder [3]. In addition, our existing fragmented health and care environment, focused on symptoms and specialities, is not suitable for managing long COVID [4], not least as the collection of respiratory, neurological, gastrointestinal and cardiac symptomology demands a range of specialist, secondary care based support. Such care is becoming increasingly unlikely owing to the currently estimated 5.6 million patients in England alone awaiting hospital-based treatment. Perhaps ignoring or negating our fragmented health system, guidance by the NHS and NICE emphasises an integrated, coordinated and multi-disciplinary health and social care approach is needed to reduce the impact of long COVID on the health and health inequalities of patients, families, friends and carers. This will

entail a systematic individualised assessment which will inform a tailored package of support with on-going monitoring, review and referral to appropriate expertise where necessary. To enable ease of access, the package of support will be offered on-line, supplemented by tailored literature in booklet form and access to other on-line information and support resources likely to help them manage ongoing symptoms.

The first port of call for many people with long COVID is usually their GP, from whom they need belief in their symptoms, empathy and understanding [5]. Ongoing support by primary care professionals during recovery and rehabilitation is crucial, but this can be bolstered by other supportive measures to ameliorate the impact of presenting symptoms. While the ideal would be the GP 'wrapping services' around the patient, navigating and delivering appropriate referral pathways on behalf of the patient [6], it could be argued that such support will be unavailable given the pressures on primary care, the tsunami of post-COVID patients and the on-going workforce challenges.

To recognise the need for holistic support and, mitigate the existing sub-optimal care for those with long-COVID, we are carrying out a feasibility study with randomisation to assess if the Optimal Health Programme (OHP), an evidence based psychosocial support programme that enables clinicians to guide and facilitate patient (and family/carer) self-management, can support symptom management. The OHP works alongside the patient to identify and implement their own recovery goals (e.g., exercise, diet, sleep) across five sessions plus a booster to achieve optimal patient self-management and improve quality of life and wellbeing.

Although originally developed for helping people with mental health problems, the OHP has been used successfully with a variety of other chronic conditions such as stroke and chronic kidney disease.

We hope that as we move long COVID patients through the OHP programme, we will see positive changes in their symptomology to support their recovery. While we do not claim that this approach may be a panacea for all, it may be a useful adjunct to improving health and wellbeing in the long COVID population.

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Contributor and guarantor information

DRT and CFS had the idea for this piece. DRT wrote the first draft and all authors contributed to the final version. DRT is the guarantor.

The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted.

Competing interests declaration

All authors declare they have no conflicts of interest