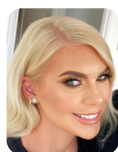


# The Role of Nutrition and the Dietitian in the Recovery from Post COVID-19 Syndrome



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According to the Office of National Statistics<sup>1</sup> an estimated 962,000 people in the UK (1.5% of the population) were experiencing self-reported 'Long COVID' as of 6 June 2021; this is down slightly from 1.021 million (1.6%) in May 2021. Of these people 40.0% first had – or suspected they had – COVID-19 at least one year previously. 65.9% reported their symptoms adversely affected the day-to-day activities. However, this may just be the tip of the iceberg as according to a recent article in *The Guardian* newspaper<sup>2</sup> more than two million adults in England have experienced Long COVID symptoms. With so much media attention on Long COVID finding the right advice and guidance can be confusing for patients. Fortunately, the debilitating nature of this condition is being recognised and NHS Trusts throughout the UK are establishing multidisciplinary teams (MDTs) to support patients with their recovery. This article looks at one of the first MDTs to be established in the UK, and shines a light on the importance of having a dietetic element within that team by showing the essential role nutrition must play in recovery from Long COVID.

## The Leeds Long COVID Community Rehabilitation Service

In December 2020, NICE guideline [NG188]<sup>3</sup> defined the following:

- Acute COVID-19: signs and symptoms of COVID-19 for up to four weeks.
- Ongoing symptomatic COVID-19: signs and symptoms of COVID-19 from 4-to-12 weeks.
- Post-COVID-19 syndrome (also known as Long COVID): signs and symptoms that develop during, or after, an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis.

Research into the management and recovery of Long COVID continues to emerge. But even prior to the above definitions being published a groundbreaking MDT was being established in Leeds to help support the rehabilitation of patients struggling with the aftermath of COVID-19.

The Leeds Long COVID Community Rehabilitation Service, was established in September 2020 and is a partnership between Leeds Community Healthcare NHS Trust and Leeds Teaching Hospitals NHS Trust. It has been developed to help people in Leeds who, after a confirmed or suspected COVID-19 infection, are experiencing new, long-lasting problems for 12-weeks

or longer which have had a significant impact on how they are able to function in day-to-day life.

The initial infection with COVID-19 can present with a wide range of different symptoms and severities and not everyone required hospital care or got a test. The nature of long-lasting problems may be very wide-ranging, and can include:

- fatigue,
- limited exercise tolerance,
- breathlessness,
- pains,
- anxiety,
- depression,
- brain fog/thinking problems,
- loss of appetite or weight,
- as well as other problems.

The Leeds Long COVID Community Rehabilitation Service consists of Physiotherapists, Occupational Therapists, Dietitians and Rehabilitation Assistants, to provide rehabilitation for people in a clinic or home setting, using face-to-face and virtual consultations. The team are supported by consultants from The Leeds Teaching Hospitals NHS Trust with specialities in rehabilitation medicine, cardiology, and respiratory medicine. Referrals into this service are via GP or Neighbourhood Team or Community Respiratory Team.

The service follows a rehabilitation model, designed to empower patients to improve and self-manage their condition. The service now draws on both local and national funding, but was initially funded through provider accessed 'COVID top-ups' from NHS England. When national funding became available this was added to NHS Leeds Clinical Commissioning Group (CCG) pre-commitment for 2021-2022 to allow for increased staffing.

The dietetic service within the team consists of two dietitians. The dietitians work closely with other MDT members to ensure dietetic support is provided at the right time for the patients. Referrals can come directly from the pathway co-ordinators at triage using the COVID-19 Yorkshire Rehabilitation Scale (C19-YRS) or during their treatment pathway with the physiotherapists or occupational therapists.

The C19-YRS was the first published patient reported tool (PROM) developed by a research team and has subsequently been recommended by NHS England as an outcome measure for first assessment, six weeks and six months within Long COVID rehabilitation.<sup>4</sup> The C19-YRS captures symptom severity including:

- altered smell and taste,
- new allergies,
- swallowing difficulties,
- nausea,
- reflux,
- changes in appetite,
- unintentional weight changes,
- bowel and bladder changes.

It also captures functional disability (such as changes to occupational engagement) and global health status (self-reported, scored on a 0-10 scale). The scale was first used in an initial post-hospital discharge follow-up study, and a self-reported version of the scale has now been developed, including translated onto a digital application platform.

The dietetic team support patients with a wide range of issues, including loss of sense of smell and taste, gastrointestinal symptoms, loss of appetite, swallowing difficulties, unintentional weight loss or gain and nausea. Weight gain and poor diet

quality are often linked with fatigue and has been an area of particular concern for patients. Around two thirds of those referred to the dietitian have more than one nutritional issue, so are often complex in nature.

## The patients and their nutritional management

Patients requiring dietetic support vary in both age and clinical presentation, however, most are within working age.

The support and advice provided can vary depending on the patient's symptomatic presentation and goals. Advice is tailored to the individual however it will often include one or more of the following:

- Assessing nutritional adequacy of the diet to aid in rehabilitation.
- Health coaching to address unwanted weight loss or weight gain.
- Advice on over-the-counter supplementation, including but not limited to, checking upper recommendations of micronutrients.
- Mediterranean diet recommendations.
- Maximising energy availability from food to help with symptoms of fatigue.
- Advice to reduce physiological and psychological stress to help reduce gastric symptoms.
- Dietary and lifestyle techniques to manage gastrointestinal symptoms.
- Advice for encouraging improvement of taste and smell changes.

Many patients are computer and internet literate and are often active in Long COVID forums and social media groups online. This has brought about new challenges including some patients following diets that have not been recommended by qualified health care professionals as well as taking large amounts of dietary supplements.

One such diet that has been suggested in these groups is the low histamine diet. Histamine intolerance is thought to be due to reduced ability of the body to break down ingested histamine in foods. The symptoms of histamine intolerance are similar to the symptoms reported by many of Long COVID patients. These may include bloating, diarrhoea, nausea, headache, rhinitis, wheezing, hypotension, arrhythmia, urticaria, itching, flushing and fatigue. Low histamine diets are sometimes used for patients who are suspected of having histamine intolerance. Although it should be noted there are no reliable tests for histamine intolerance. A low histamine diet is not advised as the evidence base surrounding the diet is low, and the diet itself is very restrictive which can result in nutritional deficiencies. In addition, there is a lack of consensus as to which types of foods are low in histamine.<sup>5,6</sup>

As an alternative, patients are encouraged to establish a Mediterranean-style diet which has many more proven health benefits including the anti-inflammatory element.<sup>7</sup>

Dietetic intervention may also include providing recommendations on over-the-counter supplements. Vitamin D is recommended for all patients during the Winter months in line with public health guidance. Dietitians are often required to check that patients are not consuming high levels of vitamins A, K, D, C as well as Niacin. When consumed in high amounts these micronutrients can increase risk of fractures, interfere with anticoagulants, result in hypercalcaemia, lead to gastric symptoms and liver damage. An upper limits resource is often provided for patients to enable self-management and to ensure they are not taking too much. Vegan or vegetarian patients may be provided with additional recommendations based on their dietary assessment.

Fatigue is the most common symptom of Long COVID.<sup>1</sup> While there isn't a specific diet for fatigue, it's presentation shares similarities with other long-term conditions such as chronic fatigue syndrome (CFS).<sup>8</sup> Where appropriate, patients are encouraged to eat healthily using the NHS Eatwell Guide model to ensure diets contain a good balance of nutrients from each food group and to ensure that carbohydrate choices have a low glycaemic index (GI). Where fatigue is particularly debilitating, making cooking and eating difficult, convenience meals and softer diets may be recommended with the focus on ensuring enough protein and calories are consumed using a nutrition support approach. With the current lack of evidence dietary intervention for managing fatigue needs to be person-centred and based on a thorough dietary assessment.

For managing gastrointestinal symptoms, many of the dietary recommendations are based on those provided for patients with IBS [NICE CG61].<sup>9</sup> This includes a regular meal pattern, fibre manipulation and advice and education around possible diet and lifestyle triggers identified on an individual basis. Patients who are suffering with gastrointestinal disturbances are also often having issues with fatigue. With these patients low GI sources of carbohydrates would be encouraged however alterations may be needed depending on type or severity of symptoms. On occasion, when first line IBS advice has not provided satisfactory relief of symptoms, the low FODMAP (Fermentable, Oligo-saccharides, Di-saccharides, Mono-saccharides and Polyols) diet has been used as a more in-depth strategy for identifying dietary triggers to symptoms.

General anxiety as well as the theory that people with Long COVID have dysautonomia with sympathetic predominance are possible explanations for the range of gastrointestinal symptoms experienced by patients.<sup>10</sup> Reassurance and signposting to mental health strategies to help stimulate the “rest and digest” centre are as important as the dietary manipulation.

Finally, taste and smell disturbances are common in this patient group. Smell training is encouraged as a way of stimulating the olfactory nerve in the nose. Patients are advised to practice smell training twice a day. Lemon, rose, eucalyptus and clove are the scents recommend as these are the scents most widely used in research.<sup>11,12</sup> In addition to smell training, dietary modifications are usually discussed. The type of modification will depend on the specific taste or smell disturbance the patient is suffering from. They may be advised to limit bitter food items, reduce salt and/or introduce sweet or sour variations of current food items. A short-term, one-to-two months, zinc trial at recommended daily requirements may also be advised. The daily requirement of zinc for men is 9.5 mg and woman 7 mg. Zinc should not be taken at levels of more than 25 mg. A patient may already be getting their recommended amount if they are taking a general multivitamin, so it is important to check current supplement intake.

## Challenges

The patient profile has been younger than expected, with many previously fit and healthy individuals. This has been challenging as many patients do not have experience of illness or rehabilitation and are often expecting a relatively ‘quick fix’, such as the low histamine diet, or supplementation with micronutrients. Having support from medics has helped patients understand the clinical evidence and best practice. Some have required support since catching COVID-19 in the first wave in March/April 2020, so have had symptoms for a very long time. Evidence is still not clear on the likely long-term impacts and it has been difficult to provide clear timescales to patients.

## Resources

The team have developed specific written resources to support patients, including:

- Smell training designed to improve and recover sense of smell.
- Support with fatigue using the principles of a low-GI diet.
- Healthy and nourishing snacking.
- Nourishing drinks.
- Coping with acid reflux and nausea.

In addition to traditional written resources, the dietitians developed virtual tools that would appeal to a wide range of audiences. In collaboration with the MDT, a virtual course was established for helping manage fatigue, and within this programme there was a module on the role of diet. Within the session participants had chance for peer discussion and would often swap self-management strategies. This was an invaluable part of the support and reduced the feeling of isolation and anxiety.

A ‘smell and taste changes’ podcast was developed and designed to support patients with self-management. This could be emailed out to patients during the triage process to help ensure the patient received this advice in a timely fashion.

## Outcomes

In the absence of a validated outcome measure for dietary assessment in Long COVID, the dietetic team developed seven Likert-scale-based outcome measures based on the typical symptoms seen in Long COVID. Results are reported quarterly to NHS Leeds CCG as part of a wider evaluation of the service. These questions are completed by the clinician alongside the patient as appropriate at each appointment. Please see **Figure 1**.

Low scores for diet quality and concerns about weight are the most common symptom reported at baseline, but the dietetic team have seen very positive responses: Rated their diet quality (1 = very poor, 2 = poor, 3 = OK, 4 = good, 5 = very good)

- *Referral: 71% of patients reported 3 or below.*
- *Discharge: 92% reported as 4 or 5.*

Rated their worry about weight (1 = very much, 2 = quite a bit, 3 = somewhat, 4 = a little bit, 5 = not at all)

- *Referral: 66% of patients worry about their weight at 3 or below.*
- *Discharge: 67% of patients worry about their weight as 4 or 5.*

## Conclusion

There are many reasons why a patient may need dietary support during their recovery from Long COVID. Dietitians and nutrition play an essential role in the recovery of COVID-19. Without proper support and nutritional counselling, it is likely that patients struggling with Long COVID will not reach their full rehab potential and recovery will take much longer adding to the burden on an already over-stretched NHS.

**Figure 1: Total score out of max 35, any increase shows an improved outcome**

- My appetite is
  - very poor
  - poor
  - average
  - good
  - very good
- When I eat
  - I feel full after eating only a few mouthfuls
  - I feel full after eating about a third of a meal
  - I feel full after eating over half a meal
  - I feel full after eating most of the meal
  - I feel full after eating a whole meal
- I feel the overall quality of my diet is
  - very poor
  - poor
  - OK
  - good
  - very good
- Food tastes
  - very bad
  - bad
  - average
  - good
  - very good or normal
- Normally I eat
  - less than one meal a day
  - one meal a day
  - two meals a day
  - three meals a day
  - more than three meals a day or 3 meals and snacks
- I feel sick or nauseated when I eat
  - most times
  - often
  - sometimes
  - rarely
  - never
- I am worried about my weight
  - very much
  - quite a bit
  - somewhat
  - a little bit
  - not at all

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