Providing optimal nutritional care to patients with long-COVID

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Abstract

A new syndrome has emerged from the COVID pandemic; post COVID syndrome (or long COVID)-which is characterised by symptoms lasting more than one month. There is considerable variation in the intensity and type of symptoms, many of which influence nutritional intake and status. Up to 1 in 7 will suffer from this syndrome.

Primary care and community nurses need better access to information about COVID-19 and nutrition. After conducting three research projects, a Nutrition and COVID-19 Recovery Knowledge Hub was developed to support access to reliable, current evidence about the interactions between nutrition and COVID-19. This article provides an overview of what the Hub provides specifically, how nutrition and COVID-19 are related and how nurses can use it to provide evidence-based nutritional care to patients with long COVID.

Background

Post COVID syndrome is a new issue emerging from the COVID pandemic, associated with numerous and varied symptoms, many of which impact nutritional status and intake. After conducting a literature review (Latif et al 2021) and research with both health professionals and service users (unpublished data), a Nutrition and COVID-19 Recovery Knowledge Hub was developed to support non-nutrition professionals in the provision of nutritional care to patients with long COVID. This article provides an overview of Hub contents and shows how nurses can use the Hub to provide evidence-based nutritional care for patients with post COVID syndrome.
While a large proportion of the population suffers only mild symptoms from COVID-19, others develop prolonged symptoms that can lead to more severe disease and hospitalization (Anderson 2020). COVID-19 has complex, multi-system effects many of which are related to diet and nutrition. NICE (2020) has defined three stages of COVID-19 (Figure 1):

Figure 1. Stages of COVID-19 [Extracted from NICE (2020)]

Where symptoms of COVID persist or arise more than four weeks after initial infection, the term long COVID is commonly used (as a patient-made name) and literature from patient groups tends to prefer this term over the term “syndrome” (Greenhalgh et al 2020, NICE 2021). On the other hand, Greenhalgh et al (2020) use the terms ‘post-acute COVID-19’ (from 3 to 12 weeks) and ‘chronic COVID-19’ for symptoms persisting more than 12 weeks. Several studies show that long COVID is a common condition affecting many
people (Gem COVID 2020, Sudre et al 2020). In December 2021, data from the Office for National Statistics estimated 1.3 million people living in private households in the UK (2.0% of the population) were experiencing self-reported long COVID (i.e. symptoms persisting four weeks or more after the first suspected COVID-19 infection, that were not explained by something else) (ONS 2022).

Current data suggest that up to 1 in 7 people will suffer from post COVID syndrome (NICE 2020), and at least 10% of non-hospitalised patients have reported symptoms lasting more than four weeks (Maxwell 2020, Pavli et al 2021), with 70% patients reporting fluctuations in symptoms and 89% changes in the intensity of symptoms over time (NICE 2020, Augustin et al 2021). People with five or more symptoms at disease onset are more likely to suffer from post-COVID syndrome (Sudre et al 2020).

New information about COVID-19 is released at a rapid rate from a variety of sources (social media, news outlets, professionals, personal experience, policy, and observational studies) making it challenging to keep up-to-date (Patel et al 2020). Additionally, some patients with long COVID identified that clear health knowledge was lacking, reporting dissatisfaction with care (NIHR 2021a). The Nutrition and COVID-19 Recovery Knowledge Hub was developed to support access to reliable, up-to-date evidence about the interactions between COVID-19 and nutrition. This article provides an overview of the protracted symptoms of COVID-19 and shows how the Hub
can assist nurses to provide evidence-based nutritional care for patients with long COVID.

Interactions between nutrition and long COVID
Anyone can experience prolonged symptoms that could result in nutritional problems following COVID-19 infection, but older adults and clinically vulnerable patients are at greatest nutritional risk. These at-risk groups may suffer significant deconditioning, muscle atrophy and anorexia (Mechanick et al 2020, Public Health England 2021) potentially leading to immune dysfunction (Ferrara et al 2020) heightening their risk of malnutrition (Baic 2021) and associated adverse clinical outcomes (Nalbandian et al 2021). Furthermore, chronic inflammation resulting from the prolonged effects of COVID may exacerbate diabetes and heart disease (Mechanick et al 2020). The long-term effects of COVID-19 are associated with an increased risk of chronic illness such as depression, stroke, chronic renal disease and type 2 Diabetes (NIHR 2021a)

Various authors (GemCOVID 2020, Davis et al 2021,NIHR 2021a, Wise 2021) have described the numerous symptoms that characterise long COVID which are presented in table 1.

Mechanisms behind long COVID symptoms
A large number of COVID-19 symptoms are affected by, and affect, diet and nutrition including smell loss, impaired taste and effects on the immune system.
COVID-19 infection causes chronic inflammation of the nasal airways, blocks the nasal passage and may destroy the olfactory sensory neurons of the nose (Glezer et al 2020). Direct inflammation of the oral cavity mucosa and damage to the taste buds may be the underlying mechanism that causes dysgeusia (bad taste in the mouth) (Mahmoud et al 2021) and anosmia (loss of smell & taste).

Hyper-activation of the immune system (sometimes referred to as the ‘cytokine storm’ in the acute stage of the infection) is a key component of COVID-19 infection (Zabetakis et al 2020). It is not yet understood why this immune system dysfunction persists in COVID-19. One contributing factor could be diet. Evidence suggests that a diet high in saturated fat and free sugars (Western-type diet) can lead to chronic activation of the immune system, and this may exacerbate immune dysfunction in COVID-19. New data continues to emerge, and more recent characterisation of symptom groups are shown in table 2. When it comes to recovery, the main nutritional concerns are catabolic muscle wasting, frailty and feeding difficulties (Nalbandian et al 2021).

Long COVID symptoms can influence dietary intake and increase the risk of nutritional problems; hence it is important that health professionals supporting these patients consider nutrition. This was the driver for the development of the Nutrition and Covid-19 Recovery Knowledge Hub.

**Nutrition and COVID-19 Recovery Knowledge Hub**
Rationale for Hub development

During the early days of the pandemic information was rapidly released by many different organisations and individual experts. Our goal was to identify and review the available information about nutrition and summarise findings so that health and social care professionals, including nurses, could identify nutritional issues and support the nutritional care of service users. First, we undertook a survey to explore how dietitians were supporting nutrition in patients with what was still undefined as long COVID (Lawrence et al 2021). Next, we reviewed the literature to inform evidence-based decision making on the nutritional care of patients hospitalised with COVID-19 infection, summarising all the published information up to March 2021 (Latif et al 2021). We convened two panels (one of patients and one of professionals) to examine the information and produce consensus statements to inform the future care of patients with COVID-19 (paper currently in progress). The key consensus statements from the panel discussions recommended the following:

- Highlight the role of nutrition for recovery following COVID-19 infection. Provide support for the nutritional care of people with long COVID.
  - To prevent and treat malnutrition
  - To strengthen the immune response to viral infections
  - To support symptom management
- Develop a resource to support safe recovery. Self-screening, self-assessment and self-referral should be guided and encouraged
Provide guidelines and validated tools to support healthcare professionals and non-nutrition experts working with service users in the screening and assessment of nutrition-related issues. This includes all health and social care professionals and people working in the third sector (voluntary and community organisations, charities, self-help and community groups, social enterprises etc.).

Purpose and funding

The Hub is a peer reviewed, freely available website managed by the University of Plymouth and funded by this institution, as well as the British Dietetic Association (BDA).

Key features include:

- Tailored for the United Kingdom, although can be used worldwide
- Regularly updated and reviewed by experts in their field
- Provides clear and concise tools to deliver high quality nutritional care
- Aims to help non-nutrition professionals to understand when to seek the advice of a nutrition expert.

How to find the information you need on the Hub

The Hub has two main divisions, one tailored for professionals and the other for patients. The professionals’ pages comprise six sections targeting the post-acute phase of COVID-19 infection and are structured according to the dietetic care process (identification, assessment, monitoring, advice, symptoms and operational challenges).
The patients’ pages are tailored for the lay person and are a great resource to signpost your patient to for information on self-screening and assessment, symptom management, personalised support and other resources.

Here we explain what information can be found in each subpage of the professionals’ Hub, what issues nurses need to be aware of and can assist with, as well as describing implications for patient care. We also illustrate how nurses can use the Hub to assist patients recovering from COVID-19.

**Identification**

It is vital to identify people at risk of malnutrition so they can get the right advice and support. Malnutrition results in decreased immunity, poorer prognosis in long term illnesses and higher mortality rates from all causes, not just COVID-19 (Malnutrition Pathway 2020).

The Hub provides nurses with information and tools for nutritional screening of different at-risk groups. All patients should be screened at first contact and then again if a significant change in clinical, psychological or social condition is identified (ref?). When oral nutritional supplements (ONS) or enteral nutrition is indicated screening should be repeated. If COVID-19 symptoms persist (i.e. long COVID) patients should be regularly re-screened.

People in care homes and those who are overweight or obese are at particular risk of malnutrition and should be screened regularly. People living in care homes will have other health issues that can make good nutrition harder to achieve while over-weight and obesity make it harder to identify malnutrition as unintentional weight loss may be masked.
Nurses should ask these key questions to flag dietary issues: Have you changed your food choices due to specific symptoms or diet concerns following COVID-19? Have you lost or changed your appetite due to COVID-19? Are you worried about an increase or loss of weight since you had COVID-19? [Adapted from (NHS 2020, O'Connor et al 2021)].

The Hub provides links to resources to help with screening, and toolkits to work with older adults affected by COVID-19 (WHO 2021). The Hub outlines the key symptoms of long COVID, their resemblance with other conditions and links for patient-led support groups.

Assessment

If screening shows a person is nutritionally at risk further assessment is necessary, because nutrition can be affected by a wide range of factors including:

- Ethnic background (e.g. Black, Asian Minority ethnic background),
- Food insecurity (disruption of food intake or eating patterns due to lack of money and other resources) (Gundersen and Ziliak 2015)
- Recent hospitalisation (Mechanick et al 2020)
- Long term health conditions which lead to inability to prepare food (e.g. breathlessness, pain, fatigue etc)
- Social isolation

Assessment should establish the causes and duration of any nutritional issues. There are no trials reported (yet) on nutritional assessment in patients with COVID so the information on the Hub is based on existing evidence from other patient groups.
The Hub provides information for nurses on how to undertake a brief but effective nutritional assessment. Additionally, there are some key topics to explore with patients that our experts developed to determine if nutritional support is needed.

1. Decreased appetite and interest in eating, as well as general challenges in maintaining weight (Barazzoni et al 2020, Cawood et al 2020)
2. actual food consumption (Barazzoni et al 2020, Cawood et al 2020) and/or compliance with dietary advice (Malnutrition Pathway 2020).
3. changes and/or distortion of smell and taste (Lawrence et al 2021)
4. specific nutrition related symptoms (e.g. gut symptoms like pain, bloating, constipation or diarrhoea)
5. food allergies and bowel habits that were not present before COVID-19
6. current dietary preferences which may vary across cultures, religions and beliefs

After assessment it may be necessary to refer patients with more complex needs to other professionals e.g. dietitians, psychologists or occupational therapists. Referral to rehabilitation specialists is recommended when patients have worsening breathlessness, unexpected chest pain, new confusion, focal weakness or PaO2<96% (Greenhalgh et al 2020). The Hub highlights the need to refer using local pathways to prevent disjointed care and explains how to refer patients to long COVID clinics and the third sector (social services).
Symptoms

A UK review (Davis et al 2021) identified the 10 most common symptoms of long COVID, listed below:

1. Systemic:
   - Fatigue
   - Headache

2. Cardio/Respiratory
   - Shortness of breath
   - Cough
   - Chest pain

3. Skeletal
   - Muscle pain
   - Joint pain

4. Gastrointestinal
   - Altered sense of smell
   - Diarrhoea
   - Altered sense of taste

Symptom severity will affect the impact of COVID-19 on nutrition and diet. Although a mild symptom may be tolerable, several mild symptoms together can be incapacitating (Malnutrition Pathway 2020). The Hub includes the symptom page as a ‘pick and mix’ approach. Each body system is listed with relevant symptoms, how these influence nutrition, and how symptoms might improve with appropriate dietary strategies (NICE 2020,Davis et al 2021, NIHR 2021b). For example, physical discomfort is common when
experiencing coughing, shortness of breath or sore throat. Cooking methods can be adapted to produce softer textures which may be better tolerated. The Hub signposts to useful resources from reputable organisations such as the British Dietetic Association (BDA) and the Royal College of Nursing (RCN). Identifying which symptoms are made worse by diet can be difficult but a food and symptoms diary can help. The Hub hosts a talk on how to use and keep food diaries and how diet can influence symptoms.

**Advice**

The Hub offers support to nurses and other non-nutritional professionals on the appropriate provision of nutritional advice to patients (Ferrara, De Rosa & Vitiello 2020). As a rule of thumb, nurses should use the “food first” principle, which means addressing nutritional needs through the use of food rather than supplements (Barazzoni et al 2020, Malnutrition Pathway 2020) in the first instance.

“Food First” interventions include advice on how to increase dietary intake using snacks, desserts and drinks while “food fortification” involves using protein and nutrient dense food and products to increase the nutritional content of meals and snacks without increasing portion sizes (Weekes et al 2009).

When food first or food fortification does not result in patients meeting their nutritional goals, oral nutritional supplementation (ONS) may be needed. This is best assessed by a dietitian or appropriately trained healthcare professional (Calder 2020, NICE et al 2020). When they are used, ONS are rarely required for more than three months. The Hub provides support for nurses on
establishing goals, management, and monitoring of food-based interventions and ON.

The Hub outlines the lack of evidence for complex diets such as antihistamine diets. This diet has been promoted as a possible cure for long COVID but there is little evidence for its use and there is also a lack of consensus whether foods high in histamine make COVID symptoms worse (British Dietetics Association 2021)

**The use of other nutrient supplements**

Vitamin and mineral supplements can potentially cause harm as well as benefit (Patel et al 2020), therefore it is advised to monitor response to any new supplement, take it for a fixed period, and introduce one supplement at a time. If possible, nurses should discuss their patient’s dietary supplement with a dietitian.

A systematic review showed a relationship between vitamin D deficiency and increased mortality in COVID-19 (Bassatne et al 2021). However, the evidence was of moderate to low quality as many studies included only patients who were critically ill and did not include patients who were never hospitalised. The role of vitamin D in COVID-19 recovery is currently in debate in the UK parliament. Nevertheless, Vitamin D deficiency should be checked for and corrected when found.

Regarding other micronutrients, daily allowances for vitamins and trace elements (particularly A, C, E, B6 and B12, Ca, Mg, Zn and Se) should be ensured for malnourished patients at risk of or with COVID-19 (Aytür et al 2020, Zabetakis et al 2020). It is known that high intakes of copper and zinc
can negatively affect the immune system (Calder 2020, Lockyer 2020) so only supplements providing the reference nutrient intake or less should be used. Care should be taken with high doses of vitamin C, since this may cause gut symptoms and the formation of renal stones (Kim and Yeom 2020). The use of probiotics is controversial including in COVID-19 infection. Our team found various weaknesses in probiotic studies, including the use of different strains and dosages, different study populations e.g. children or older adults, not including cofounders such as BMI, small samples, and potential conflicts of interest (Gutiérrez-Castrellón et al 2022). The Hub cautions that there is a lack of good quality evidence for the benefits of probiotics in recovery from COVID-19, however many patients will want to try them. Fortunately, food products containing probiotic bacteria are safe and well-tolerated, so the potential for harm is very low. The Hub suggests caution with the use of nutraceuticals and herbal remedies as there are no human studies for their use in COVID-19 (Naidu et al 2021).

Operational challenges

To minimise transmission of COVID-19, face-to-face follow-up consultations have been discouraged, thus increasing the use of telehealth. This presents nurses with operational challenges such as remote rehabilitation, technology available to patients and triaging processes (Cawood et al 2020, Iannaccone et al 2020, Lee et al 2021). The Hub provides a range of ideas to ensure strong links between acute and community settings (Cawood et al 2020), provide virtual consultations taking into account nutrition-related risks (Lawrence et al 2021), using telehealth particularly to assess dysphagia
(Miles et al 2020) and how to reach patients who may not have access to relevant technologies.

Limitations of the Hub

Although we provide some local examples of good practice, the Hub is designed for national use and therefore does not include specific guidance. Individual trusts and health boards therefore need to consider local resources when using the Hub.

In addition, whilst every effort is made to keep up with new findings, time and resources are limited. Therefore, it is acknowledged that there will be a lag between the emergence of literature and Hub updates.

Strengths and future plans

Our research team responded rapidly to the COVID-19 situation by obtaining immediate funding and by adapting our research methods to the pandemic scenario. We achieved the aim of delivering a freely available resource to support the nutritional care of patients with COVID-19, for use by both patients and professionals.

The Hub has been reviewed by several health and social care professionals including representatives from physiotherapy, general practice, nursing, occupational therapy, and pharmacy to ensure the content meets their respective needs. In addition, a cohort of patients with long COVID assessed the patient pages. This makes the Hub applicable to patients seeking trustworthy, up-to-date information and the practitioners supporting them. The
Hub includes a series of freely available talks by nutritional experts on topics relevant for patients and professionals alike.

Research around COVID-19 recovery is published daily. We are therefore constantly reviewing and updating the evidence and policy for the Hub. A systematic and rigorous process to assess the quality of new papers, policy documents and patient literature is established, but more funding is needed to maintain this task.

Conclusion

Long COVID is a new condition with a high symptom burden affecting patients’ physical and psychological health. As a result, research in to long COVID, including any associations with diet and nutritional status, is constantly emerging. Evidence-based advice is crucial for nurses in primary care who may encounter patients suffering with long COVID. We have provided an overview of nutritional issues related to long COVID and nutrition related underpinning mechanisms and a structured breakdown of how the Hub can support key aspects of nutritional care. By using the Hub, nurses can support patients nutritionally to prevent further complications and improve clinical outcomes.
References


NICE, PHE and SACN (2020) COVID-19 rapid guideline: vitamin D. *vitamin D* 15.
NIHR (2021a) Living with Covid19 – Second review. NIHR Evidence. Available at: https://evidence.nihr.ac.uk/themedreview/living-with-covid19-second-review/


Table 1: Long COVID symptoms and other effects

<table>
<thead>
<tr>
<th>Gut</th>
<th>Psychological and cognitive dysfunctions</th>
<th>Respiratory</th>
<th>Systemic</th>
<th>Functional, social and occupational effects</th>
<th>Metabolic associated problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Loss of taste and smell (anosmia)</td>
<td>• Sleep disorders</td>
<td>• Coughing</td>
<td>• Dizziness</td>
<td>• Low work productivity</td>
<td>• Obesity</td>
</tr>
<tr>
<td>• Reduced or increased appetite</td>
<td>• Anxiety</td>
<td>• Breathlessness</td>
<td>• Decreased activity endurance</td>
<td>• Diabetes</td>
<td></td>
</tr>
<tr>
<td>• Reduced food intake</td>
<td>• Fear</td>
<td>• Gas trapping</td>
<td>• Post-exertional malaise</td>
<td>• High blood pressure</td>
<td></td>
</tr>
<tr>
<td>• Feeling full</td>
<td>• Apathy</td>
<td>• Early satiety</td>
<td>• Muscle and weight loss</td>
<td>• Heart disease</td>
<td></td>
</tr>
<tr>
<td>• Lack of enjoyment of food and eating</td>
<td>• Depression</td>
<td>• Dry mouth</td>
<td>• Low energy or tiredness</td>
<td>• Sedentariness</td>
<td></td>
</tr>
<tr>
<td>• Dry mouth</td>
<td>• Despair</td>
<td></td>
<td>• Weakness</td>
<td>(due to lockdowns, shielding or other reasons)</td>
<td></td>
</tr>
<tr>
<td>• Swallowing problems (dysphagia) (particularly after intubation in ICU)</td>
<td>• Hallucinations</td>
<td></td>
<td>• Pain, headaches, chest tightness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Diarrhoea or hyperactive bowel sensations</td>
<td>• Low mood</td>
<td></td>
<td>• Fatigue</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Increased need for specific nutrients and/or fluid when intake may be poor</td>
<td></td>
<td></td>
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<td></td>
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</tr>
</tbody>
</table>


Table 2. Characterisation of patients with long COVID from different authors

<table>
<thead>
<tr>
<th>Groups of symptoms described in the literature (NIHR 2021a)</th>
<th>(Sudre et al 2020)</th>
<th>(Amenta et al 2020)</th>
<th>(Ceravolo et al 2020)</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with fatigue, headache and upper respiratory complaints (shortness of breath, sore throat, persistent cough and loss of smell)</td>
<td>Residual symptoms e.g. speech and swallow deficits following dysphagia</td>
<td>Symptoms continuing from the acute phase of COVID-19 and its treatment.</td>
<td></td>
</tr>
<tr>
<td>People with additional multi-system complaints, including ongoing fever and gastroenterological symptoms</td>
<td>Organ dysfunction symptoms for instance pulmonary pathology leading to cough</td>
<td>Symptoms causing a new health condition for example neurological symptoms with the later development of stroke-like symptoms</td>
<td></td>
</tr>
<tr>
<td></td>
<td>New inflammatory symptoms for instance cardiac problems ongoing inflammation and sustained low O₂ saturation, as well as issues with blood clotting and lung function.</td>
<td>Late onset symptoms appearing because of COVID-19 but after the end of the acute phase.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Symptoms which impact on a pre-existing health condition or disability.</td>
<td></td>
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</tbody>
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