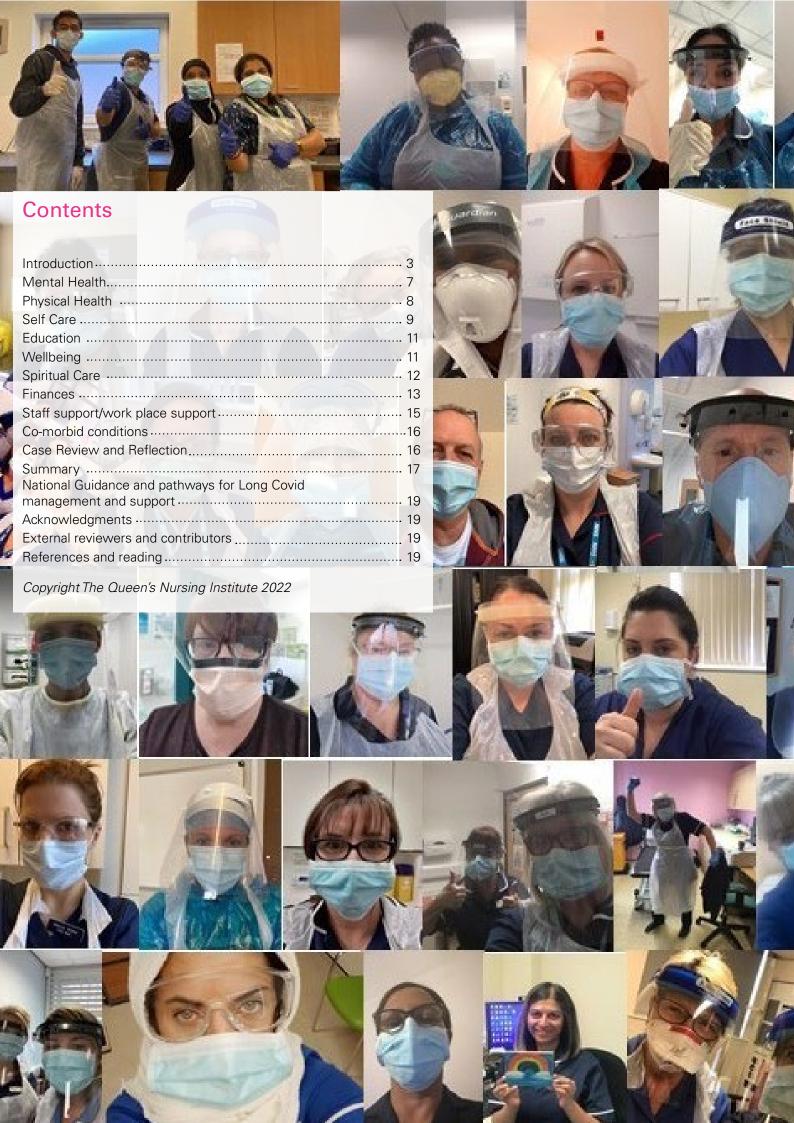


# Living with Long Covid A Community and Primary Care Nursing Resource





There is more recent recognition that Long Covid is a multisystemic condition and a multi-disciplinary response would be beneficial.



#### Introduction

The Queen's Nursing Institute (QNI) was commissioned by NHS England to create, develop and run a community of practice for nurses to meet with and learn from 'Experts' with Long Covid.

Following the publication of the NHS After Care Needs of Inpatients Recovering from Long Covid guidance, published in 2020, the QNI published its own resources for community and primary care nurses. This new document, 'Living with Long Covid, A Community and Primary Care Nursing Resource', updates and expands upon the previous document created by the QNI in 2020.

The Queen's Nursing Institute developed a successful Long Covid Nurse Expert Group during the pandemic. The group meets bi-monthly and focuses on listening to and learning from experts by experience, best practice, and national guidance. The group aims to inform and shape practice within the field of Long Covid. This is achieved by meeting with professionals, sharing good practice, and learning from experts within the field. The group aims to raise awareness of Long Covid, create a 'go to' area for nurses, advocating for people's lived experiences of Long Covid, and recognising the ongoing needs of people affected. The learning is also shared wider, with resources and information available on our webpages Long Covid Nurse Expert Group - The Queen's Nursing Institute.

#### The aim of this document is:

- To provide information primarily to nurses working in the community, care homes and primary care
- To highlight the roles of the wider multi-disciplinary team to ensure access to the required clinical knowledge, care responses and skills when caring for people during their recovery and rehabilitation from the virus
- To help nurses assist people, families, carers, and employers to work towards managing post-covid symptoms realistically regaining everyday life activities and returning to independent living
- To recognise and further establish the essential role, skills, and knowledge that community nurses provide in the recovery of post-covid syndrome
- To provide a comprehensive summary of evidenced based practice and signpost nurses to useful resources to aid excellence in care
- To assist nurses in assessment of post-covid symptoms, to support knowledge and skills for community nurses surrounding planning packages of care, care planning and liaison with the multi-professional team in the health and social care system.

This resource is to be used to support learning and NOT to mandate how learning is achieved. It is essential that all registered nurses continue to work within their scope of practice and their capabilities when developing extended skills in practice. The emphasis must always be on maintaining and providing safe, high quality and effective care.

In the development of this resource, an in-depth literature review was completed and peer reviewed prior to the review of the document (Thrupp, 2022). The literature search was completed as a cross sectional review, utilising a convenience sampling method. The search was online, to enable the most up-to-date articles to be reached, using broad search terms. The terms used were 'Long Covid' and 'post covid syndrome'. The timeframe included articles published since 2021. 82,800 results were returned for 'Long Covid'. 'Post covid syndrome' returned slightly fewer results, 31,800. Twitter #longcovid searches were also added into the literature.

The themes emerging from the searches indicated that Long Covid is generally focused on physical symptoms and referencing those symptoms aids definition of the condition. There is more recent recognition that Long Covid is a multi-systemic condition, and a multi-disciplinary response would be beneficial. The literature informed the development



of this document. Listening to the feedback within the Long Covid Nurse Expert Group, the QNI acknowledges that signposting and awareness of assessment tools, supportive groups and guidance would be beneficial. It must be noted that within the timescale of the resource development, Long Covid research has continued to evolve, and the learning is ongoing.

This resource has been developed, and peer reviewed (please note acknowledgements) and 'tested out' with commissioners and within the Long Covid nurse expert group. In the community, nurses are treating, supporting, signposting, leading on care for patients with Long Covid and supporting them to live as independently as possible. They are supporting families, in caring and supporting their loved ones with Long Covid.

This document hopes to empower that role further by providing reference to literature, websites, and possible resources.

It is important to recognise that nurses need to collaborate with many health care professionals to support the Long Covid patient. Therefore, this document will signpost to many supportive professional sites to aid knowledge within this area.

The Royal College of Occupational Therapists have produced guidance (May, 2020) regarding three P's: 'pace, plan and prioritise'. This guidance aims to inform patients about pacing and how this can improve and facilitate recovery, which is essential for people to return to their activities of daily living, and if possible, their working lives.

The role physiotherapy has in supporting rehabilitation in post-covid patients must be recognised. The British Society of Rehabilitation Medicine has produced recommendations for rehabilitation services for adults aged 16 years and over in particular, addressing the need to support patients with more complex rehabilitation needs (Phillips et al, 2020).

Supportive rehabilitation is further extended to the role of Occupational Health. It has been widely recognised that Occupational Health input is vital for our working populations. Occupational Health professionals support people in their working lives, and liaise with, provide specialist advice and guidance to individuals, employers, and other health professionals to adopt a multi-disciplinary approach in helping people to prepare, both mentally and physically for their transition back into their job roles.

It needs to be acknowledged that, whilst much work has been done to investigate and analyse the health disparities that Covid, and post-covid syndrome has caused, there remains a lot more to be done. The evidence that Covid-19 and its disproportionate impact upon Black, Indigenous, and Latinx communities serves as a stark reminder to health services that further work is needed to investigate the health inequalities within our health systems (Nana-Sinkham et al., 2021). It is also recognised that middle aged women have a higher risk of debilitating ongoing symptoms, causing a disproportionate impact particularly on middle aged women who are overweight (Torjesen, 2021).

These factors must be considered and acknowledged when completing assessments and supporting patients with postcovid syndrome. Community nurses are highly skilled at assessing complexity and in doing so within the community, and homes where patients thrive and survive. Community nurses are also the best placed clinicians to communicate patient focused assessments to those they serve.

#### **Protective Factors to consider**

Whilst the pandemic continues to challenge the workforce tremendously, community nurses have many protective factors that can support them in their work:

- Access to appropriate Personal Protective Equipment (PPE)
- Staff wellbeing and support via Occupational Health department
- Collaborative working- community nurses are well connected within their communities and have insight to local
- Community nurses see the patient, in their reality their community therefore the 'unspoken' from the patient is visible to the nurse.
- Clinical supervision should be paramount for nurses- time to reflect and de-brief
- Self-care and kindness for staff needs to be also be paramount, to protect the workforce
- Access to supportive networks to gain insight such as Queen's Nursing Institute Long Covid Nurse Expert Group

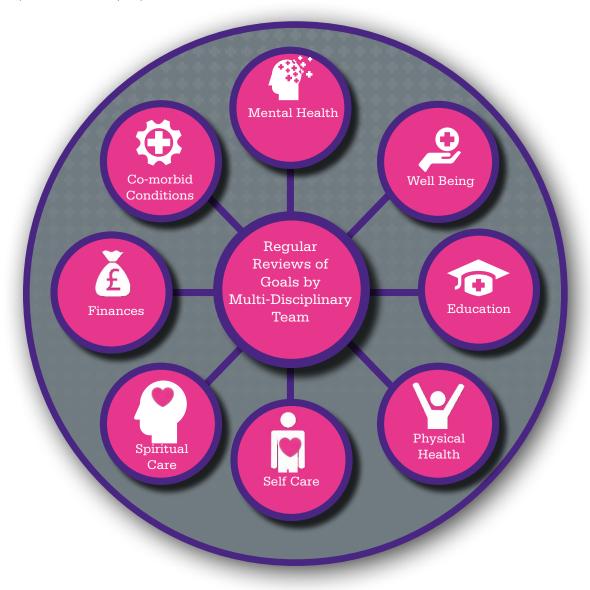
It has been widely recognised that Occupational Health input is vital for our working populations.



#### **Challenging Factors to consider**

- Lone working
- Professional isolation
- Staff sickness
- Access to Personal Protective Equipment
- Succession planning
- Training and education need

Figure 1. An overview of the main areas post-covid treatments and support could be focused to ensure holistic and best possible recovery is provided.





Post-traumatic stress disorder is something that also needs to be considered in post-covid syndrome. It should be recognised that patients who have been hospitalised or received Intensive Care treatment are considered higher risk of PTSD.

#### Mental Health

The psychological aspects of Long Covid are widely recognised, with most care providers integrating this into the care pathway for post-covid syndrome care.

NICE guidance (2022) acknowledged that providing 'good' quality information to people suffering from post-covid syndrome is key in helping alleviate some anxieties in people who are experiencing prolonged symptoms. NIHR (2020) informs that approx. 30% of people who have had Covid-19, 3 months following are continuing to report anxiety and/or depression- it can be assumed that due to growing numbers of post-covid syndrome cases the numbers of people needing psychological support will also increase.

Post-traumatic stress disorder is something that also needs to be considered in post-covid syndrome (Tucker et al, 2021) it should be recognised that patients who have been hospitalised or received Intensive Care treatment are considered higher risk of PTSD.

The persistent ever-changing landscape of Covid-19 has created an increase in the public's emotional wellbeing declining. Social isolation has been challenging for many members of society is widely reported, and for those who have gone from spending a large proportion of their time in the workplace, to suddenly not being able to attend their work, this has had a significant impact on their mental health. This is widely recognised within literature (Choi et al 2020, Javed et al 2020).

#### **Factors to consider during Nurse Assessment:**

- Low mood
- Anxiety (many manifestations)
- Depression (many manifestations)
- Isolation (social, professional, and physical)
- Change in personality
- Cognitive decline
- Physical symptoms changing in-line with mood

- Fatigue (does not ease with rest)
- Sexual health and relationships
- Consider sense of loss, what the person has changed in their life due to illness and how this affected their psychological wellbeing.
- Medications- contraindicators and how this may affect or exacerbate symptoms.
- Unhelpful thinking patterns

#### **Care Considerations:**

- Referral to talking therapies
- Review of self-help literature and possible digital support
- Social prescribing
- Listen to and believe the patients lived experiences
- Early referral / intervention to other specialist services such as Occupational Health for our working communities
- Provide choice
- Memory/mood journal
- Persistent pain clinic referral
- Goal setting
- Mindfulness
- Coping style

## Tools that may be of use (click the link):

- GAD screening tool: Generalised Anxiety Disorder Assessment
- Patient health questionnaire: Patient Health Questionnaire
- Talking therapies: NHS talking therapies: www.nhs.uk
- Kooth (young people 11plus): www.kooth.com
- Long Covid children and families support: Long Covid Kids



Long Covid adults support Home: Long Covid Support

• CAMHS resources: CAMHS

Support with Fatigue: Your COVID Recovery

Age Uk Long Covid support: Age UK

• Local Improving access to psychological therapy services: Improving Access to Psychological Therapies (IAPT)

• Qualified therapist finder: www.hcpc-uk.org

British Psychological Society: www.bps.org.uk

• British association for Behavioural Cognitive therapy: www.babcp.com



#### Physical Health

People suffering from long-term symptoms of Long Covid are reporting varied and complex issues. Many people report periods of remission and relapse. Long Covid is a multi-systemic condition (NHSEI 2020) People with chronic health conditions are at increased risk of developing complications and/or health conditions because of contracting Covid-19. Consider people within 'higher risk' categories, such as disadvantaged communities, middle aged women, black, Indigenous, and Latinx communities. (Nana-Sinkham et al 2021, Torjesen 2021).

The physical signs and symptoms may vary from patient to patient. Person centred care is paramount in all assessments.

#### **Factors to consider during Nurse Assessment:**

- Breathing
- Time and length of assessment (allow patient time)
- Health disparities
- Access to service
- Mobility
- Assess co-morbidities
- Blood testing, results
- Fluid intake/output assessment
- Cognitive assessment

- Dietary intake
- Loss of smell and taste
- Smoking status
- Alcohol and drug status
- Speech and language
- Patient / client motivation, desire, goals and aims
- Fitness for work
- Over exertion -staying within anaerobic threshold
- Sleep disruption
- Menstrual cycle

#### **Care Considerations:**

- Referral to Long Covid clinic, with interim support
   form universal services
- Pacing support- referral to occupational health
- Neurological rehabilitation support
- Physical assessment- e.g., x-ray/ECG/Echo
- Triggers of physical symptoms
- Chest physiotherapy

- Aids that may be required at home / at work referral to OT / Access to Work [e.g., REMPLOY]
- Referral to dietician
- Referral to smoking cessation
- Referral to physiotherapy
- Referral to drug and alcohol abuse support team
- Speech and language therapy

#### Tools that may be of use:

- Plan, Pace and Prioritize Recovering from COVID-19: Post viral-fatigue and conserving energy RCOT
- Post-Covid Clinics (referral via GP- at present)
- Migraine Long Covid support Post COVID-19 Migraine
- Physiotherapy Long Covid Physio
- Speech therapy support Coronavirus (COVID-19) guidance & resources | RCSLT
- Alcohol and Drug support line 0800787 797 Home With You
- Long Covid: the symptoms and tips for recovery | BHF
- Long Covid | Asthma + Lung UK (blf.org.uk)

People suffering from long-term symptoms of Long Covid are reporting varied and complex issues.

- Long Covid Hub Fifth Sense
- Breathing pattern disorder support



#### Self-Care

Self-care has been a focus during the pandemic, as the public have been urged to stay home and stay well. Self-care is key in the recovery journey of Long Covid (post-covid clinic oxford 2022).

Digital resources have been encouraged to aid self-care throughout the pandemic as a reactive approach to Covid-19 symptom management, however self-care should also be recognised as proactive management of overall wellbeing.

Being aware of patterns, and potential stress factors could be supportive to patients in their long-term recovery (Sudre et al 2021).

## **Factors to consider during Nurse Assessment:**

- Goal setting and aspirations
- Routine
- Diet
- Hygiene
- Sleep patterns
- Intellect ability

- Ability to access resources-please ensure resources are available or offered online. Printouts, and translation may be necessary
- Screen time in accessing online support-may impact on health? Can this be audio? Consider reasonable adjustments
- Family life, role, care commitments?

#### **Care Considerations:**

- Mindfulness
- Breathing techniques
- Pacing
- Family/community support
- Mentor/talking therapy (consider local charity support) •
- Exercise, yoga, tia-chi (exercise with low anaerobic •

#### threshold)

- Complementary therapies
- Progress diary
- Soothing activities
- Self-compassion
- Counselling

#### Tools that may be of use

- Self-Help guide post viral fatigue
- Mindfulness Mindfulness for Long Covid
- Mindfulness exercises Mindfulness Exercises to Follow
- Diet 'Long Covid' Nutrition in Focus
- What to eat when you have COVID-19 or Long Covid
- https://www.selfcareforum.org/
- www.accessbct.com mindfulness therapy



It is estimated that children and young people have missed over ¾ of their educational learning time during Covid-19. This has been found to have a detrimental effect to learning, and understanding, wellbeing and mental health and increased social and health disparities.

#### Education

Children, young people, and students' education has been affected due to Covid-19 for over 2 years. This has resulted in significant loss of educational activity and time- which has been alluded to an educational crisis for the world (UNICEF 2020, Hoofman 2021)

It is estimated that children and young people have missed over ¾ of their educational learning time during Covid-19. This has been found to have a detrimental effect to learning, and understanding, wellbeing and mental health and increased social and health disparities.

Educational establishments are for some a place of safety and refuge - children have not had access to food, shelter and this has resulted in safeguarding concerns also being raised.

#### Factors to consider during Nurse Assessment:

- Is the child, young person/student able to attend school
- Emotional wellbeing
- Stages of learning that has been missed
- Access to home learning, equipment
- Safeguarding factors, supervision- food- shelter
- Impact to the wider family consider if this could impact on family and child safety, consider safeguarding elements.

#### **Care Considerations:**

- Part time / reduced timetables
- Self-help support
- Referral to tier 2 mental health support or CAMHS if needed
- Safeguarding procedures
- Supporting families with food banks, etc
- Support in community

#### Tools that may be of use

- Assessment of children, young people, and family's needs The Assessment Triangle
- CAMHS information and support Guide to CAMHSs
- Support on School Attendance and guidance
- Kooth (young people 11 plus) www.kooth.com
- Long Covid children and families support Long Covid Kids

# Wellbeing

Wellbeing has been a key feature during the latter part of the pandemic, urging the public to take an active and key role in their wellbeing has been a clear message (Williams 2021).

Precautions remain in place and the public are encouraged and engage in immunisation programmes, hand washing, and social distancing continues to be communicated as priority.

Many digital innovations have been used since and during the pandemic started, providing an alternative support pathway so people can access but remain at home, isolating as much as possible. Isolation may be due to being unwell, may be work related, may be due to co-morbid condition. Your Covid Recovery (NHS England 2021) Zoe (2021) being two sites' people can gain advice and support regarding Long Covid recovery.

Whilst digital support can often provide a much-needed support route for some patients, it is important to consider patients that may not be able to use this or chose not to and provide alternatives.

#### **Factors to consider during Nurse Assessment:**

- Diet
- Exercise
- Stress levels and impact
- Environmental factors
- Social-economic factors (housing, finances? due to low/loss of income – job loss / sick leave, also isolation

if not able to go to work, and potential safeguarding issues if at home more [domestic violence issues])

- Personal routine
- Co-morbid conditions
- Consider smoking
- Alcohol intake assessment

#### **Care Considerations:**

- Social prescribing
- Access to services
- Financial burdens- food banks etc.
- Housing (gardens, housing in good state of repair)
- Routine and motivation

- External support/family support
- Early referral to occupational health for working communities
- Activity diary- with regular review and conversation
- Smoking cessation support
- Alcohol reduction support

#### Tools that may be of use

- Digital support to enable patients to self-care with minimal professional support Your COVID Recovery
- Digital support (patient study) ZOE COVID Study
- To find local projects to support health Local charities and community groups
- Health care projects support-local Healthwatch
- Park activators (local physical health motivational teams in local green spaces)
- Social prescribing Social prescribing
- Food banks Find a Food Bank The Trussell Trust
- Be Sugar Smart Welcome | Sugar Smart UK
- Quit smoking NHS
- Alcohol support NHS

## Spiritual Care

During the pandemic, the government guidelines encouraged social distancing, lockdown, and minimal human contact- this (as we know) has had a huge effect on care in all aspects, including spiritual care (Froma 2020).

Loss has been a major outcome for many families, physical, emotional, loss of health, finance and many other areas contribute to this. During the pandemic and the sense of spiritual care being lost is discussed by Vandenhoeck et al (2021), recognising that the feeling of having 'someone present' was lost.

Acknowledging that Personal Protective Equipment was a barrier at this point, however spiritual care that was present, with Personal Protective Equipment in place, was still present rather than completely absent.

Spiritual care, however, continues to be extremely important part of Nursing, and with many patients continuing to suffer with Long Covid it is something that many patients will benefit from engaging in.

#### **Factors to consider during Nurse Assessment:**

- Beliefs
- Spirituality
- Faith
- Rituaals
- Accessibility to support
- Community links/networks
- Nurse awareness / knowledge of the concept of
- spiritual care- access to training modules in this specialist area
- Isolation
- Anger
- Grief
- Loss of purpose/meaning
- Fear- fear of the unknown

During the pandemic, the government guidelines encouraged social distancing, lockdown, and minimal human contact- this has had a huge effect on care in all aspects, including spiritual care.

#### **Care Considerations:**

- Loss experienced
- Trauma experienced
- Access to support-local networks

- Adequate time to consider / assess this aspect of care
- Use of digital support, and accessibility

#### Tools that may be of use

- For people who may want to access church online services Access Church
- Utilise the HOPE or FICA assessment to gain understanding Hope assessment
- Information for healthcare professionals Providing spiritual care | Information for healthcare professionals

#### **Finances**

It is clear from widespread evidence that the economic crisis of Covid-19 remains something society will be challenged with for some years to come. Poverty is being reported as the biggest threat to child health and development within the UK, and globally (2021 BMJ).

Community Nurses will be challenged, yet it could be argued are best placed of all health professionals, to support the public with issues connected with poverty and the health disparities resulting from them.

#### **Factors to consider during Nurse Assessment:**

- **Employment**
- Are symptoms affecting employability?
- If absent from work, referral onto Occupational Health for assessment re fitness to return to work support / • adjustments etc.
- Debt consider referral to CAB for support
- Review of finances
- Dietary needs and accessibility to food
- Heating and fuel poverty
- Access to transport
- Income-job security

#### **Care Considerations:**

- Referral to CAB
- Do they have access to financial assistance via their work i.e., welfare funds?
- Are they able to apply for benefits?
  - Foodbanks
  - Local community grants and charity support

#### Tools that may be of use

- Financial support-Long Covid
- Apply for a needs assessment via social services needs assessment by social services
- Returning to work after absence Acas



Community Nurses will be challenged, yet it could be argued are best placed of all health professionals, to support the public with issues connected with poverty and the health disparities resulting from them.

## Staff support/work place support

In 2021, the Office of National Statistics (ONS) suggest that approximately 122,000 healthcare workers and 31,000 social care workers are self-reporting symptoms of Long Covid.

#### **Factors to consider during Nurse Assessment**

- Do they have adequate support / opportunity to rest and recover at home?
- What caring responsibilities do they have at home - children, other family members - i.e., elderly / disabled etc.?
- Are symptoms affecting ability to care for self / others - independence re Activity of Daily Living?
- Are symptoms affecting ability to undertake role? Can a 'lighter duties' approach support?
- What reasonable adjustments can be made?
- Physical symptoms

- Hours Nurse works, review of these with HR and other relevant parties
- Breaks- consider plan for gradual return with regular reviews
- Emotional support
- Motivation, desires, aims, goals
- Does the employee have access to Occupational Health - i.e., private health care sector may not have this provision available to staff.
- Cut down driving?

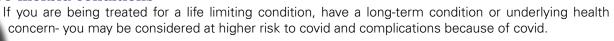
#### **Care Considerations:**

- Referral to occupational health Nurse
- Consider rapid assessment
- Referral to LC/post COVID assessment clinic
- Emotional wellbeing support
- Pay status and the impact of this on health and wellbeing
- Awareness and training for team members
- Hydration at work
- DSE assessment, adaptation workplace environment
- Physiotherapy referral
  - Union support

## Tools that may be of use:

- For staff rapid assessment mental health and wellbeing hubs
- Access to a range of health and wellbeing offers through the national support programme, including free access to a range of mental health and wellbeing apps, talking therapies through the Samaritans helpline and a range of coaching and counselling offers
- All patients across the country have access to support via online rehab services at Your COVID Recovery | Supporting your recovery after COVID-19
- Returning to the workplace after the COVID-19 lockdown toolkits | The Society of Occupational Medicine
- Support and information for managers and leaders manager support
- For NHS employers supporting staff with Covid-19
- Access to work Access to Work: get support if you have a disability or health condition

# Co-morbid conditions



#### Factors to consider during Nurse Assessment:

- Does the patient have any long-term conditions that place them at higher risk to Long Covid?
- Are the long-term conditions well managed?
- Is the patient engaging in recommended healthcare follow up for the treatment of their long-term condition?
- Is the patient able to access services they need for their health needs during periods of isolation?
- Does the patient have supportive network?

#### **Care Considerations:**

- Professional liaison with other care providers
- Education regarding co-morbidity and how this can affect patient
- Care planning
- Isolation of patient, due to shielding or prolonged isolation networks to support

#### Tools that may be of use:

- Care planning
- Managing people with long-term conditions
- Managing long-term conditions in the community-children and young people
- NHS England, House of Care a framework for long term condition care

#### Case Review and Reflection

Consider the scenario and what your nursing assessment would be for the case study below:

#### 'Jules' – a 29 year old female, full time worker.

Jules contracted Covid during late march 2020 - she noticed a slight headache and some loss of smell, she did not feel too unwell initially. However 2-3 days later she was in bed, fatigued and feeling unwell with a persistent cough.

Jules was eating very little as she could not taste much, and felt nauseous when she did eat. She was sleeping a intermittent times through the day - due to the fatigue and often missed calls and video-calls with her family and friends. Jules took regular pain relief and tried to keep fluids up.

Living alone, Jules felt disconnected from her previously active life and after 2 weeks noticed her mood was starting to change. Jules has been off sick from her job for 3 weeks now, she feels pressued to go back to work- as she does not get sick pay- she is a keyworker. If she does not attend work and get paid, she is concerned she won't be able to pay her rent this month. Jules is actively involved in her niece's life, helping her sister with childcare twice a week, Jules loves this part of her life and is struggling to keep this commitment at the moment.

Jules was contacted by her General Practice Nurse at her GP surgery for an routine asthma review - she informed the nurse of her recent illness and stated that she felt she needed further assessment. She has downloaded the zoe app, to try and look up some self-care techniques however, due to fatigue and headaches she has not looked into this too much - as she feels unwell.

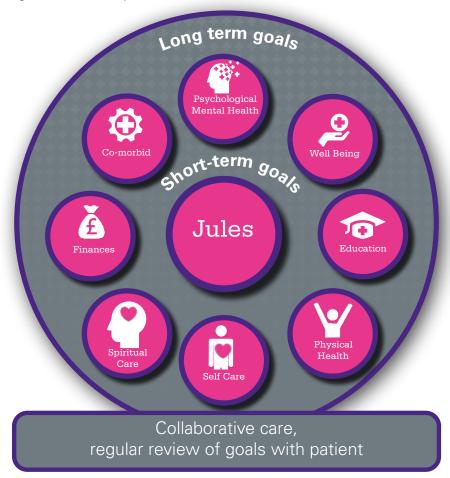
What considerations can the nurse support Jules with?

Consider each area that has been outlined within the document.

Recognising the inter-connectivity between the different roles that compliment and are essential to work alongside each other is of paramount importance when supporting patients with Long Covid.



Figure 2. Case study



Recognising the inter-connectivity between the different roles that compliment and are essential to work alongside each other is of paramount importance when supporting patients with Long Covid.

#### Summary

The Queen's Nursing Institute has aimed to provide a reference point, a document that supports, aids decision making and navigation through services for nurses supporting patients and families with Long Covid.

This document has been produced at a time where the learning around Long Covid is rapid paced and therefore we urge practitioners to ensure practice is reviewed, reflected on, and informed with the best possible evidence base available at the time of care planning.

The integration of services for the best possible outcomes for patients with Long Covid is paramount. Collaboration and communication, the fundamental aspects of excellence in Nursing care need to remain at the heart of patient care.

Nurses are central to and dedicated professionals in caring for patients holistically, in the right place, at the right time for the right reasons. Nurses will continue to advocate and enable patients with Long Covid to reach their potential, whilst providing excellence in care for those they serve.





#### National Guidance and pathways for Long Covid management and support

To support community Nurses in the management and support of long covid, NHSE have produced the following documents. These are vital in ensuring that Nurses are following the recommended pathways:

Updated commissioning guidance for post COVID-19 services

Long COVID: advice and resources for healthcare professionals in primary care

NHS England » Guidelines for supporting our NHS people affected by Long COVID

Coronavirus » Post-COVID Syndrome (Long Covid) (england.nhs.uk)

e-learning module to enhance knowledge and learning: Long Covid - eLearning for healthcare

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Eve Thrupp, QN, Nursing Programmes Manager (Leadership), The QNI

#### Sub-editors:

Sharon Aldridge-Bent MBE, QN, Director of Nursing Programmes (Leadership), The QNI Matthew Bradby, Head of Communications, The QNI

#### External Reviewers and contributors

- Carol Stonham, MBE RN, MSc, QN, PCRS Executive Chair
- Tracie Mckelvie, Registered Nurse Specialist Nurse Practitioner in Occupational Health
- Laura Devereaux, School Nurse, Clinical practice Educator
- Salli Pilcher, RN BSC DN, QN, Associate Director of Quality & Nursing
- Dr Kate Lippett, BA Hons MSc, PhD, RN Programme Manager (Treatments), Wessex Cancer Alliance, Senior Research Fellow, University of Southampton
- Marisa Spice, Learning & Development Manager/Operations Manager (RGN, QN)
- Debbie Duncan, BSC PGCAP PGDIP MSC FHEA AKC ARNS RGN RM NT QN, Lecturer (Education) | School of Nursing & Midwifery

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The Queen's Nursing InstICUte
1A Henrietta Place
London W1G 0LZ

020 7549 1400 mail@qni.org.uk

www.qni.org.uk

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