



HEALTH AND WELLBEING BOARD BRIEFING NOTE

LONG COVID SYNDROME

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Summary

This report seeks to provide an update on the current services available for Long COVID, a new condition which is experienced by some people who are recovering from COVID-19. People affected by Long COVID experience a wide range of long-term symptoms some of which include pain, fatigue, shortness of breath, confusion, and memory problems. Many Long COVID patients in Kent and Medway report that Long COVID has affected their work and their mental health as well as their social life.

In the past months, services for Long COVID have been scaled up significantly to cater to this emerging need. The Kent and Medway Post COVID Assessment Service (PCAS) has been offered since 14 May. The NHS Long COVID plan for 2021/22¹ published on 15 June 2021, aims to make new funds and services for Long COVID available. This report will give an overview of the services and support that are currently available for Long COVID in Medway. This report will also highlight some of the Long COVID findings in Kent and Medway.

1. Definition

- 1.1. 'Long COVID' also referred to as Post COVID-19 Syndrome or Long COVID Syndrome is a new and complex condition with wide-ranging symptoms that can change over time. Long-COVID includes both ongoing symptomatic COVID-19 (4-12 weeks after onset) and Post COVID-19 Syndrome (more than 12 weeks)². People affected by Long COVID experience long-term symptoms including but not limited to pain, fatigue, shortness of breath, confusion, joint or muscle pain, anxiety, depression, and memory problems (commonly called brain fog).

¹ National Health Service (NHS). (2021). Long COVID: the NHS plan for 2021/22. <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2021/06/C1312-long-COVID-plan-june-2021.pdf>

² National Institute for Health and Care Excellence (NICE). (2020). COVID-19 rapid guideline: managing the long-term effects of COVID-19. <https://www.nice.org.uk/guidance/ng188/chapter/Context>

1.2. In an ONS survey³, 65% of respondents with self-reported Long COVID stated that Long COVID symptoms had negatively impacted their day-to-day activities. The most reported symptom was fatigue (55%), which was followed by shortness of breath (39%), loss of smell (33%), and difficulty concentrating (30%).

2. Long-COVID Prevalence

2.1. As of 2 October 2021, around 1.2 million people living in private households in the UK, representing 1.9% of the population, self-reported experiencing Long COVID. This marks an increase of around 100,000 people, or 0.2% of the population since 5 September 2021.

2.2. There were an estimated 149,000 individuals living in private households in the South East who self-reported experiencing Long COVID as of 2 October 2021, corresponding to 1.68% of the population⁴. This is below the England average of 1.9%.

2.3. The prevalence of self-reported Long COVID is highest among people aged between 35 to 69 years, females, people living in more deprived areas, people working in health or social care, and people with an activity-limiting health condition or disability.

2.4. Recently, there has been an increase in self-reported Long COVID among young adults aged between 12 to 16 or 17 to 24 years. Additionally, in August and September of 2021, there was a notable increase in Long COVID amongst people working in the hospitality sector⁵.

2.5. UK-wide data on self-reported Long COVID shows that out of those self-reporting Long COVID, 20% first had, or suspected that they had, COVID-19 in the past 12 weeks, 71% first had COVID-19 more than 12 weeks ago, and 35% first had COVID-19 at least one year previously⁶. In a consultation among Kent and Medway Long COVID patients, the majority (40%) had been unwell for over 6 months.

2.6. Given the dynamic nature of the pandemic, it is difficult to fully quantify the exact prevalence or specific number of people in Medway who have ongoing symptoms of long COVID. On this basis the current prevalence as noted for the

³ Office for National Statistics (ONS). (2021). Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 4 November 2021.

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronavirusCOVID19infectionintheuk/4november2021>

⁴ Office for National Statistics (ONS). (2021). Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK.

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/datasets/alldatarelatingtoprevalenceofongoingsymptomsfollowingcoronavirusCOVID19infectionintheuk>

⁵ Office for National Statistics (ONS). (2021). Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 7 October 2021.

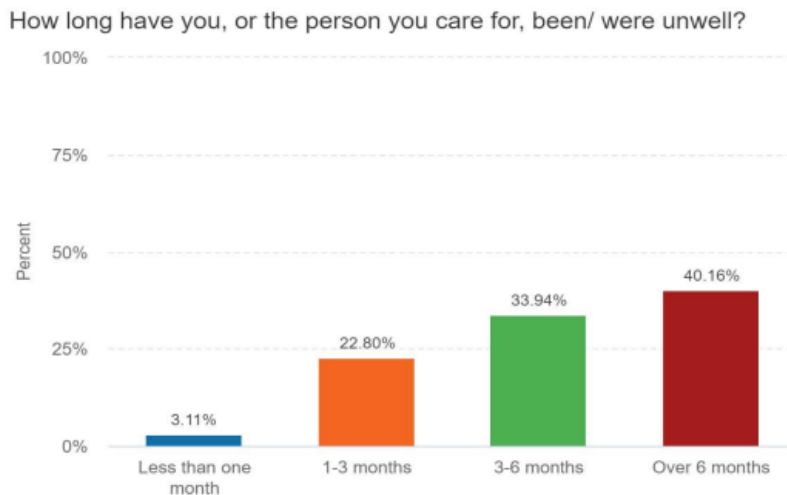
<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronavirusCOVID19infectionintheuk/7october2021>

⁶ Office for National Statistics (ONS). (2021). Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 4 November 2021.

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronavirusCOVID19infectionintheuk/4november2021>

South East should be applied in Medway. Further work is underway to quantify local prevalence. The board will be updated in due course when this work is completed.

Figure 2. Duration of Long COVID symptoms among Long COVID patients in Kent and Medway⁷



3. Long COVID Patient Needs

- 3.1. The Kent and Medway Clinical Commissioning Group (CCG) carried out a patient consultation with 512 individuals experiencing Long COVID in Kent and Medway between March to May 2021⁸.
- 3.2. Findings showed that more than 70% said that Long COVID has affected their work and their mental health, and 62% stated that it has affected their social life.

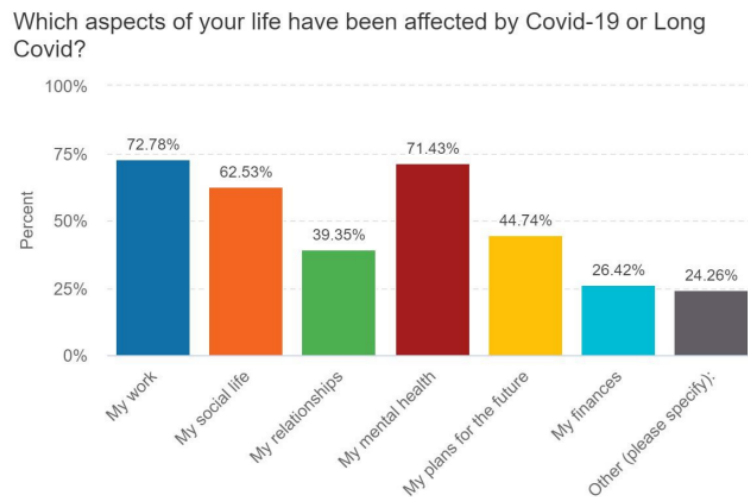
⁷ Figure taken from: Kent and Medway Clinical Commissioning Group (CCG). (2021). Patient experiences of Long COVID in Kent and Medway: Engagement report March to May 2021.

https://www.kentandmedwayccg.nhs.uk/application/files/2916/2930/4168/Kent_and_Medway_Long_COVID_Patient_Engagement_Findings_Report_FINAL.pdf

⁸ Kent and Medway Clinical Commissioning Group (CCG). (2021). Patient experiences of Long COVID in Kent and Medway: Engagement report March to May 2021.

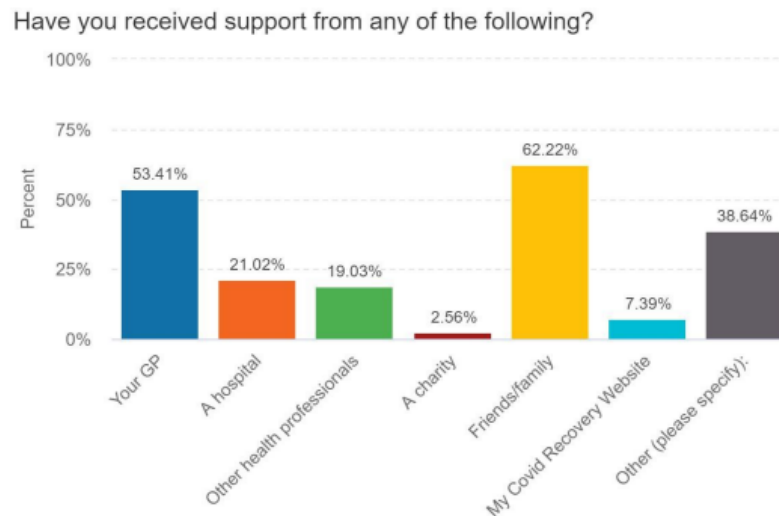
https://www.kentandmedwayccg.nhs.uk/application/files/2916/2930/4168/Kent_and_Medway_Long_COVID_Patient_Engagement_Findings_Report_FINAL.pdf

Figure 3. Effects of Long COVID on patient's lives in Kent and Medway⁹



3.3. Most of the respondents experiencing Long COVID and Kent and Medway said they received support from friends and family (62%), followed by GPs (53%). Patients thought that there was a lack of information as well as a lack of clinical understanding amongst healthcare professionals about Long COVID.

Figure 4. Experiences of support of Long COVID patients in Kent and Medway¹⁰



3.4. Findings from the patient consultation concluded that the following steps should be taken by the CCG and partners to support individuals in their recovery from Long COVID:

⁹ Figure taken from: Kent and Medway Clinical Commissioning Group (CCG). (2021). Patient experiences of Long COVID in Kent and Medway: Engagement report March to May 2021.

https://www.kentandmedwayccg.nhs.uk/application/files/2916/2930/4168/Kent_and_Medway_Long_COVID_Patient_Engagement_Findings_Report_FINAL.pdf

¹⁰ Figure taken from: Kent and Medway Clinical Commissioning Group (CCG). (2021). Patient experiences of Long COVID in Kent and Medway: Engagement report March to May 2021.

https://www.kentandmedwayccg.nhs.uk/application/files/2916/2930/4168/Kent_and_Medway_Long_COVID_Patient_Engagement_Findings_Report_FINAL.pdf

- Establish patient led support groups
- Create a single point of contact for advice and recovery management
- Carry out an information campaign
- Offer employment and financial advice and support
- Offer ongoing mental health support

4. Current service provision for Long COVID patients

4.1. Currently there are a wide variety of resources and support for people experiencing Long COVID. Current resources for Kent and Medway residents experiencing Long COVID include:

- The Kent and Medway Post COVID Assessment Service (PCAS). This service has been offered since 14 May 2021¹¹. It comprises an expert team of professional who will assess a person's condition and provide support in accessing services to help recovery. Generally, patients are seen within six weeks, but the service continues to receive a high number of referrals. The service has had over 1,200 referrals since its inception.
- A new GP Enhanced Service for Long COVID across England¹², with £30 million made available by the NHS to support the rollout¹³. The Enhanced Service is offered to all GP practices until 31 March 2022 and is a national specification that cannot be varied locally. All GP practices can sign up to the ES given they meet the requirements. In Kent and Medway, over 90% of GP practices have signed up to the Enhanced Service. Additionally, 250 GPs attended the virtual Long COVID Best Practice Forum and Education in October 2021.
- Kent and Medway CCG have set up a Long COVID Patient Reference Group where Long COVID patients and their carers can provide feedback and explain their needs¹⁴.
- Currently, an important piece of work around inequalities and Long COVID in Kent and Medway is being undertaken to ensure the service is reaching those that need it.
- Extensive patient engagement has been undertaken to determine what matters to them and where efforts to develop services and improve pathways for Long COVID patients should be placed.
- Plans for additionally received Long COVID funding are being put in place via a K&M Steering Group. Key priorities include a peer & carer support offer, ongoing care coordination and case management, vocational rehabilitation as well as improving diagnostics and specialist pathways.
- Information on Mental Wellbeing Support can be found on the Kent and Medway mental well-being information hub¹⁵.

¹¹ Kent and Medway Clinical Commissioning Group (CCG). Long COVID. <https://www.kentandmedwayccg.nhs.uk/your-health/coronavirus/your-COVID-recovery>

¹² National Health Service (NHS). (2021). Enhanced service specification: Long COVID 2021/22. <https://www.england.nhs.uk/wp-content/uploads/2021/06/C1313-ess-long-COVID-21-22.pdf>

¹³ National Health Service (NHS). (2021). Long COVID: the NHS plan for 2021/22. <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2021/06/C1312-long-COVID-plan-june-2021.pdf>

¹⁴ Kent and Medway Clinical Commissioning Group (CCG). Improving services for people recovering from COVID-19. <https://www.kentandmedwayccg.nhs.uk/get-involved/our-involvement-work/improving-services-people-recovering-COVID-19>

¹⁵ Kent and Medway Clinical Commissioning Group (CCG). Mental wellbeing information hub. <https://www.kentandmedwayccg.nhs.uk/mental-wellbeing-information-hub>

- The NHS website ‘Your COVID Recovery’¹⁶ offers supporting information on recovery after COVID-19, including advice on self-care.
- Local service provided by ‘A Better Medway’¹⁷ can also support recovery. This includes specialist services to enable people to reaching a healthy weight, stop smoking, become more active or engage in other social activities to improve mental wellbeing.
- The NHS is establishing 15 Long COVID paediatric hubs across England to coordinate care for children and young people¹⁸. The NHS has also established a specific workplace Long COVID programme for staff ‘NHS Our People’. The enables NHS workers to access free confidential support, wellbeing apps for physical and mental health and direct wellbeing services are available for NHS workers¹⁹.

5. Additional considerations for service development

- 5.1. Services for Long COVID must be accessible and inclusive. There is a risk of underrepresentation of vulnerable groups in the planning and development of Long COVID services. For example, in the patient consultation of Kent and Medway CCG, BAME communities and those living in deprived areas were underrepresented despite having been particularly badly affected by COVID-19. Therefore, further engagement and outreach work for vulnerable groups and communities to include their opinions in the planning of services is needed. As mentioned above, an important piece of work focusing on inequalities and Long COVID is currently underway. The Kent and Medway CCG have provided an update and paper on local Long COVID Services, to the Health and Adults Overview and Scrutiny Committee meeting of the 9th December 2021.

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¹⁶ National Health Service (NHS). Your COVID Recovery. <https://www.yourCOVIDrecovery.nhs.uk/>

¹⁷ Medway Council. A Better Medway. https://www.medway.gov.uk/info/200221/a_better_medway

¹⁸ National Health Service (NHS). (2021). Long COVID: the NHS plan for 2021/22. <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2021/06/C1312-long-COVID-plan-june-2021.pdf>

¹⁹ National Health Service (NHS). Supporting our people. <https://people.nhs.uk/>

Background papers

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