

CSP COVID-19 Rehabilitation Standards

Palliative rehabilitation and end of life care: physiotherapy service delivery

Version 2, published 29th September 2021

How these standards were developed

The standards are underpinned by national guidance and standards, in particular by National Institute for Health and Care Excellence (NICE), National Institute for Health Research (NIHR), government and profession-specific guidance on COVID-19. COVID-19 is a new condition with an emerging evidence base.

The standards draw on available evidence, expert opinion and the lived experiences of people with Long COVID.

The standards will be reviewed and updated as the knowledge base and expert experience develop.

Acknowledgements

The Chartered Society of Physiotherapy wishes to acknowledge the expert peer reviewers for their contribution to the development of these standards.

Expert peer reviewers

ACPOPC (Association of Chartered Physiotherapists in Oncology and Palliative Care) – Version 1 and 2

AGILE (Chartered Physiotherapists working with older people) - Version 1

Reviewers of the CSP COVID-19 Community Rehabilitation Standards [RS3]

CSP project team

Authors:

Fran Hallam Gabrielle Rankin Julie Blackburn (standard 7)

Reviewers:

Tamsin Baird Ruth ten Hove Rachael Wadlow

Palliative rehabilitation and end of life care: physiotherapy service delivery

CSP Standards [RS2] are one of a series of CSP COVID-19 Rehabilitation Standards.

They can be used in conjunction with:

- CSP Standards [RS1]: <u>Rehabilitation of adults who are hospitalised due to acute</u> <u>COVID-19 or Long COVID: physiotherapy service delivery</u>
- CSP Standards [RS3]: Community rehabilitation: physiotherapy service delivery

Scope

These standards cover rehabilitation and physiotherapy care for adults of 18 years and over with COVID-19 who are approaching the end of their life and are likely to die within 12 months. This includes people who are likely to die from COVID-19 and people with COVID-19 who have advanced, progressive, incurable conditions or life-threatening acute conditions. These standards also cover support for their families and carers.

The standards apply to rehabilitation and physiotherapy delivered in all settings. Rehabilitative palliative care integrates rehabilitation, enablement, self-management and self-care into the holistic model of palliative care.² For people at the end of life, responsive and compassionate care ensures that the person is as comfortable as possible if their condition continues to deteriorate.³

The standards apply to anyone with rehabilitation needs who has acute COVID-19 or Long COVID, and their families and carers. Acute COVID-19 describes signs and symptoms of COVID-19 for up to 4 weeks.⁴ Long COVID is a term commonly used to describe signs and symptoms that continue or develop after acute COVID-19.⁴ For more information about Long COVID, see <u>CSP COVID-19 Rehabilitation Standards</u> <u>RS3 (community rehabilitation: physiotherapy service delivery).</u>

In these standards the term COVID-19 encompasses acute COVID-19 and Long COVID.

The standards are for the physiotherapy workforce delivering rehabilitation in a multidisciplinary care context. The standards are key for facilitating safe and rapid decision making and ensuring the delivery of consistent, high quality, personalised assessment and physiotherapy. They should be used in conjunction with local policies and procedures.

- ¹ End of life care for adults (2017) NICE quality standard QS13
- ² <u>Tiberini R, Richardson H</u> (2018) Rehabilitative Palliative Care: Enabling people to live fully until the day. Hospice UK
- ³ Care of dying adults in last days of life (2017) NICE quality standard QS144
- ⁴ <u>COVID-19 rapid guideline: managing the long-term effects of COVID-19</u> (2020) NICE guideline NG188

Updates in version 2

Version 2 of these standards has been updated in line with CSP standards RS1 and RS3. Also, to take into account updated guidance and emerging evidence including people's lived experiences regarding:

- sequelae of COVID-19 including Long COVID
- clinical risk stratification, functional screening tools and ongoing assessment
- personalised symptom management
- monitoring response to rehabilitation and individualising timing, intensity and frequency of rehabilitation
- supported self-management and self-monitoring, including principles of pacing and energy management
- impact of inequities and disparities in outcome.

In these standards the term COVID-19 encompasses acute COVID-19 and Long COVID.

Quality standards

- 1. Holistic assessment, planning and review
- 2. Personalised rehabilitation and symptom management
- 3. Supported self-management
- 4. Communication and information sharing with people with COVID-19
- 5. Integrated and coordinated rehabilitation
- 6. Evaluation, audit and research
- 7. Personal Protective Equipment (PPE) and infection control.

Standard 1:

Holistic assessment, planning and review

Quality statement 1

- 1. People with COVID-19 approaching the end of life are offered comprehensive holistic assessments with the opportunity to discuss, co-produce and review a personalised rehabilitation and care plan.
 - 1.1 Undertake a person-centred, holistic needs assessment coordinating, as appropriate, with the individual's family and carers and the multidisciplinary team and taking into account the emerging evidence about the multidimensional sequelae of COVID-19 and variation in outcomes from COVID-19
 - **1.2** Assessment and review informs the identification of people approaching the end of life
 - 1.3 Consider risk stratification and functional screening to inform personalised rehabilitation planning
 - 1.4 Rehabilitation planning, goal setting and outcome measurement is personalised and where possible, involves shared decision making based on what matters to the individual and their individual strengths, needs and preferences
 - 1.5 Physiotherapy assessments contribute to the overall multidisciplinary needs assessment and to the identification of specialist expertise requirements
 - 1.6 Assessments, care planning and reviews are timely and responsive to the person's likely prognosis, their changing clinical and rehabilitation needs, their response to rehabilitation and their personalised outcome measures
 - 1.7 Identify the needs and preferences of families and carers of people with COVID-19 and provide information about how they can access advice, support and a carer's assessment.

Rationale

People with COVID-19 often present with a wide range of clinical, physical, psychological (including cognitive), emotional, cultural, social and spiritual needs. A holistic assessment considers the overall health and wellbeing of the person. The emerging evidence about the aetiology and sequelae of COVID-19, including inequalities and disparities in outcomes, should be taken into account. Age, gender, areas of deprivation, ethnic minority groups, disabilities, comorbidities such as diabetes and obesity, occupation, and lifestyle factors such as smoking are associated with disparities in risk and outcomes. Pre-existing health conditions affect individual needs and prognosis. Fatigue is a commonly reported symptom by people with palliative diagnoses, therefore it may be difficult to ascertain how much of these symptoms is due to COVID-19 and how much is the underlying disease. The impact of COVID-19 related restrictions on individuals and services should also be considered.

Identification of people approaching the end of life may be initiated by either health or social care professionals in any setting. People who have signs and symptoms that suggest they may be in the last days of life are monitored for further changes to help determine if they are nearing death, stabilising or recovering.

Risk stratification requires awareness of the person's prognosis as well as COVID-19 sequelae that contraindicate rehabilitation and require onward referral and investigation. It also identifies people at risk of rapid deterioration and with symptoms that require careful monitoring during rehabilitation. For further detail about risk stratification and screening prior to rehabilitation, see the *World Physiotherapy briefing paper 9 (2021)* and Alberta Health Services Rehabilitation and Allied Health Practice Considerations Post COVID-19 (2021) http://alberta Health Services Rehabilitation and Allied Health Practice Considerations Post COVID-19 (2021). For evidence about COVID-19 sequelae and investigations, see the Post-acute COVID-19 syndrome review article (*Nalbandian et al, 2021*) and the *Management of post-acute COVID-19 in primary care paper (Greenhalgh et al, 2020*). For details about urgent specialist referral see section three of the *NICE COVID-19 rapid guideline: managing the long-term effects of COVID-19 (2020)*.

COVID-19 is a multisystem condition and therefore a wide range of expertise from across health and social care settings and support services, specialities and multidisciplinary teams (MDT) may be required for individualised assessments, rehabilitation and care planning. Focussing on assessing needs and including a comprehensive clinical history, helps the person and MDTs to develop an individualised rehabilitation plan. Outcome measures should be personalised and repeated as part of ongoing assessment, monitoring response to rehabilitation and informing the rehabilitation plan.

Functional screening tools identify problems that are likely to require more detailed evaluation by members of the MDT and inform development of the personalised rehabilitation plan. Screening also helps to stratify rehabilitation requirements in terms of who, how and when rehabilitation is delivered including specialist expertise requirements. Functional screening tools have been developed for people with Long COVID, for example the COVID-19 Yorkshire Rehabilitation Scale (C19-YRS) (C19-YRS); Sivan, Halpin and Gee, 2020). Functional screening tools have also been developed specifically for people who have received critical care, for example PICUPS-Plus for people who are progressing towards discharge from hospital and PICUPS-Community which is a self-reported tool for monitoring ongoing rehabilitation needs following discharge to community settings (National Post-Intensive Care Rehabilitation Collaborative, 2020).

Some people with COVID-19 may have post-exertional symptom exacerbation (PESE), also known as post-exertional malaise (PEM). One definition of PESE is the triggering or worsening of symptoms that can follow minimal cognitive, physical, emotional or social activity, or activity that could previously be tolerated. The timing of PESE after exertion is variable and unpredictable. This should be taken into account when assessing people with COVID-19 and planning their rehabilitation. For more information on PESE, see the Long COVID Physio website. The NIHR Living with COVID-19 second review (2021) synthesises the evidence in relation to the use of exercise as part of rehabilitation.

Personalised assessment and needs-based planning involves shared decision making between the individual and the professionals supporting them, putting the person at the centre of decisions about their rehabilitation. People's personal strengths, preferences, aspirations and needs help inform the choice of goals, rehabilitation planning and outcome measurements. Both the MDT and the person have a role and responsibility for contributing to the decision making process. The MDT contribute information and discuss the diagnosis, cause of disease, prognosis, and the potential benefits, risks and consequences of different rehabilitation and care options where appropriate. Whereas, the person contributes the experience of their illness, triggers that may exacerbate their symptoms, how they manage their illness, social circumstances, attitudes to risk, values and preferences. Shared decision making and person-centred goals has been shown to significantly improve the experience of people approaching the end of their life and enhance their quality of life (*NHS England, 2020*). Providing the person gives consent, carers should be supported to actively participate in decision making and care planning.

For a person approaching the end of life, assessments and personalised care planning should be carried out in a sensitive way and in their best interests, with appropriate consent. Personalised care planning should encompass all aspects of end of life care, taking into account the preferences of the person approaching the end of life, and their families and carers. Advance/anticipatory care planning is one part of personalised care planning and involves discussions about an individual's priorities about care or treatment and ensures that they are respected in the event of deteriorating health. This may need to be revisited and revised as the situation changes.

Timing of assessments needs to be individualised due to the diverse clinical presentations of COVID-19, the episodic nature of symptoms and late onset of new symptoms. Any pre-existing conditions also need to be taken into account. Needs assessment, outcome measurement, personalised care planning and review should be an ongoing and proactive process involving the individual that is both planned and responsive to changing needs.

The clinical status and symptoms of some people with COVID-19 can fluctuate for example, oxygen saturation levels, heart rate, and symptoms occurring with PESE. This requires careful monitoring and should inform the ongoing assessment and rehabilitation plan. The timing, length and setting of an individual's assessments and rehabilitation should be flexible and adapted based on the individual's symptoms, needs and preferences. Consideration of current <u>national</u> and local guidance should inform whether needs assessments are undertaken in person or remotely. This may impact on the assessment tools which can be used, for instance measurement of blood oxygen saturation or using a validated pulse oximeter.

Regular needs assessment helps ensure signs of deterioration and/or worsening disability are recognised and appropriate care and/or rehabilitation is in place. Regular review by the MDT should identify any individual needs for equipment including oxygen provision, adaptations and specialist input to help maximise independence and maintain it for as long as possible. This may also reduce the length of hospital stay, avoid hospital admission, and ensure the person remains in their preferred place of care.

It is important to identify carers, including family members or friends, and assess their needs and preferences at the earliest opportunity. Carers should be encouraged to recognise their role and rights and provided with information about accessing advice and support. Anyone who is an unpaid carer for a family member or friend has the statutory right to a carer's assessment with their local authority. This provides the opportunity to discuss what matters most to them, including their health and wellbeing and any help and support they may need.

Source Guidance

<u>COVID-19 rapid guideline: managing COVID-19</u> (2021) NICE guideline NG191, recommendations 4, 5 and 6.1.1

COVID-19 rapid guideline: managing the long-term effects of COVID-19 (2020) NICE guideline NG188, recommendations 1.5, 1.8, 2.1-2.4, 3.5, 3.6, 5.4, 6.1, 6.2, 6.5

Shared decision making (2021) NICE guideline NG197, recommendations 1.2-1.4

Supporting adult carers (2021) NICE quality standards QS200, standards 1-3

End of life care for adults: service delivery

(2019) NICE guideline NG142, recommendations 1.1-1.3, 1.5-1.7, 1.9, 1.10

Patient experience in adult NHS services

(2019) NICE quality standard QS15, standards 3 and 6

Care of dying adults in last days of life

(2017) NICE quality standard QS144, standards 1 and 2 QS144

End of life care for adults (2017) NICE quality standard QS13, standards 1-4, 7 and 9

Rehabilitation after critical illness in adults

(2017) NICE quality standard QS158, standards 3 and 4

Mental wellbeing and independence for older people

(2016) NICE quality standard QS137, standard 1

<u>Transition between inpatient hospital settings and community or care home settings</u> <u>for adults with social care needs</u> (2016) NICE quality standard QS136, standard 2

<u>End of life care guidance when a person is imminently dying from COVID-19 lung</u> <u>disease</u> (2020) Scottish palliative care guidelines, NHS Scotland

Hospital discharge service: policy and operating model

(2021) Department of Health and Social Care, section 5.4

<u>Living with COVID19. Second Review. A dynamic review of the evidence around ongoing COVID19 symptoms (often called Long COVID)</u>

(2021) National Institute for Health Research

Long COVID: the NHS plan for 2021/22 Version 1 (2021) NHS England

<u>National guidance for post-COVID syndrome assessment clinics Version 2</u> (2021) NHS England

<u>Updated estimates of coronavirus (COVID-19) related deaths by disability status,</u> <u>England: 24 January to 20 November 2020</u> (2021) Office for National Statistics

COVID-19 Clinical Advice. Supporting people with COVID-19 related illness in the community setting: Clinical management of those with moderate to severe illness Version 2.1 (2020) Scottish Government

COVID-19: Review of disparities in risks and outcomes (2020) Public Health England

<u>Developing a modelling resource to understand the rehabilitation needs of people</u> <u>during, and following, the COVID-19 pandemic</u> (2020) Welsh Government

<u>Framework for supporting people through Recovery and Rehabilitation during and after the COVID-19 Pandemic</u> (2020) Scottish Government

<u>Hospital discharge service requirements: COVID-19 (Wales)</u> (2020) Welsh Government

<u>Implementing phase 3 of the NHS response to the COVID-19 pandemic</u> (2020) NHS England

Rehabilitation: a framework for continuity and recovery 2020 to 2021 (2020) Welsh Government

Reducing health inequalities associated with COVID-19. A framework for healthcare providers (2020) NHS Providers

Hospital discharge service: policy and operating model (2021) Department of Health and Social Care

Inclusion Health: applying All Our Health (2021) Public Health England

RightCare: Community Rehabilitation Toolkit

(2020) NHS RightCare NHS RightCare: Frailty Toolkit (2019) NHS RightCare

RightCare: Progressive Neurological Conditions Toolkit (2019) NHS RightCare

Palliative and End of Life Care Delivery Plan

(2017) NHS Wales and the Welsh Government, themes 1-5

Commissioning guidance for rehabilitation (2016) NHS England

Palliative Care Adult Network Guidelines. 4th edition

(2016) Watson M et al, last days of life chapter

NHS Standard Contract for Specialised Rehabilitation for Patients with Highly Complex Needs (All Ages) (2013) NHS England

<u>COVID-19 Clinical management: living guidance</u> (2021) World Health Organisation

<u>Evaluating and Caring for Patients with Post-COVID Conditions: Interim Guidance</u> (2021) Centers for Disease Control and Prevention

In the wake of the pandemic: Preparing for Long COVID (2021) World Health Organisation

World Physiotherapy Response to COVID-19 briefing paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise (2021) World Physiotherapy

<u>A National COVID-19 Resilience Programme: Improving the health and wellbeing of older people during the pandemic</u> (2020) The Physiological Society

Build back fairer: the COVID-19 Marmot Review (2020) Institute of Health Equity

COVID-19 and Palliative, End of Life and Bereavement Care in Secondary Care.

Version 2 (2020) Northern Care Alliance NHS Group and the Association for Palliative Medicine of Great Britain and Ireland

<u>COVID-19: Managing the COVID-19 pandemic in care homes for older people</u> Version 4 (2020) British Geriatrics Society

Keeping Me Well: COVID-19 Rehabilitation Model

(2020) Cardiff and Vale University Health Board

Rehabilitation in the wake of COVID-19 - A phoenix from the ashes

Version 1 (2020) British Society of Rehabilitation Medicine report

Responding to COVID-19 and beyond: A framework for assessing early rehabilitation needs following treatment in intensive care.

Version 1 (2020) National Post-Intensive Care Rehabilitation Collaborative

Royal College of General Practitioners - Written evidence (COV0051). Ongoing or persistent symptoms of COVID-19 (Long COVID) (2020) UK Parliament

<u>Ambitions for Palliative and End of Life Care: A national framework for local action</u> <u>2021-2026</u> (2021) National Palliative and End of Life Care Partnership, ambitions 1-3

My role in tackling health inequalities: a framework for allied health professionals (2021) The King's Fund

<u>Silver Book II: quality urgent care for older people</u> (2021) British Geriatrics Society

<u>Digital Inclusion in Health and Care: Lessons learned from the NHS Widening Digital</u> <u>Participation Programme (2017-2020)</u> (2020) Good Things Foundation

End of Life Care in Frailty

(2020) British Geriatrics Society guidance series, rehabilitation chapter

National care standards: hospice care (2005) Scottish Executive, standard 2

<u>Chartered Society of Physiotherapy COVID-19 Rehabilitation Standards.</u>

<u>Rehabilitation of adults who are hospitalised due to acute COVID-19 or Long COVID:</u>

<u>physiotherapy service delivery [RS1]</u> (2021) Chartered Society of Physiotherapy

<u>Chartered Society of Physiotherapy COVID-19 Rehabilitation Standards. Community rehabilitation: physiotherapy service delivery [RS3]</u>
(2021) Chartered Society of Physiotherapy

<u>Digital or physical consultations: supporting you to make safe decisions about patient contact</u> (2021) Chartered Society of Physiotherapy

<u>Chartered Society of Physiotherapy's Code of Members' Professional Values and Behaviour</u> (2019) Chartered Society of Physiotherapy, principles 1-3

Standards of proficiency - Physiotherapists

(2013) Health and Care Professions Council, standards 1-11 and 14

Standard 2:

Personalised rehabilitation and symptom management

Quality statement 2

- 2. People with COVID-19 approaching the end of life are offered holistic, equitable rehabilitation and/or symptom management as early as clinically appropriate, based on their personalised needs assessment and rehabilitation plan.
 - 2.1 Rehabilitation and symptom management is holistic and undertaken in discussion with the multidisciplinary team, taking into account the person's clinical needs and preferences
 - 2.2 During rehabilitation the person's clinical presentation (e.g. respiratory and cardiovascular function) may require close monitoring
 - 2.3 Timing, intensity, frequency and setting of rehabilitation is personalised and flexible to the person's individual needs, symptoms and response to rehabilitation
 - 2.4 Principles of pacing and energy management, including recognition of signs of post-exertional symptom exacerbation, are incorporated into rehabilitation interventions
 - 2.5 The physiotherapy workforce share knowledge, skills and expertise with the multidisciplinary teams, families and carers so that rehabilitation and symptom management is integrated within daily care and activity
 - 2.6 Rehabilitation and symptom management includes facilitation of participation in meaningful life roles
 - 2.7 The potential of technology-enabled rehabilitation requires consideration, taking into account the person's needs, symptoms and preferences
 - 2.8 Families and carers of people approaching end of life are offered holistic support appropriate to their current needs and preferences.

Rationale

Palliative care integrates rehabilitation, enablement, self-management, self-care and symptom management into the holistic model of palliative care. Effective rehabilitation is personalised and takes into account the physical, psychological (including cognitive), emotional, social and economic impacts of COVID-19. People with COVID-19 approaching end of life may have other health conditions and may have very different abilities and rehabilitation needs. Rehabilitation should take into account the complex interaction between the person's health conditions, the contexts and environments they live in, their values and beliefs, to actively reduce inequalities.

The aim of symptom management is to optimise the person's clinical status and ability to undertake activities of daily living, to do the things that matter most and/or rehabilitation. People approaching end of life may deteriorate quickly and the aim of symptom management will be to achieve optimum comfort level.

Delays in starting rehabilitation can increase the risk of further deterioration in the person's condition and lead to reduced independence. Starting rehabilitation early can improve physical, psychological (including cognition) and emotional wellbeing. However, people with COVID-19 often have complex clinical presentations and therefore the decision of when it is appropriate to start rehabilitation requires discussion with them and the multidisciplinary team (MDT). The sequelae of COVID-19 can be unpredictable and episodic, requiring ongoing input from the MDT to tailor rehabilitation.

Fatigue/exhaustion, breathlessness, oxygen desaturation and 'brain fog' are examples of symptoms that may be exacerbated by exertion. Oxygen desaturation may occur on exertion and can be unrelated to oxygen saturation at rest and the degree of dyspnoea. Pre-existing conditions should be taken into account when assessing desaturation on exertion. Symptoms must be assessed, monitored and managed carefully during and following rehabilitation. For further details, see the *World Physiotherapy briefing paper* 9 (2021).

Physiotherapists who are experiencing Long COVID have developed a <u>website</u> which includes resources about rehabilitation for some of the frequent sequelae of COVID-19, for example breathing pattern disorders, autonomic dysfunction and postural orthostatic tachycardia syndrome and brain fog. Considerations for COVID-19 rehabilitation are outlined in guidance developed by <u>Alberta Health Services (2021)</u>.

"Stop. Rest. Pace", energy and activity management, and heart rate monitoring may be effective rehabilitation approaches for people experiencing post-exertional symptom exacerbation (PESE). These approaches aim to stabilise and improve symptom severity over a period of time and optimise function.

Timing, intensity, frequency and setting of rehabilitation is individualised taking into account the person's needs assessment, their personalised care plan, the fluctuating nature of COVID-19 and response to rehabilitation. Facilitating rehabilitation and symptom management little and often and integrated into daily care and activity minimises the risk of complications and empowers people to optimise physical functioning and independence.

The physiotherapy workforce provides a vital role in sharing their expertise to enable all the MDTs, families and carers (formal and informal) to be actively involved in delivering personalised rehabilitation plans, to optimise the person's independence and social participation.

Rehabilitation is an active and enabling process which includes supporting and working with the person, their carers and those involved in helping them to achieve their personal goals in relation to meaningful life roles. A survey from the Office for National Statistics (*ONS, 2021*) reported 63.7% of people with Long COVID experienced limitation to daily activities. Another survey reports that 71% of people with Long COVID said it was affecting family life and 39% said it was impacting their ability to care for dependents (*NIHR, 2021*). For further information about supporting people in relation to education, work and meaningful life roles, see *CSP COVID-19 Rehabilitation Standards RS3 (Community rehabilitation: physiotherapy service delivery)*.

Regular review by the MDT can ensure the provision of equipment and adaptations is responsive to the person's changing needs. Providing equipment and adaptions without delay maximises the impact on the person's quality of life, their functional ability and reduces the likelihood of harm from adverse events. Rehabilitation may also enable people to remain in their own home when this is their preferred place of care.

The delivery of rehabilitation takes into account the person's needs and preferences, equity considerations and risk assessment of providing in person care. The physiotherapy workforce should consider and assess suitability of remote consultation and online rehabilitation resources available. Digital and assistive technology has great potential to support rehabilitation and optimise the person's independence.

Families and carers may need emotional and psychological support. Many carers struggle to maintain their own wellbeing and often overlook their own needs because of their caring responsibilities. The physiotherapy workforce have a role to play in providing support as well as helping carers access advice, relevant services and support groups.

Source guidance

COVID-19 rapid guideline: managing COVID-19

(2021) NICE guideline NG191, recommendations 4 and 6.1.2-6.1.5

COVID-19 rapid guideline: managing the long-term effects of COVID-19

(2020) NICE guideline NG188, recommendations 3.5, 5.3, 5.5, 6.2, 6.4, 6.5, 8.2

Shared decision making (2021) NICE guideline NG197, recommendations 1.2-1.4

Supporting adult carers (2021) NICE quality standards QS200, standards 1, 3 and 4

Patient experience in adult NHS services

(2019) NICE quality standard QS15, standards 3, 4 and 6

End of life care for adults (2017) NICE quality standard QS13, standards 4-7

Motor neurone disease (2016) NICE quality standard QS126, standards 3 and 5

Hospital discharge service: policy and operating model

(2021) Department of Health and Social Care, section 5.4

Living with COVID19. Second Review. A dynamic review of the evidence around ongoing COVID19 symptoms (often called Long COVID)

(2021) National Institute for Health Research

Long COVID: the NHS plan for 2021/22 Version 1 (2021) NHS England

National guidance for post-COVID syndrome assessment clinics

Version 2 (2021) NHS England

<u>COVID-19 Clinical Advice. Supporting people with COVID-19 related illness in the</u> <u>community setting: Clinical management of those with moderate to severe illness</u>

Version 2.1 (2020) Scottish Government

COVID-19: Review of disparities in risks and outcomes (2020) Public Health England

<u>Developing a modelling resource to understand the rehabilitation needs of people</u> <u>during, and following, the COVID-19 pandemic</u> (2020) Welsh Government

End of life care guidance when a person is imminently dying from COVID-19 lung disease (2020) Scottish palliative care guidelines, NHS Scotland

<u>Framework for supporting people through Recovery and Rehabilitation during and after the COVID-19 Pandemic</u> (2020) Scottish Government

<u>Reducing health inequalities associated with COVID-19. A framework for healthcare providers</u> (2020) NHS Providers

Inclusion Health: applying All Our Health (2021) Public Health England

<u>Rehabilitation: a framework for continuity and recovery 2020 to 2021</u> [HTML] | GOV.WALES

RightCare: Community Rehabilitation Toolkit (2020) NHS RightCare

A Digital Framework for Allied Health Professionals (2019) NHS England

<u>The Topol Review: Preparing the healthcare workforce to deliver the digital future</u> (2019) NHS Health Education England

Palliative and End of Life Care Delivery Plan

(2017) NHS Wales and the Welsh Government, theme 4

Commissioning guidance for rehabilitation (2016) NHS England

<u>eHealth and Care Strategy for Northern Ireland: Improving health and wealth</u> <u>through the use of information and communication technology</u> (2016) Health and Social Care Board

<u>Informed Health and Care: A Digital Health and Social Care Strategy for Wales</u> (2015) Welsh Government

NHS Standard Contract for Specialised Rehabilitation for Patients with Highly Complex Needs (All Ages) (2013) NHS England

COVID-19 Clinical management: living guidance (2021) World Health Organisation

<u>Evaluating and Caring for Patients with Post-COVID Conditions: Interim Guidance</u> (2021) Centers for Disease Control and Prevention

In the wake of the pandemic: Preparing for Long COVID (2021) World Health Organisation

World Physiotherapy Response to COVID-19 briefing paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise (2021) World Physiotherapy

<u>A National COVID-19 Resilience Programme: Improving the health and wellbeing of older people during the pandemic</u> (2020) The Physiological Society

Build back fairer: the COVID-19 Marmot Review (2020) Institute of Health Equity

COVID-19 and Palliative, End of Life and Bereavement Care in Secondary Care.

Version 2 (2020) Northern Care Alliance NHS Group and the Association for Palliative Medicine of Great Britain and Ireland

Keeping Me Well: COVID-19 Rehabilitation Model

(2020) Cardiff and Vale University Health Board

COVID-19: Managing the COVID-19 pandemic in care homes for older people Version 4 (2020) British Geriatrics Society

Rehabilitation in the wake of COVID-19 - A phoenix from the ashes

(2020) British Society of Rehabilitation Medicine report, Version 1

Responding to COVID-19 and beyond: A framework for assessing early rehabilitation needs following treatment in intensive care.

Version 1 (2020) National Post-Intensive Care Rehabilitation Collaborative

<u>Ambitions for Palliative and End of Life Care: A national framework for local action</u> <u>2021-2026</u> (2021) National Palliative and End of Life Care Partnership, ambitions 1, 2 and 6

My role in tackling health inequalities: a framework for allied health professionals (2021) The King's Fund

<u>Silver Book II: quality urgent care for older people</u> (2021) British Geriatrics Society

<u>Digital Inclusion in Health and Care: Lessons learned from the NHS Widening Digital</u> <u>Participation Programme (2017-2020)</u> (2020) Good Things Foundation

Personalised Care Institute Curriculum (2020) Personalised Care Institute

Tiberini R, Richardson H

(2018) Rehabilitative Palliative Care: Enabling people to live fully until the day. Hospice UK

Palliative Care Adult Network Guidelines.

4th edition (2016) Watson M et al, last days of life chapter

National care standards: hospice care (2005) Scottish Executive, standard 2

Chartered Society of Physiotherapy COVID-19 Rehabilitation Standards.

Rehabilitation of adults who are hospitalised due to acute COVID-19 or Long COVID:

physiotherapy service delivery [RS1] (2021) Chartered Society of Physiotherapy

<u>Chartered Society of Physiotherapy COVID-19 Rehabilitation Standards. Community rehabilitation: physiotherapy service delivery [RS3]</u>

(2021) Chartered Society of Physiotherapy

<u>Chartered Society of Physiotherapy's Code of Members' Professional Values and Behaviour</u> (2019) Chartered Society of Physiotherapy, principle 1-4

Standards of proficiency - Physiotherapists

(2013) Health and Care Professions Council, standards 1-11 and 14

Quality standard 3:

Supported self-management

Quality statement 3

- 3. People with COVID-19 approaching the end of life are offered equitable supported self-management to develop their capability to manage the impact of COVID-19 and maximise independence and wellbeing.
 - 3.1 Shared decision making is used to enable a person to feel empowered to make choices about managing their health and wellbeing
 - 3.2 Self-management is personalised taking into account a person's level of engagement, dependency on others, health literacy and understanding in order to tailor support and resources accordingly
 - 3.3 Emerging evidence about the multi-dimensional sequelae of COVID-19 and variation in outcomes from COVID-19 informs education and advice given including discussion about when to seek support
 - **3.4** Utilise the expertise and benefits of family, carer, peer and community support where appropriate
 - 3.5 Utilise technology where appropriate to support self-management and self-monitoring taking into account digital inclusion considerations
 - **3.6** A co-produced, self-management strategy is part of the documented rehabilitation and care plan and includes regular review/monitoring.

Rationale

Supported self-management is a key component of rehabilitation and is based on the personalised rehabilitation, goals and outcome measurement. Supported self-management helps people to build knowledge, skills and confidence for managing the impact of COVID-19 and to maximise their independence and wellbeing. The physiotherapy workforce should coordinate with the multidisciplinary teams (MDTs) involved to tailor support according to the individual's needs and preferences.

Shared decision making (SDM) is a collaborative process which empowers a person to make informed decisions about managing their health and care. SDM conversations should include an honest acknowledgement of uncertainties, and open discussion about the potential benefits, risks and consequences of self-management approaches. Support should be tailored to the person's needs to ensure the individual, their families and carers as appropriate, are actively involved in SDM.

Awareness of a person's level of engagement or activation, dependency on others, health literacy and understanding enables equitable access to information, training and education resources which are tailored accordingly. Activation describes the knowledge, skills and confidence a person has in managing their own health and care. Targeted interventions that develop skills and health literacy in achievable steps and build confidence and autonomy may help to increase a person's level of activation. It is important to take into account how some symptoms of COVID-19, for example brain fog or fatigue, in addition to any pre-existing symptoms, may impact on a person's ability to self-manage and to work collaboratively with them to individualise strategies. For people with high levels of dependency on others, self-management may be achieved through close working with families and carers.

Long COVID is not yet a well understood illness with many uncertainties, and varied and often relapsing-remitting symptoms. Education about this should be offered and self-management support should provide opportunities to discuss the impact this has on the person and any feelings of worry or distress.

It is of critical importance to offer self-management support and advice about pacing, rest and recovery time. Information and support for symptom management should be available. People should be supported to self-monitor their symptoms and to know when to seek advice from a healthcare professional.

Supported self-management is enhanced by the expertise, capacity and potential of families, carers, peers and communities (NHS England and NHS Improvement, 2020). Peer support involves people drawing on shared personal experience to provide knowledge, social interaction, emotional assistance or practical help to each other, often in a way that is mutually beneficial. Evidence shows peer support can help people feel more knowledgeable, confident and happy and less isolated and alone (National Voices, 2015).

Technology, for example, patient networks, online platforms, apps, can support people to self-manage their rehabilitation and care depending on clinical suitability. Supported self-monitoring at home, for example heart rate and blood pressure and pulse oximetry, may utilise technology and ensure people with COVID-19 are undertaking self-management activities within safe parameters. Collaborative review of data from technology is an important component of supported self-management which can build confidence and provide motivation. Digital inclusion takes into account access to technology and an individual's ability and preference to use digital tools and apps to self-manage and self-monitor.

COVID-19 symptoms can be episodic, unpredictable and fluctuating in severity and some people may present with new symptoms at a later stage. Regular review of COVID symptoms and symptoms from pre-existing conditions by the MDT ensures that self-management support is responsive to the person's changing needs.

Source guidance

COVID-19 rapid guideline: managing COVID-19 (2021) NICE guideline NG191, recommendation 4

<u>COVID-19 rapid guideline: managing the long-term effects of COVID-19</u> (2020) NICE guideline NG188, recommendations 2.4, 5.1, 6.2, 6.4, 7.2

Shared decision making (2021) NICE guideline NG197, recommendations 1.2-1.4

<u>Living with COVID19. Second Review. A dynamic review of the evidence around ongoing COVID19 symptoms (often called Long COVID)</u>

(2021) National Institute for Health Research

Long COVID: the NHS plan for 2021/22 Version 1 (2021) NHS England

National guidance for post-COVID syndrome assessment clinics Version 2 (2021) NHS England

<u>COVID-19 Clinical Advice. Supporting people with COVID-19 related illness in the community setting: Clinical management of those with moderate to severe illness</u> Version 2.1 (2020) Scottish Government

COVID-19: Review of disparities in risks and outcomes (2020) Public Health England

<u>Developing a modelling resource to understand the rehabilitation needs of people</u> <u>during, and following, the COVID-19 pandemic</u> (2020) Welsh Government

<u>Framework for supporting people through Recovery and Rehabilitation during and after the COVID-19 Pandemic</u> (2020) Scottish Government

<u>Reducing health inequalities associated with COVID-19. A framework for healthcare providers</u> (2020) NHS Providers

Inclusion Health: applying All Our Health (2021) Public Health England

Rehabilitation: a framework for continuity and recovery 2020 to 2021 (2020) Welsh Government

RightCare: Community Rehabilitation Toolkit (2020) NHS RightCare

A Digital Framework for Allied Health Professionals (2019) NHS England

NHS RightCare: Progressive Neurological Conditions Toolkit (2019) NHS RightCare

<u>The Topol Review: Preparing the healthcare workforce to deliver the digital future</u> (2019) NHS Health Education England

<u>Universal Personalised Care: Implementing the Comprehensive Model</u> (2019) NHS England

<u>Scotland's Digital Health and Care Strategy: enabling, connecting and empowering</u> (2018) Scottish Government

Commissioning guidance for rehabilitation (2016) NHS England

<u>eHealth and Care Strategy for Northern Ireland: Improving health and wealth</u> <u>through the use of information and communication technology</u> (2016) Health and Social Care Board

<u>Informed Health and Care: A Digital Health and Social Care Strategy for Wales</u> (2015) Welsh Government

<u>Evaluating and Caring for Patients with Post-COVID Conditions: Interim Guidance</u> (2021) Centers for Disease Control and Prevention

In the wake of the pandemic: Preparing for Long COVID (2021) World Health Organisation

World Physiotherapy Response to COVID-19 briefing paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise (2021) World Physiotherapy

<u>A National COVID-19 Resilience Programme: Improving the health and wellbeing of older people during the pandemic</u> (2020) The Physiological Society

Build back fairer: the COVID-19 Marmot Review (2020) Institute of Health Equity

<u>How has COVID-19 changed the landscape of digital inclusion?</u> (2020) Centre for Ageing Better

Keeping Me Well: COVID-19 Rehabilitation Model (2020) Cardiff and Vale University Health Board

<u>Ambitions for Palliative and End of Life Care: A national framework for local action</u> <u>2021-2026</u> (2021) National Palliative and End of Life Care Partnership, ambitions 1 and 2 My role in tackling health inequalities: a framework for allied health professionals (2021) The King's Fund

Silver Book II: quality urgent care for older people (2021) British Geriatrics Society

<u>Digital Inclusion in Health and Care: Lessons learned from the NHS Widening Digital</u> <u>Participation Programme (2017-2020)</u> (2020) Good Things Foundation

<u>Personalised Care Institute Curriculum</u> (2020) Personalised Care Institute

The PRISMS taxonomy of self-management support: derivation of a novel taxonomy and initial testing of its utility

(2016) Pearce, G., et al, Journal of Health Services Research & Policy, 21(2):73-82.

<u>Chartered Society of Physiotherapy COVID-19 Rehabilitation Standards.</u>

<u>Rehabilitation of adults who are hospitalised due to acute COVID-19 or Long COVID:</u>

<u>physiotherapy service delivery [RS1]</u> (2021) Chartered Society of Physiotherapy

<u>Chartered Society of Physiotherapy COVID-19 Rehabilitation Standards. Community rehabilitation: physiotherapy service delivery [RS3]</u>
(2021) Chartered Society of Physiotherapy

<u>Chartered Society of Physiotherapy's Code of Members' Professional Values and Behaviour</u> (2019) Chartered Society of Physiotherapy, principle 1-4

Standards of proficiency - Physiotherapists

(2013) Health and Care Professions Council, standards 1-11 and 14

Standard 4:

Communication and information sharing with people with COVID-19

Quality statement 4

- 4. Communication with people with COVID-19 approaching the end of life and their families and carers is effective, with empathetic listening and information shared in an accessible and sensitive way, personalised to their needs and preferences.
 - 4.1 Communicate information in a personalised, accessible and timely way, in order to facilitate decision making and support rehabilitation, symptom management, self-management and discharge between settings
 - **4.2** Preferences for sharing information and involvement of family members and carers in decision making are established, respected and reviewed throughout care
 - 4.3 The physiotherapy workforce communicate personalised information using consistent and appropriate language/terminology and ensure that the individual, their families and carers can demonstrate understanding of all information
 - **4.4** Ensure that members of the multidisciplinary team with relevant expertise are involved in assessing and supporting the person's communication needs
 - **4.5** Utilise technology where appropriate taking into account access, digital literacy, needs and preferences.

Rationale

All communication and information provision should be sensitive to the needs and preferences of the person approaching the end of life and their families and carers, including those who do not wish to have such conversations at the present time. Those who do not wish to have information should have their preferences respected.

Communication should be informed by current knowledge and experience about the sequelae of COVID-19 and Long COVID, impact of inequalities and disparities in outcomes. Effective communication involves empathetic listening and sharing of experiences with an honest acknowledgement of the uncertainties. Timely and responsive communication and information sharing recognises that communication is a two-way process and that the person's circumstances and needs are likely to change over time.

Ensuring that people have an understanding of the roles of healthcare professionals involved in their care, and how to contact them if they need to, is an essential part of effective communication. People and their families and carers need to be informed of safety-netting arrangements and urgent care provision available if their clinical condition, needs and preferences change. Provision of information tailored to a person's preferences, which they can understand and act on, ensures that they are actively involved in shared decision making.

Families and carers can play a significant role in supporting the rehabilitation and care of people with COVID-19 approaching the end of their life. If a person agrees, it is important that they are involved in discussion and decision making. They can provide information about the person's needs and circumstances beyond medical conditions or physical needs, and may detect changing needs.

People with COVID-19 may become ill and deteriorate quite quickly and may not be able to fully participate in decision-making. Every effort should be made to involve those close to them in decision making. Honest conversations with people and their families may be challenging, but it is important that they do take place. It is important that there is a coordinated multidisciplinary team (MDT) approach to communication. Palliative care teams are skilled at these conversations and may be able to offer support.

Communication should be personalised to take into account an individual's symptoms, such as cognition deficits and prolonged delirium. In addition, laryngeal and intubation related injury and compromised respiratory function may affect the person's ability to speak. Assessment and advice from healthcare professionals with relevant expertise about the optimal means of communication may be required. Additional support such as an interpreter, translator or advocate may be required. Conversations may need to take place using Personal Protective Equipment (PPE) or remotely. The physiotherapy workforce should be mindful of how this may affect communication with the person, families and carers. Other ways of communicating to meet their needs should be considered. Extra time may be necessary for effective communication.

It is important to use language and terminology that is understood and acceptable to patients especially in relation to Long COVID. For further information, see <u>CSP COVID-19</u> <u>Rehabilitation Standards RS3 (Community rehabilitation: physiotherapy service delivery)</u>. Digital resources may facilitate communication and provision of information but digital literacy and access, symptoms, skills and confidence should be taken into account. The physiotherapy workforce should be aware of additional services available locally, for example provision of equipment and training, and support access to these services if required. Specialised technology, communication aids and equipment can be utilised to support people with cognitive and language impairments to communicate effectively.

Source guidance

COVID-19 rapid guideline: managing COVID-19

(2021) NICE guideline NG191, recommendations 4, 5.1.2 and 6.1.1

COVID-19 rapid guideline: managing the long-term effects of COVID-19

(2020) NICE guideline NG188, recommendations 2.4, 5.1, 6.2, 6.4, 7.2

Shared decision making (2021) NICE guideline NG197, recommendations 1.2-1.4

Patient experience in adult NHS services

(2019) NICE quality standard QS15, standards 2-6

End of life care for adults (2017) NICE quality standard QS13, standard 2

<u>Transition between inpatient hospital settings and community or care home settings</u> <u>for adults with social care needs</u> (2016) NICE quality standard QS136, standard 5

COVID-19: Review of disparities in risks and outcomes (2020) Public Health England

<u>End of life care guidance when a person is imminently dying from COVID-19 lung</u> <u>disease</u> (2020) Scottish palliative care guidelines, NHS Scotland

<u>Framework for supporting people through Recovery and Rehabilitation during and after the COVID-19 Pandemic</u> (2020) Scottish Government

<u>Reducing health inequalities associated with COVID-19. A framework for healthcare providers</u> (2020) NHS Providers

Inclusion Health: applying All Our Health (2021) Public Health England

RightCare: Community Rehabilitation Toolkit (2020) NHS RightCare

A Digital Framework for Allied Health Professionals (2019) NHS England

<u>The Topol Review: Preparing the healthcare workforce to deliver the digital future</u> (2019) NHS Health Education England

Palliative and End of Life Care Delivery Plan

(2017) NHS Wales and the Welsh Government, themes 1, 4 and 5

Commissioning guidance for rehabilitation (2016) NHS England

<u>eHealth and Care Strategy for Northern Ireland: Improving health and wealth</u> <u>through the use of information and communication technology</u> (2016) Health and Social Care Board

<u>Informed Health and Care: A Digital Health and Social Care Strategy for Wales</u> (2015) Welsh Government

NHS Standard Contract for Specialised Rehabilitation for Patients with Highly Complex Needs (All Ages) (2013) NHS England

<u>COVID-19 clinical management: living guidance</u> (2021) World Health Organisation

<u>Evaluating and Caring for Patients with Post-COVID Conditions: Interim Guidance</u> (2021) Centers for Disease Control and Prevention

World Physiotherapy Response to COVID-19 briefing paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise (2021) World Physiotherapy

Build back fairer: the COVID-19 Marmot Review (2020) Institute of Health Equity

COVID-19 and Palliative, End of Life and Bereavement Care in Secondary Care.

Version 2 (2020) Northern Care Alliance NHS Group and the Association for Palliative Medicine of Great Britain and Ireland

<u>Health Equity in England: The Marmot review 10 years on</u> (2020) Institute of Health Equity

How has COVID-19 changed the landscape of digital inclusion? (2020) Centre for Ageing Better

<u>Keeping Me Well: COVID-19 Rehabilitation Model</u> (2020) Cardiff and Vale University Health Board

Long COVID: the NHS plan for 2021/22 Version 1 (2021) NHS England

<u>Living with Covid19: A dynamic review of the evidence around ongoing Covid19</u> <u>symptoms (often called Long COVID)</u> (2020) National Institute for Health Research

<u>Ambitions for Palliative and End of Life Care: A national framework for local action</u> <u>2021-2026</u> (2021) National Palliative and End of Life Care Partnership, ambitions 1-4

My role in tackling health inequalities: a framework for allied health professionals (2021) The King's Fund

<u>Digital Inclusion in Health and Care: Lessons learned from the NHS Widening Digital</u> <u>Participation Programme (2017-2020)</u> (2020) Good Things Foundation

Personalised Care Institute Curriculum (2020) Personalised Care Institute

National care standards: hospice care (2005) Scottish Executive, standard 2

<u>Developing services for Long COVID: lessons from a study of wounded healers</u> (2021) Ladds, E., et al, Clinical Medicine Journal, 21(1):59-65

Chartered Society of Physiotherapy COVID-19 Rehabilitation Standards.

Rehabilitation of adults who are hospitalised due to acute COVID-19 or Long COVID:

physiotherapy service delivery [RS1] (2021) Chartered Society of Physiotherapy

<u>Chartered Society of Physiotherapy COVID-19 Rehabilitation Standards. Community rehabilitation: physiotherapy service delivery [RS3]</u>
(2021) Chartered Society of Physiotherapy

<u>Chartered Society of Physiotherapy's Code of Members' Professional Values and Behaviour</u> (2019) Chartered Society of Physiotherapy, principles 1-3

Standards of proficiency - Physiotherapists

(2013) Health and Care Professions Council, standards 2, 3, 5-10, 14

Quality Statement 5:

Integrated and coordinated rehabilitation

Quality statement 5

- People with COVID-19 approaching the end of life receive equitable, personalised rehabilitation and care that is seamlessly coordinated within multidisciplinary teams, and integrated across all relevant settings and services.
 - 5.1 People with COVID-19 have timely, equitable access to the most appropriate services/teams based on their personalised rehabilitation plan
 - 5.2 The individualised rehabilitation plan of people with COVID-19 is communicated effectively with the person and with relevant health and social care teams responsible for their ongoing care at every transfer point along their care pathway
 - 5.3 Liaise with coordination teams to ensure that transfer arrangements, including equipment provision and appropriate referrals to appropriate services for the necessary ongoing care, are in place before completing the transfer
 - 5.4 The physiotherapy workforce are aware of, and contribute to the development of, optimal rehabilitation models and palliative care pathways, referral criteria, follow-up arrangements and urgent care pathways.

Rationale

Clearly defined, equitable rehabilitation and care models and referral processes are required to ensure people in all settings, including care homes and hospices, can access the right support from the right service and/or member of the multidisciplinary team (MDT) at the right time. Access to physiotherapy services must be equitable and informed by local population need and disparities in outcome for people approaching the end of their life.

Due to the multisystem nature of COVID-19, holistic rehabilitation and care services are best delivered by MDTs which include the professionals required to meet individualised needs of people with COVID-19. This involves coordinating and integrating the necessary expertise. People approaching the end of their life also require access to palliative expertise. In-house hospital and/or local community palliative care teams may be able to provide advice and support. Utilisation of remote approaches should be considered such as virtual clinics, meetings, advice and support.

Effective information sharing and MDT meetings are essential to ensure close collaboration between health and social care practitioners within and across different services and organisations. People's needs and symptoms may change quickly and responsive, coordinated communication within MDTs is essential.

Continuity of rehabilitation with regular assessment, self-management advice and support, maximises independence and wellbeing. Any new physical, psychological or emotional problems identified require referral to appropriate services. Coordination of services ensures timely, safe and effective rehabilitation including appropriate documentation, care packages, equipment and medication.

An agreed transition plan at each point of transfer ensures that a person's specific needs are met, transfers to other services are successful and the likelihood of hospital re-admission is reduced. This enables continuity of care and improves the person's experience of transfer along their care pathway. All people identified as being in the last days or weeks of their life need rapid and well coordinated transfer to the care of palliative care teams and/or community teams. For further information about coordination of hospital discharge to community settings see CSP COVID-19 Rehabilitation Standards RS1 (Rehabilitation of adults who are hospitalised due to acute COVID-19 or Long COVID: physiotherapy service delivery).

Emerging evidence about COVID-19 and rehabilitation needs is starting to inform *guidance* around the principles of integrated Long COVID rehabilitation models. Models should be sustainable, integrating support from the voluntary, charitable, community, leisure and social enterprise sectors. For more information about COVID-19 rehabilitation models, see *CSP COVID-19 Rehabilitation Standards RS3 (Community rehabilitation: physiotherapy service delivery).*

There is limited guidance on rehabilitation models and care pathways for people with COVID-19 approaching the end of their life. In England, a 'transfer of care hub' should be in place to ensure all relevant services can be linked in order to provide appropriate care and support for people identified as being in the last days or weeks of their life (Department of Health and Social Care, 2021, section 3.8 and 3.29).

Local palliative care services will differ in their provision and referral criteria, therefore the physiotherapy workforce needs to be aware of local services and refer as appropriate. It is important to be aware of arrangements and urgent referral pathways available if the person's clinical condition, needs and preferences change.

The physiotherapy workforce needs to be flexible and responsive to meet the unique needs of people with COVID-19 and facilitate the development of palliative rehabilitation and care models. Services should be co-produced working in equal partnership with people who use physiotherapy and rehabilitation services, carers and communities to design and develop services and models. It is important to give voice to seldom heard groups, including people approaching the end of their life. It helps to develop inclusive participation and enable people to feel more involved with the services they use (Social Care Institute for Excellence).

Source guidance

COVID-19 rapid guideline: managing COVID-19

(2021) NICE guideline NG191, recommendation 4

COVID-19 rapid guideline: managing the long-term effects of COVID-19

(2020) NICE guideline NG188, recommendations 1/10, 3.1, 3.3, 5.5, 6.5, 7.4, 8.1, 8.2, 8.4

Cerebral palsy in adults (2020) NICE quality standard QS191, standard 1

<u>End of life care for adults</u> (2017) NICE quality standard QS13, standard 8 and 9

Patient experience in adult NHS services

(2019) NICE quality standard QS15, standards 2-4 and 6

People's experience using adult social care services

(2019) NICE quality standard QS182, standard 3

Motor neurone disease (2016) NICE quality standard QS126, standards 3 and 5

<u>Living with COVID19. Second Review. A dynamic review of the evidence around</u> ongoing COVID19 symptoms (often called Long COVID)

(2021) National Institute for Health Research

Long COVID: the NHS plan for 2021/22 Version 1 (2021) NHS England

National guidance for post-COVID syndrome assessment clinics

Version 2 (2021) NHS England

COVID-19: Review of disparities in risks and outcomes

(2020) Public Health England

<u>Developing a modelling resource to understand the rehabilitation needs of people during, and following, the COVID-19 pandemic</u>

(2020) Welsh Government

<u>Framework for supporting people through Recovery and Rehabilitation during</u> and after the <u>COVID-19 Pandemic</u> (2020) Scottish Government

<u>Implementing phase 3 of the NHS response to the COVID-19 pandemic</u> (2020) NHS England

<u>Reducing health inequalities associated with COVID-19. A framework for healthcare providers</u> (2020) NHS Providers

Inclusion Health: applying All Our Health (2021) Public Health England

Hospital discharge service: policy and operating model (2021) Department of Health and Social Care

Hospital discharge service requirements: COVID-19

(Wales) (2020) Welsh Government

RightCare: Community Rehabilitation Toolkit (2020) NHS RightCare

NHS RightCare: Progressive Neurological Conditions Toolkit (2019) NHS RightCare

<u>Universal Personalised Care: Implementing the Comprehensive Model</u> (2019) NHS England

Commissioning guidance for rehabilitation (2016) NHS England

NHS Standard Contract for Specialised Rehabilitation for Patients with Highly Complex Needs (All Ages) (2013) NHS England

COVID-19 Clinical management: living guidance

(2021) World Health Organisation

In the wake of the pandemic: Preparing for Long COVID (

2021) World Health Organisation

Build back fairer: the COVID-19 Marmot Review (2020) Institute of Health Equity

Palliative and End of Life Care Delivery Plan

(2017) NHS Wales and the Welsh Government, themes 1-5

Palliative Care Adult Network Guidelines 4th edition

(2016) Watson M et al, pathways and frameworks chapter

Rehabilitation in the wake of COVID-19 - A phoenix from the ashes

(2020) British Society of Rehabilitation Medicine report, Version 1

<u>Royal College of General Practitioners - Written evidence (COV0051). Ongoing or persistent symptoms of COVID-19 (Long COVID)</u> (2020) UK Parliament

Health Equity in England: The Marmot review 10 years on (2020) Institute of Health Equity

<u>Keeping Me Well: COVID-19 Rehabilitation Model</u> (2020) Cardiff and Vale University Health Board

Responding to COVID-19 and Beyond: A framework for assessing early rehabilitation needs following treatment in intensive care.

Version 1 (2020) National Post-Intensive Care Rehabilitation Collaborative

<u>Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026</u>

(2021) National Palliative and End of Life Care Partnership, ambitions 1-4 and 6

My role in tackling health inequalities: a framework for allied health professionals (2021) The King's Fund

<u>A Multidisciplinary NHS COVID-19 Service to Manage Post-COVID-19 Syndrome</u> <u>in the Community</u>

(2021) Parkin, A., et al, Journal of Primary Care & Community Health, 12:1-9

Chartered Society of Physiotherapy COVID-19 Rehabilitation Standards.

Rehabilitation of adults who are hospitalised due to acute COVID-19 or Long
COVID: physiotherapy service delivery [RS1]

(2021) Chartered Society of Physiotherapy

<u>Chartered Society of Physiotherapy COVID-19 Rehabilitation Standards.</u>
<u>Community rehabilitation: physiotherapy service delivery [RS3]</u>
(2021) Chartered Society of Physiotherapy

<u>Chartered Society of Physiotherapy's Code of Members' Professional Values</u> <u>and Behaviour</u> (2019) Chartered Society of Physiotherapy, principles 1-4

Standards of proficiency - Physiotherapists

(2013) Health and Care Professions Council, standards 1-11 and 14

Quality standard 6:

Evaluation, audit and research

Quality statement 6

- 6. Physiotherapy services undertake evaluation, audit, research and share good practice to understand the needs of people with COVID-19 approaching the end of their life, improve the quality of services, optimise experience and outcome, and address health inequalities.
 - 6.1 Consider the evidence and data requirements for understanding the needs of people with COVID-19, assessing quality of physiotherapy service delivery, measuring patient and carer experience and outcomes, and monitoring for inequalities throughout rehabilitation models
 - 6.2 Physiotherapy services collaborate with people with COVID-19, their families and carers to co-produce, evaluate, improve and redesign services, rehabilitation and care models
 - 6.3 Physiotherapy services have robust systems of measurement and monitoring that, where appropriate, are standardised to enable local evaluation and also regional and national interpretation
 - **6.4** Good practice, knowledge and lessons learnt are shared locally, regionally, nationally and internationally.

Rationale

The epidemiology, prognosis and rehabilitation needs of people with COVID-19 are not yet fully understood. Developing the evidence base, standards and guidance around COVID-19 and the impact on palliative rehabilitation is essential to provide a foundation for future improvements in COVID-19 rehabilitation and care. Early data and evidence is highlighting that disparities in the risk, impact and outcomes from COVID-19 exist. Monitoring of health outcomes and social determinants of health through data collection will further improve our knowledge of the health inequalities of COVID-19. This will improve our understanding of aspects of equity, such as access, process and outcomes, in order to develop equitable palliative rehabilitation and care services.

Co-production working in equal partnership with people approaching the end of their life and their families and carers should be integral to the evaluation of physiotherapy services, as well as service design and development. They should also be offered the opportunity to be involved in all stages of research. It is important that their expertise, knowledge and experience is incorporated into the evidence base for COVID-19 (Callard and Perego, 2021). Patient advocacy groups, for example Long COVID Physio, are playing a key role influencing research and developing knowledge about lived experience and lessons learnt but there is a need to learn more about the experiences of people with COVID-19 approaching the end of their life.

The physiotherapy workforce need to collaborate in the evaluation of rehabilitation service delivery. Robust systems of measurement and monitoring, including national datasets, can help address gaps in palliative rehabilitation provision and initiate quality improvement programmes. National and regional comparison supports the reduction in variation in access to, and quality of, palliative rehabilitation services. The physiotherapy workforce needs to be aware of and engage in data collection at a local, regional and national level. Available data and emerging research findings can facilitate evaluation and service improvement initiatives.

The COVID-19 pandemic has changed the delivery of palliative rehabilitation and care and new, innovative approaches are being developed. Knowledge, skills and training should be shared between services in all settings. It is important that any changes and lessons learnt are captured, evaluated, and shared widely to inform future rehabilitation models. National databases and co-produced research are essential to learn more about people with COVID-19 who are approaching the end of their life. As COVID-19 is a global pandemic, it is essential to actively seek opportunities to share data and evidence internationally.

Source guidance

<u>COVID-19 rapid guideline: managing the long-term effects of COVID-19</u> (2020) NICE guideline NG188, recommendation 8.3

Shared decision making (2021) NICE guideline NG197, recommendations 1.1-1.4

Long COVID: the NHS plan for 2021/22 Version 1 (2021) NHS England

National guidance for post-COVID syndrome assessment clinics Version 2 (2021) NHS England

<u>COVID-19: Review of disparities in risks and outcomes</u> (2020) Public Health England

<u>Developing a modelling resource to understand the rehabilitation needs of people during, and following, the COVID-19 pandemic</u> (2020) Welsh Government

<u>Evaluating the impact of rehabilitation services post COVID-19</u> (2020) Welsh Government

Framework for supporting people through Recovery and Rehabilitation during and after the COVID-19 Pandemic (2020) Scottish Government

<u>Implementing phase 3 of the NHS response to the COVID-19 pandemic</u> (2020) NHS England

Inclusion Health: applying All Our Health (2021) Public Health England

RightCare: Community Rehabilitation Toolkit (2020) NHS RightCare

Commissioning guidance for rehabilitation (2016) NHS England

<u>eHealth and Care Strategy for Northern Ireland: Improving health and wealth</u> <u>through the use of information and communication technology</u> (2016) Health and Social Care Board

<u>Informed Health and Care: A Digital Health and Social Care Strategy for Wales</u> (2015) Welsh Government

<u>Ladder of engagement</u> (n.d.) NHS England

In the wake of the pandemic: Preparing for Long COVID (2021) World Health Organisation

Living with COVID19. Second Review. A dynamic review of the evidence around ongoing COVID19 symptoms (often called Long COVID)

(2021) National Institute for Health Research

<u>The Independent SAGE Report 32: Independent SAGE Report on Long COVID</u> (2021) The Independent Scientific Advisory Group for Emergencies (SAGE)

Build back fairer: the COVID-19 Marmot Review (2020) Institute of Health Equity

<u>Rehabilitation in the wake of COVID-19 - A phoenix from the ashes</u> (2020) British Society of Rehabilitation Medicine report, Version 1

<u>Health Equity in England: The Marmot review 10 years on</u> (2020) Institute of Health Equity

<u>Keeping Me Well: COVID-19 Rehabilitation Model</u> (2020) Cardiff and Vale University Health Board

Responding to COVID-19 and Beyond: A framework for assessing early rehabilitation needs following treatment in intensive care.

Version 1 (2020) National Post-Intensive Care Rehabilitation Collaborative

<u>Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026</u>

(2021) National Palliative and End of Life Care Partnership, ambitions 1 and 2

My role in tackling health inequalities: a framework for allied health professionals (2021) The King's Fund

<u>A Co-production Model. Five values and seven steps to make this happen in</u> <u>reality</u> (2016) Coalition for Collaborative Care

<u>Developing services for Long COVID: lessons from a study of wounded healers</u> (2021) Ladds, E., et al, Clinical Medicine Journal, 21(1):59-65

<u>Chartered Society of Physiotherapy's Code of Members' Professional Values</u> <u>and Behaviour</u> (2019) Chartered Society of Physiotherapy, principles 1-4

Standards of proficiency - Physiotherapists

(2013) Health and Care Professions Council, standards 2, 5-7, 9-12 and 14.

Quality standard 7:

Personal Protective Equipment (PPE) and infection control

Quality statement 7

- 7. The physiotherapy workforce have access to the correct and appropriate level of Personal Protective Equipment when providing care in person.
 - 7.1 Liaise with local infection control policies, in conjunction with national guidance on Personal Protective Equipment so that:
 - 7.1.1 People who are hospitalised or in the community and the physiotherapy workforce are appropriately protected from transmission of the COVID-19 virus during physiotherapy care
 - **7.1.2** A risk assessment is completed to ensure staff have access to appropriate Personal Protective Equipment prior to physiotherapy care
 - 7.1.3 Adequate training is available to ensure the safe application and removal of Personal Protective Equipment
 - 7.1.4 Personal Protective Equipment is disposed of in the correct manner and clinical waste disposal policies are adhered to
 - 7.1.5 The physiotherapy workforce are aware of reporting procedures if the correct level of Personal Protective Equipment is not available.

Rationale

Healthcare-associated infections are caused by a wide range of microorganisms including COVID-19 virus. COVID-19 can have wide ranging effects on morbidity and mortality for people receiving or providing healthcare. Employers are under a legal obligation to adequately control the risk of exposure to viruses where exposure cannot be prevented. The provision and use of Personal Protective Equipment (PPE), including respiratory protective equipment, will ensure that the risk of transmitting the virus to people and other staff is minimal. The evidence around PPE is emerging and the physiotherapy workforce should keep up to date with the most recent guidance. For more information, see the <u>CSP's personal protective equipment (PPE) guidance, resources and FAQs.</u>

Employees have an obligation to make full and proper use of any control measures, including PPE, provided by their employer. Ultimately, where the physiotherapy workforce consider there is an increased risk to themselves or the individuals they are caring for, they should carry out local risk assessments to determine what level of PPE is required. There is also a need to ensure that training is provided about risk assessment and to ensure the correct type of PPE is used, applied, removed and disposed of safely. The physiotherapy workforce should familiarise themselves with local policies and procedures regarding PPE access for carers.

Source Guidance

<u>Cleansing and PPE waste at a healthcare waste management facility: RPS C1</u> (2021) Environment Agency

<u>COVID-19: how to work safely in domiciliary care in England</u> (2020) Department of Health and Social Care

<u>Coronavirus (COVID-19): personal protective equipment (PPE) hub</u> (2020) Department of Health and Social Care

<u>COVID-19: Guidance for maintaining services within health and care settings:</u> <u>infection prevention and control recommendations</u> (2020) Department of Health and Social Care.

<u>Coronavirus (COVID-19): unpaid carers providing personal care</u> (2020) Scottish Government

<u>Coronavirus (COVID-19): personal protective equipment (PPE) hub</u> (2020) Department of Health and Social Care

<u>Guidance on shielding and protecting people who are clinically extremely vulnerable from COVID-19</u> (2021) Department of Health and Social Care

<u>PPE waste from home healthcare workers treating patients with COVID-19: RPS C5</u> (2021) Department of Health and Social Care

Personal protective equipment (PPE) - guidance, resources and FAQs (2021) CSP

<u>COVID-19 rapid guideline: managing symptoms (including at the end of life) in</u> <u>the community</u> (2020) NICE guideline NG163, recommendations 1 and 10

<u>Healthcare-associated infections: prevention and control in primary and community care</u> (2017) NICE quality standard CG139, standards 1.1.1-1.1.3

Managing risk: infection prevention and control (2020) HCPC

<u>Chartered Society of Physiotherapy's Code of Members' Professional Values</u> <u>and Behaviour</u> (2019) Chartered Society of Physiotherapy, principles 1-3

Standards of proficiency - Physiotherapists

(2013). Health and Care Professions Council, standards 1-7, 10 and 15



14 Bedford Row London WC1R 4ED

Web: www.csp.org.uk

Email: enquiries@csp.org.uk

Tel: **020 7306 6666**

THE CHARTERED SOCIETY OF PHYSIOTHERAPY

is the professional, educational and trade union body for the United Kingdom's 60,000 chartered physiotherapists, physiotherapy students and support workers.