

Moving forward stronger

Addressing deterioration in people with long-term conditions during the pandemic



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The challenge and our recommendations

The COVID-19 pandemic has been devastating. Across the UK, over 150,000 people have had their lives cut short by the virus.¹ Alongside this, many people with pre-existing long-term health conditions have deteriorated faster than usual since the pandemic began.

This increased rate of deterioration is due to both the effects of having COVID-19 as well as the measures taken to contain the virus – such as ‘lockdowns’ that reduced social contact and suspended rehabilitative services. During the first wave of the pandemic, many professionals who provide rehabilitation were deployed to acute services for COVID-19 patients, while community rehabilitation services moved to primarily offering virtual support. As a result, rehabilitation services were unable to provide the same level of support that they did pre-COVID-19. These community services are vital in managing and helping to support people with long-term conditions.

How can the government support people with long-term conditions?

With the right rehabilitation support from community services such as allied health professionals, it is possible for people to manage their long-term health conditions effectively. As a result, many can slow down or prevent deterioration of their conditions. Some people may even be able to reverse some of the deterioration that they experienced and regain some abilities.

However, a clear strategy and direction is needed to provide such support to the hundreds of thousands of people living with long-term health conditions in the UK. This is why we, a range of charities supporting people with long-term health conditions and organisations representing rehabilitation professionals, are calling on national and local government to:

- **fully fund a national two-year rehabilitation strategy that ensures people with significantly deteriorated long-term conditions get the therapeutic support they need**
- **appoint a national clinical lead to implement this rehabilitation strategy**
- **ensure local partners – such as local authorities and Integrated Care Systems (ICS) – develop and deliver their own localised rehabilitation strategy, and that each ICS has a regional rehabilitation lead.**

To support these recommendations, several organisations have contributed a short summary of how COVID-19 has impacted people with long-term health conditions, why a rehabilitation strategy is needed urgently and what an effective strategy needs to include.

Contributors:



Supporters:



Moving forward stronger

Charity
perspective

Alzheimer's Society

The 850,000 people living with dementia in the UK have been worst hit by COVID-19. They account for more than a quarter of all COVID-19 related deaths in England and Wales during the first wave of the pandemic.² Many people living with dementia have also seen their conditions worsen much faster over the course of the pandemic.

While dementia is a progressive condition, meaning it always gets worse over time, the rate of its deterioration has significantly increased since the pandemic began. An Alzheimer's Society survey on the effects of lockdown found that 82% of people affected by dementia reported significant deterioration of symptoms in loved ones.³

There are a number of reasons for this increased rate of deterioration including:

- **changes to community rehabilitation services:** dementia is a complex neurological condition which can affect a range of cognitive and physical abilities. In order to maintain their abilities for as long as possible, a person with dementia needs a range of community rehabilitation services, such as occupational therapists, physiotherapists, and speech and language therapists. However, during the pandemic many of these services have been suspended - restricted to only providing critical care or delivered remotely. Not everyone with dementia will be confident or comfortable using digital services, and the condition itself may mean these approaches are not suitable for some people.
- **a lack of social contact:** social contact is vital for people with dementia to ensure they can continue to maintain, practice and use their cognitive and communication skills. Restrictions on social contact have caused many people's skills to decline, along with their mental health and physical wellbeing.
- **dropping diagnosis rates:** our own analysis of NHS Digital data shows that diagnosis rates have dropped from 67.4% in March 2020 to 61.8% in May 2021. This means that more people are developing dementia but not receiving a diagnosis, putting them at risk of further deterioration as they are unable to access specialist post-diagnostic support to manage their condition, such as allied health professionals. Even for people with a diagnosis, data shows that only 36.9% of people with dementia had a care plan initiated or reviewed in the previous 12 months, as of May 2021.⁴

Why a rehabilitation strategy is needed

A rehabilitation strategy that enables people with dementia to recover from the impact of the pandemic can reduce this deterioration of cognitive or physical symptoms. In order to do so, the strategy must urgently:

- provide people living with dementia with intensive support from professionals in community care
- consider the needs of informal carers, who are an essential part of rehabilitation for people with dementia. While NHS England has developed a 'Dementia Wellbeing in the COVID Pandemic'⁵ resource, it does not adequately cover the rehabilitation needs of people living with dementia and their carers
- develop a plan that local bodies can complement with their own local plans, tailored to the needs of people with dementia in their community.



Stroke Association

The consequences of stroke are life changing and often devastating – two thirds of stroke survivors leave hospital with a disability. Yet, with effective rehabilitation and support, survivors can often make significant strides towards recovery in the first few weeks and months after a stroke.

Stroke rehabilitation before the pandemic

Whilst acute stroke care has steadily improved across England in recent years, rehabilitation and long-term support have long-lacked the data and investment needed to drive urgent improvements. Before the COVID-19 pandemic:

- almost half of stroke survivors reported feeling abandoned after leaving hospital, with the care and support they received seen as a ‘postcode lottery’.⁶
- in 2019-20, only 34% of stroke survivors received guideline levels of physiotherapy, and only 19% received the right amount of speech and language therapy. This shows how dependent people’s recoveries are on where they live rather than on what they need.⁷

Stroke rehabilitation since the pandemic

The situation has only deteriorated over the past year. Our ‘Stroke Recoveries at Risk’ report found that the COVID-19 pandemic has affected every aspect of stroke treatment and care, and has especially disrupted rehabilitation and support.⁸

- 39% stroke survivors who had a stroke last year felt they had not received enough rehabilitation therapies, including physiotherapy.
- 69% stroke survivors reported feeling more anxious and depressed.

While many stroke survivors have benefitted from access to virtual rehabilitation and healthcare during the pandemic, many more had therapy cancelled or postponed without an alternative.

Why a rehabilitation strategy is needed

Urgent investment in rehabilitation is needed now so that all stroke survivors can make their best possible recoveries. Governments and health systems must do more, and go further, to mitigate the pandemic’s impact on many stroke recoveries. This means:

- investing in the training and expansion of professionals who provide vital physiotherapy, speech and language therapy and occupational therapy
- funding services so that stroke survivors receive rehabilitation for as long as they need, rather than for a set timeframe
- supporting the mental health rehabilitation needs of stroke survivors in the same way as physical rehabilitation.

The benefits of planning, providing and prioritising effective rehabilitation services are clear, for both stroke survivors and the NHS. As we look to rebuild the capacity of the NHS in a post-COVID-19 society, a long-overdue focus on rehabilitation is essential in helping stroke survivors rebuild their lives and make their best possible recoveries.

Macmillan Cancer Support

Why is rehabilitation important for people with cancer?

Cancer treatment does not just mean chemotherapy, radiotherapy or surgery. Whether the aim of cancer treatment is a full recovery or to reduce symptoms, prehabilitation and rehabilitation are important for both maintaining and improving health and wellbeing.

Prehabilitation is beneficial to people with a cancer diagnosis because it:

- empowers the individual to prepare for often difficult treatment, with a focus on improving quality of life and physical and mental resilience
- improves long-term health through focusing on positive health behaviour change.

Rehabilitation is beneficial because it:

- maximises the outcomes of cancer treatment
- minimises symptoms of treatment such as fatigue or breathlessness
- increases independence by addressing practical needs that can arise from cancer treatment and the associated side effects.

How has the COVID-19 pandemic affected cancer prehabilitation and rehabilitation?

Rehabilitation has changed dramatically for many people with cancer during the pandemic. Macmillan professionals tell us that disruption to cancer services has meant that there are more people being diagnosed at a later stage with more complex rehabilitation needs. Many people with cancer have been shielding for more than a year, and as a result their physical and mental health has suffered.

Whilst the need has increased, the availability of services providing prehabilitation and rehabilitation has become more limited. Many services are now remote. Allied health professionals have been relocated to COVID-19 wards during the peaks of the pandemic. Changes to when and where people receive cancer treatment have also made it more difficult to deliver good quality rehabilitation. Surgery or chemotherapy can be cancelled or brought forward suddenly due to COVID-19 disruption, and treatment might be in a different hospital than usual to reduce the risk of COVID-19 infection.

Why a rehabilitation strategy is needed

Rehabilitation services need to feature in any recovery plan for the NHS in the aftermath of the pandemic. Many people with cancer will be in worse physical health and have more complex needs due to the impact COVID-19 has had on the health system.

The SafeFit trial (pump-primed by Macmillan) has shown the importance of exercise, nutrition and emotional support as components of prehabilitation and rehabilitation to people with cancer. One SafeFit participant told us:

'I feel confident - I'll be returning to work soon after almost a year, it doesn't seem as daunting as it was before.'

Any effective rehabilitation strategy must consider these components as well.

Centre for Mental Health

The COVID-19 pandemic has affected people's mental health worldwide. In England alone, an estimated 10 million people have additional mental health support needs as a direct result of the pandemic.⁹ Two-thirds of these are people who had pre-existing mental health difficulties that have worsened as a direct result of the virus and its effects on our lives.

There is evidence that people with schizophrenia in particular face a substantially higher mortality risk from the virus: up to three times the average for the population as a whole. This may be due to the co-occurrence of poor physical health that already reduces the life expectancy of someone with psychosis by two decades. The UK vaccination programme acknowledged this greater risk by including people with a 'severe mental illness' within the priority group of people of working age with long-term conditions. It is nonetheless a sobering reminder of the greater risk some people face, and why future vaccination and health screening programmes should follow suit in recognising this.

First-person accounts and surveys have pointed to a range of ways that the pandemic has worsened people's pre-existing mental health conditions. For example:

- Access to food and supermarkets was a particular challenge for people with mental health difficulties, including those with eating disorders. Many described feeling especially anxious in shops, and not being able to obtain 'safe' foods during the first lockdown in particular.
- Restricted access to informal mental health support, for example from families, friends and support groups, caused large numbers to report a worsening of their condition.

Mental health services have gone to great lengths to adapt to the pandemic, for example the creation of new methods of remote working and the establishment of 24/7 crisis lines – often within days. This has made it easier for some people to get support. For many others, however, COVID-19 has made help a lot harder to access, especially for people who are digitally excluded. There will be a lot to learn from how services have changed over the last year, and what that means for the longer-term.

Why a rehabilitation strategy is needed

In order to ensure people with mental health difficulties are properly supported as we move on from the pandemic, we need a renewed focus on supporting the physical health of people living with a mental illness. A rehabilitation strategy can help ensure that:

- mental health services are fully prepared for any future crises
- there is a relentless effort to tackle inequalities in mental health
- discrimination against people with a mental illness is addressed wherever it manifests, including in the NHS.

Age UK

The COVID-19 pandemic has had a drastic impact on many older people's physical and mental health. Prolonged periods of isolation and reduced opportunities for physical activity has left older people with diminished mobility, strength, and fitness, and at increased risk of falls.

Age UK research has found that 27% of older people are no longer able to walk as far as they could before the pandemic, while 17% feel less steady on their feet. At the same time, older people have told us that they feel anxious, have lost confidence in leaving their homes, and are fearful for the future. Isolation and limited stimulation has also resulted in cognitive decline, with 22% of older people reporting that they find it harder to remember things than they did before.¹⁰

Older people who were already living with long-term conditions have been particularly impacted. Many have had reduced access to the healthcare which they need to keep well, or have had the strategies they use to manage their conditions, such as exercise or support groups, taken away from them. The impact of this is stark. 45% of older people living with a long-term health condition report being in more pain than they were before the pandemic, while 21% have seen a loss to their independence.

Why a rehabilitation strategy is needed

As we come out of lockdown, rehabilitation services will be essential in helping people to manage long-term conditions and restore lost fitness and quality of life. However, as it stands we know that older people are not always able to access the therapeutic support that they need.

That is why it is so important that the government develops a funded rehabilitation strategy which ensures therapeutic support is available for all older people who need it. It will also be essential that older people can access the mental health support they need to help process and recover from the impact of the pandemic.

'45% of older people living with a long-term health condition report being in more pain than they were before the pandemic'

Moving forward stronger

Allied health
professional
perspective

The College of Podiatry

People living with long-term conditions have seen their conditions deteriorate considerably quicker during the pandemic. This includes increased deterioration in foot health, which has particularly affected people with dementia in care homes. This can be seen in two main ways:

- **A decline in mobility:** This is due to a suspension of activity provision in care homes following the outbreak of COVID-19. Physical activity can help people with dementia to maintain muscle function and circulation in their lower limbs. Being less active can result in muscle wastage and reduced circulation.
- **An increase in pressure ulcers:** Throughout the pandemic, many NHS podiatry services received an increase in requests for assistance with pressure ulcers, mainly within non-nursing care homes. Alongside this, when an outbreak of COVID-19 occurred within care homes, residents were often isolated in their rooms to minimise spread of infection. This resulted in an increase in pressure ulcers in at risk patients.¹¹ Podiatrists have witnessed some residents go from mobilising with aids to requiring wheelchairs, and some have become bed bound.

Musculoskeletal (MSK) conditions

MSK conditions that impact wellbeing and lifestyle including inflammatory rheumatology, joint hypermobility and osteoarthritis, rely on regular rehabilitation to improve function, strength and activity. Podiatry interventions including gait retraining, foot orthoses, footwear changes, functional exercises and activity modifications have been particularly impacted by a reduction in provision due to the pandemic.

As a result of reduced services, people with MSK conditions have experienced:

- more complex and unnecessary health problems
- more neurogenic pain due to increased immobility
- more physical weakness and frailty due to a reduction in activity

Why a rehabilitation strategy is needed

Prior to the pandemic many nursing and care homes received Check Protect Refer (CPR) for feet training. This provides staff with the skills to prevent pressure ulcers, and to enable early identification and rapid referral when they do occur.¹² Where care homes had received this training, there were lower rates of reported ulceration. A rehabilitation strategy can help ensure that CPR training is provided to all nursing and care homes. As part of this, the Care Quality Commission (England), Care Inspectorate (Scotland), the Care and Social Services Inspectorate Wales, and the Regulation and Quality Improvement Authority (Northern Ireland) should include this training as a mandatory requirement.

Physical activity also needs to increase in wards and residential homes to enable people to obtain a pre-pandemic baseline of activity. This will also reduce the likelihood of falls and pressure ulcers. To achieve this, a rehabilitation strategy needs to ensure that:

- activity coordinators are in place to help people maintain their muscle bulk
- carers can access education about falls prevention, including activity ideas for residents.

Royal College of Speech and Language Therapists

Many long-term health conditions can affect people's ability to communicate, and can cause problems with eating, drinking and swallowing. Communication is central to who we are and how we interact, key to our relationships, physical and mental health, jobs, leisure activities and our role in society.

Communication difficulties can leave people without a voice, denying them equality of access and opportunity. While eating, drinking and swallowing problems can result in malnutrition, choking, pneumonia and chest infections. They can also lead to a lack of enjoyment in food and social activities that involve food.

This makes speech and language therapy particularly important for people with long-term conditions and their families. Speech and language therapists can support people to manage their condition and maintain their quality of life. They also train other professionals to recognise and support with these difficulties.

Why a rehabilitation strategy is needed

The ability to communicate and eat and drink safely are basic human rights. Any person with a communication or swallowing difficulty should have a right to access speech and language therapy when and where they need it.

A report from the Royal College of Speech and Language Therapists¹³ shows that where people did not receive the speech and language therapy they needed during the first UK-wide lockdown, it led to a deterioration in their cognitive function and memory¹⁴, communication and swallowing ability¹⁵ and mental health¹⁶. Even where people did receive therapy, some of the new ways of it being delivered, such as online over video, have not suited everyone.

A rehabilitation strategy is essential to:

- address historic unwarranted variation in access to services
- help community services to respond to existing and new clients' increasingly complex needs
- support people with long COVID.¹⁷

Before the pandemic, too many people with long-term conditions did not have access to the therapy that they and their families needed. We need to build back better to ensure that people with long-term conditions have their needs identified and appropriately supported.



Royal College of Occupational Therapists

Occupational therapists have a vital role to play in the rehabilitation of people with pre-existing long-term conditions who are recovering from the effects of the pandemic and COVID-19.

Social distancing and the closure of community rehabilitation services has led to a lack of social contact for many people with long-term conditions. As a result, there has been a significant deterioration in many people's physical and mental health. This means rehabilitation support from occupational therapists and multi-disciplinary teams is essential.

An occupational therapist can work with a person living with a long-term condition, such as dementia, to help them identify their biggest challenges when carrying out independent living and day to day activities. Whether it is adaptations to their home environment or improving basic skills such as motor function, reasoning skills or communication.

As we start to focus on the recovery from the pandemic, there are many different health groups that need to be prioritised. People living with long-term neurological conditions, such as dementia and Parkinson's, are a key example of this. Many require ongoing care either in a care home or their own residence. This has been an ongoing challenge since the start of the pandemic as there has been significant disruption to the rehabilitation support that many people receive.

Why a rehabilitation strategy is needed

We have seen and expect further increased demand and longer waiting lists due to the pandemic. This will negatively impact people who have rehabilitation needs unrelated to COVID-19. Many of these people have experienced reduced support and deterioration of health and wellbeing since the pandemic began. This is why getting the government to focus on the longer-term plan and medium-term needs of rehabilitation support is key to the recovery from the pandemic and COVID-19.

Many of our professionals work in adult social care and provide essential ongoing support to enable people to carry out their everyday activities. Social care plays a vital role in the community-based care that many older people particularly rely on. It needs a greater focus when it comes to reform and additional funding.

Occupational therapy is a bridge between acute hospital settings and people's homes. Therefore, the support that our members give, particularly in rehabilitation, is essential to the future and keeping people well for longer, whilst alleviating pressure on local services, such as GPs.



Chartered Society of Physiotherapy

The COVID-19 pandemic has severely diminished the quality of life of thousands of people with long-term health conditions. The halting of rehabilitation services and social isolation, caused by the closure of day centres and multiple lockdowns, has left a devastating legacy for this group.

Too many people were already missing out before the pandemic. This report shows just how much rehabilitation needs have grown, without the resourcing in place to meet them.

At the Chartered Society of Physiotherapy, we have been campaigning to see an expansion in community rehabilitation to ensure that everyone gets the help they need to live as well as they can, for as long as they can.

Politicians and healthcare decision-makers must now recognise that without urgent action to expand rehabilitation services, we face the risk of large-scale deterioration in health, much of it irreversible. This will affect mobility and cognition, impact on people's ability to work and to remain active and independent.

To respond to this emerging threat to our national health, we need a radical new approach to rehabilitation provision.

This requires a rehabilitation strategy that will:

- increase provision for people in the community so that they can access rehabilitation early enough to make a real difference
- expand the rehabilitation workforce – making full use of the long-term growth in physiotherapy graduate numbers, creating new advanced clinical practice roles in the community and using the potential to expand the roles of support workers and exercise professionals
- design rehabilitation services that are personalised to meet individual needs, particularly where people are managing more than one long-term condition
- address barriers to access – making it easy for people to be referred or refer themselves, delivering more services in non-medical settings, avoiding digital exclusion and ensuring carers are welcome too
- equip the rehabilitation workforce with the training and education to provide joined-up care for people with a range of mental and physical conditions
- work in partnership with individuals, carers and families to ensure that the inequalities in care that contributed to high and unequal death toll from COVID-19 are never repeated.

To support these changes a government-led review of rehabilitation provision is needed to address the postcode lottery and scale up examples of excellence and innovation.

Ultimately, we need action that demonstrates that the nation's health is the highest priority for government as we rebuild from the pandemic.

But the solutions are available and with the right investment and backing, a fairer future is possible.

British Dietetics Association

The importance of dietetics services for people with long-term health conditions

People living with long-term conditions often experience difficulties with eating and drinking at all stages. For example, for people with dementia, these problems can include the person forgetting to eat or drink, difficulties in preparing food and drinks or recognising food items, and changes in taste and appetite. These problems can result in unintentional weight loss, muscle loss, weight gain, incontinence issues or dehydration. They can be a major source of concern for people with long-term conditions and their support network.

Nutrition and hydration are essential to any rehabilitation programme and vital for maintaining independence, wellbeing, quality of life and delaying functional decline. They can support rebuilding of muscle, maintenance of immune response and enable someone to participate in rehabilitation and independently manage activities. However, the COVID-19 pandemic has changed the way dietetics services are delivered, restricting people's access to support at a time when their condition may have worsened.

Why a rehabilitation strategy is needed

Whether the rehabilitation focus is on cognition or the effects of deconditioning (a loss of fitness and muscle tone), people must be supported to improve their food and fluid intake. Failure to do so will limit the impact of rehabilitation.

Both malnutrition and weight gain are aspects of living with long-term conditions and there are many strategies that can be employed to support someone to eat and drink well. In advanced stages of illness, nutrition support strategies are vital to achieving realistic goals focused on quality of life and end of life care needs.

Rehabilitation services must engage with their dietetic services, as dietitians are experts in supporting people to optimise nutrition and hydration and are ideally placed to provide education and training to health and social care staff who deliver rehabilitation and recovery services. Dietitians can also provide individualised support to those who require specialist input.

To support those with long-term conditions, the BDA call for the government to:

1. ensure that the expertise of dietitians is recognised and included in any guidance or policy-making for rehabilitation services
2. increase focus on the importance of good nutrition and hydration for people living with long-term conditions, via a funded national campaign
3. provide ring-fenced additional funding for local authorities to ensure that people living with long-term conditions have equitable access to affordable food as a core strategy to prevent malnutrition.

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