



World Health
Organization

European Region

Policy brief on integrating rehabilitation into palliative care services

Abstract

World Health Organization (WHO) policy on universal health coverage states that both rehabilitation and palliative care are essential components of quality health services and should be integrated within health systems using a multiprofessional workforce. Rehabilitation in palliative care can deliver many benefits for people and health systems but access to interventions is limited by a range of barriers including limited resource, siloed organization of services and attitudes of professionals and funders. While integrated rehabilitation has been achieved in high-income countries in health services for people with chronic long-term conditions or trauma, it remains under-resourced and highly variable within palliative care services. This policy brief aims to understand how integrating rehabilitation in palliative care services may improve the quality, accessibility, effectiveness and cost-effectiveness of health services for people approaching end of life. It provides practical and actionable information and recommendations to support health ministers and leaders in health systems planning to integrate rehabilitation in palliative care services.

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Abbreviations

CAT	COPD assessment test
CCQ	clinical COPD questionnaire
COPD	chronic obstructive pulmonary disease
WHO	World Health Organization

Background

With ageing populations and increasing morbidity, the number of people globally living with disability and experiencing suffering towards the end of life is set to almost double by 2060 (1). Palliative care improves the quality of life for people with life-limiting illness and those close to them, through the prevention and/or relief of suffering from diagnosis to end of life (1). This is achieved through the timely identification, assessment and treatment of physical, psychosocial or spiritual symptoms and concerns. Each year, an estimated 40 million people worldwide and nearly 5 million people in the European Region need palliative care, yet only about 14% and 35%, respectively, receive it (2, 3).

Suffering in advanced illness is often caused by a decline in function and the related loss of roles and routines, independence and sense of dignity (4–7). Rehabilitation can help address these issues. Rehabilitation within palliative care empowers people with incurable health conditions to actively manage their condition, reduces symptoms and enables individuals to stay independent and socially active. This allows them to enjoy the best possible quality of life, right up to the end of their life (8). Physiotherapists, occupational therapists, dietitians, psychologists, speech and language therapists and other rehabilitation and/or allied health professionals should ideally be included as core members of palliative care teams (8). However, all staff can provide rehabilitation and can be “function-focused” in their approach to care (9).

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Rehabilitation in palliative care

The World Health Organization (WHO) defines rehabilitation as a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment (10). Fundamentally, rehabilitation supports individuals to reach their fullest potential using a set of measures to achieve and maintain optimal day-to-day functioning (11) and often entails a problem-solving process (12) that is tailored to the individual’s priorities, needs and goals (12). Many health conditions result in difficulties in functioning which occur as a result of impairments in body functions (e.g. pain, muscle weakness), limitations in activities (e.g. self-care, walking) and restrictions in participation (e.g. community life, work). Functioning is defined through the WHO International Classification of Functioning, Disability and Health (13).

As treatments improve, people are living longer with life-limiting, disabling multiple long-term conditions and the burden of disease is related to time lived with disability, not just premature death (14). People with advanced disease can have rapidly changing personal and clinical situations. As their health condition deteriorates over time, so too do personal goals and needs change, including those related to their day-to day functioning. Their situation requires regular review (9) and, in many circumstances, rehabilitation helps people to live as comfortably and fully as possible until death (15). Rehabilitation also assists families in their caregiving roles.

There is a wide array of interventions for rehabilitation that can be integrated into palliative care. Some of the most common interventions for rehabilitation within palliative care include the following (8, 16–21):

- muscle strengthening and range of movement exercises;
- positioning for functioning, pain relief, oedema control, prevention of contractures and pressure areas;
- training in activities of daily living and mobility;
- environmental modifications in the home;
- provision and training in the use of assistive products;
- addressing caregiver and family needs, for example through caregiver training; and
- support for social interaction and participation such as through adapting activities.

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The benefits of rehabilitation have been shown among people living with advanced cancer, respiratory disease, cardiac disease, chronic kidney disease, frailty and dementia. These benefits include the following (10, 21–38):

- reduced distress associated with fatigue, breathlessness and pain
- reduced impact of symptoms on daily activities and roles
- maintained or improved physical fitness for functional daily activities
- positive experiences and benefits beyond improvements in physical function)
- improved psychological well-being, including confidence, security and hope and
- meaningful social support.

The effectiveness of interventions can be increased by (39-41):

- using goals to personalize interventions
- involving family members and carers)
- skilled communication and
- strong interdisciplinary team-working (sharing skills and tasks across professions).

This policy brief was developed based on current palliative care and rehabilitation literature. Case studies are presented from five European countries that illustrate how rehabilitation can be integrated into palliative care. Most of the evidence on rehabilitation in palliative care comes from studies in high-income countries, where rehabilitation services are well established within health systems. The services are often provided by experienced, highly trained health care professionals, well resourced services and home care that is supported by a culture of formal care. While rehabilitation is predominantly delivered by rehabilitation workers, such as physiotherapists and occupational therapists, many of the interventions for rehabilitation can also be provided by other health workers trained in the delivery of rehabilitation care as part of task-sharing.

Opportunities to integrate rehabilitation into palliative care

The concept of universal health coverage highlights that both rehabilitation and palliative care services are available within health care (42, 43). Both should be available across care settings for all people throughout the life course (11, 42). While progress continues to be made on the integration of rehabilitation into areas of care, such as for chronic respiratory disease (30), stroke (44) and cardiac conditions (45), it often remains under-resourced and underdeveloped within palliative care (9).

Integrating rehabilitation into palliative care services can improve access to and quality and efficiency of health care. Integration also has the potential to be a sound financial investment, as it improves a person's health and functioning and can prevent secondary conditions and reduce further palliative care needs. Rehabilitation integrated into palliative care can enable the provision of quality holistic care.

Rehabilitation and palliative care services are traditionally organized around differing but complementary goals for care (46).

- Both rehabilitation and palliative care deliver multiprofessional services, targeting the goals, needs and priorities important to people and their families.
- Palliative care services are organized around the relief of suffering for people living with incurable disease.
- Rehabilitation services are organized around supporting people with health conditions to function in their daily activities and roles.

Rehabilitation and palliative care services increasingly occupy shared spaces in health systems. There is an opportunity to improve access to high-quality function-oriented care for people with life-limiting conditions. This can be achieved through investment in palliative care and rehabilitation services with expanded scope of practice.

- Palliative care services are challenged to give a higher priority to function-oriented care (9), including extending the multiprofessional palliative care team to include rehabilitation specialists (16, 46).
- Rehabilitation services for people with multiple long-term conditions can widen their scope of practice. Interventions are required to help people to manage the impact of disabling symptoms and psychological distress on their daily activities, social participation and quality of life (47).
- Rehabilitation within palliative care should support people during periods of recovery, disease progression and declining physical capability (20, 25, 34, 37, 48, 49).

The possible benefits of integrating rehabilitation into palliative care include (50):

- timely referral to rehabilitation when indicated;
- improved coordination of care through multiprofessional team engagement during assessments, care planning and delivery;
- better attention to the impact of a health condition on a person's day-to-day functioning;
- more holistic and inclusive approach to the identification of person-centred outcomes;
- improved experiences of quality care for people with advanced illness and their families; and
- potential for efficiencies in health service costs.

Barriers and solutions for better integration of rehabilitation into palliative care

Although the benefits of integrating rehabilitation into palliative care are recognized, there are issues that act as barriers to expanding rehabilitation to people with life-limiting illnesses. These are described in Table 1 below along with evidence-based solutions, working examples of which can be found in the case studies.

Table 1. Barriers to expanding rehabilitation and evidence-based solutions

Barrier (51)	Evidence-based solution (16, 52-56)
Limited prioritization, planning and resourcing of rehabilitation in health care	<ul style="list-style-type: none"> • Include rehabilitation and function-oriented care in palliative care policy and guidelines • Prioritize rehabilitation within relevant health planning efforts to ensure it is strengthened and will be available for integration into palliative care • Develop medical, nurse and rehabilitation and/or allied health professional training curriculums to ensure that the concepts and practices of rehabilitation in palliative care are understood • Provide training and models of care that support palliative care nurses, community nurses and community health workers in gaining skills and achieving competencies in delivering agreed elements of basic rehabilitation care • Fund and expand the training for rehabilitation and/or allied health professionals (undergraduate and postgraduate qualifications)
Design and organize palliative care services for the integration of rehabilitation	<ul style="list-style-type: none"> • Systematic screening and referral processes designed to identify functional difficulties in people who can benefit from rehabilitation, to optimize functioning and well-being • Ongoing use of patient reported measures to screen for changes in functioning over time • Offer services across settings; home, clinical, rural and urban communities, tele-health • Deliver flexible, needs-based and tailored approaches leading to immediate benefits • Where existing rehabilitation (e.g. single disease programmes) result in barriers to palliative care, support development of a wider scope of rehabilitation care

Barrier (69, 70)

Low demand from patients due to perceptions that

- medical treatments will reverse functioning difficulties
- rehabilitation is burdensome or time consuming and/or ineffective
- participation is difficult to prioritize during the busy work of living with advanced illness
- rehabilitation is not culturally appropriate when approaching end of life

Evidence-based solution (9, 16, 40, 63, 71,72)

- Develop and disseminate patient education materials to improve patient understanding of the benefits of rehabilitation
- Public messaging on how rehabilitation addresses outcomes important to people
- Involve patients and the public in the design of new rehabilitation services
- Bring rehabilitation services closer to patients to address geographical, transport and time barriers
- Develop tailored goals and rehabilitation programmes that minimize the effort required to participate in rehabilitation
- Support the active involvement of carers in rehabilitation

Barrier (9,73-77)

Knowledge and attitudes of health care funders and health professionals that

- medical treatments will reverse decline in functioning
- the practical difficulties people experience during daily activities are a lower priority
- rehabilitation may not be effective or offer false hope

Evidence-based solution (9, 73-77)

- Disseminate evidence of effectiveness
- Develop online training; inclusion of rehabilitation in medical, nursing, rehabilitation and/or allied health professional and palliative care training programmes

The COVID-19 pandemic has demonstrated that public health emergencies introduce additional barriers to rehabilitation provision in palliative care. Rehabilitation services were among the most disrupted clinical services during the pandemic (78). Established services for people with advanced disease, including in palliative care, were widely affected (59, 61, 79, 80).

Many clinics and resources responded and endeavoured to reduce barriers by moving rehabilitation services online (59, 61). This delivery format may also improve access to palliative rehabilitation for people who previously struggled to access services owing to the constraints of illness, social circumstances and/or geographical location (61). However, online delivery may introduce new inequities in care and disadvantage people unable or unwilling to access digital resources. The ongoing technology requirements and workforce implications should be considered when funding and regulating these models of rehabilitation. Planning for future pandemics should anticipate how rehabilitation services will be adapted and sustained.

Policy options and opportunities for action to strengthen rehabilitation in palliative care

Suffering due to life-limiting illness is expected to escalate, with the fastest increases occurring in low-income countries, among older people and among people with dementia. This has led to calls for global action to integrate palliative care into health systems as “an ethical and economic imperative” (81). Efforts to integrate and expand availability of palliative care within health systems also affords the opportunity to integrate rehabilitation.

Policy and programme decision-makers within palliative care should be made aware of key reference documents that can support the integration of rehabilitation into palliative care:

- WHO Rehabilitation in health systems (10);
- World Health Organization: Making fair choices on the path to universal health coverage (UHC) (42);
- Rehabilitation 2030 Initiative and its call for action (82);
- World Health Organization: World report on disability 2011 (83);
- World report on ageing (84); and
- Global report on assistive technology (85).

Expanding rehabilitation within palliative care will require consideration of local contextual factors. Policy and programme decision-makers should take the particularities of their health system into account to enable provision of effective, sustainable and scalable rehabilitation within palliative care.

Policy and programme recommended actions (76, 77, 82, 86-93):

- Prioritize the integration of rehabilitation into palliative care through national and international consensus statements, policies, and guidelines, and frameworks for clinical practice
- Support health care plans and budgeting for the mobilization of sufficient rehabilitation resources and their efficient use, including in the context of palliative care
- Routinely collect information in health services on rehabilitation availability, quality and utilization, also include information on functioning, and morbidity and mortality, to inform planning
- Extend rehabilitation services according to need, which can relate to complexity of disease and disability, symptoms and concerns and potential to benefit from these services
- Ensure that prequalification education programmes and curriculums for health care professionals address the lack of trained rehabilitation professionals
- Develop professional development courses to enable existing palliative care workers, including nurses and community health workers, to build rehabilitation competencies
- Create practice partnerships and networks to share knowledge and skills that can help speed up implementation of high-quality rehabilitation within palliative care
- Obtain additional evidence on models of rehabilitation in palliative care with research in low- and middle-income countries, building on models that already demonstrate effectiveness
- Develop strategies to address negative perceptions, beliefs and attitudes towards rehabilitation in palliative care, including inclusion of rehabilitation in global quality of care reports
- Ensure that enhancing awareness among policy-makers, health care professionals and members of the public accommodates cultural values and beliefs around palliative care and rehabilitation

Case studies
**Rehabilitation
in palliative
care**

A centre of expertise for patients with complex chronic lung diseases with integrated rehabilitation care, Ciro, Horn, Netherlands

Ciro serves the whole population of the Netherlands, together with four other centres for pulmonary rehabilitation. People with chronic lung disease are referred to Ciro to attend a course of pulmonary rehabilitation if they have a clinical chronic obstructive pulmonary disease (COPD) questionnaire (CCQ) score that is greater than or equal to 1.9 or COPD Assessment Test (CAT) score that is greater than or equal to 18 and two or more exacerbations in the last year or one or more hospital admissions because of their COPD.

Care is provided by a multiprofessional team including respiratory, cardiac and internal medicine physicians, physician assistants, specialist nurses, physiotherapists, occupational therapists, dietitians, psychologists, social workers and art therapists. In addition, a physician of old age medicine and palliative care leads a palliative care team who are integrated within the wider multiprofessional team. This team includes specialist physiotherapists, occupational therapist and psychosocial professionals who have extra training and/or expertise in palliative care. Because the facility has a palliative care team, Ciro can admit people with more severe chronic lung disease. The palliative team facilitates early access to palliative medicine, rehabilitation and psychosocial interventions for people beginning pulmonary rehabilitation with a poorer prognosis. People receiving support from the palliative rehabilitation team follow the standard eight-week pulmonary rehabilitation programme, but focus on functional and well-being outcomes. Additional opportunities are offered, including participation in goal-setting, shared decision-making and advance care planning. Pharmacological and non-pharmacological interventions are provided to help people manage symptoms, such as breathlessness, fatigue and anxiety, that affect their daily activities and their participation in the pulmonary rehabilitation programme. Assistive devices can be provided, including walking aids. These sessions are offered one-to-one or in group settings during the person's inpatient stay. If needed, they can participate in an extended programme, lasting up to 12 weeks, so they have time to achieve their goals and gain benefits.

The palliative team helps people develop plans for future acute episodes and pays extra attention to people's home environment to optimize their well-being following discharge. The physician in old age medicine and palliative care contacts the person's general practitioner prior to discharge and the palliative team liaises with local providers to organize ongoing rehabilitation in the community where indicated.

The palliative team at Ciro provides early access to palliative medicine and rehabilitation in an innovative and accessible service. As hospices in the Netherlands usually provide inpatient services for people in the last three months of life, Ciro provides an opportunity for people living with advanced chronic lung disease to benefit from palliative rehabilitation earlier in their illness. Community-based rehabilitation is usually provided by primary care teams. Currently, palliative rehabilitation for people with advanced chronic lung disease is provided only in specialist centres such as Ciro.

Integrated rehabilitation in outpatient palliative care, Vejle University Hospital, Vejle, Denmark

Community rehabilitation for people with all health conditions is the responsibility of local municipalities in Denmark. These are usually exercise-based services that are open to people with any health condition and are conducted in local centres rather than the person's home.

Prior to 2013, medical and nursing palliative care consultations in Vejle were usually conducted in people's homes after the completion of their oncology treatment. The palliative care teams were aware that, by this time, many people were too unwell to benefit from exercise-based rehabilitation. They also observed that people with advanced cancer undergoing oncology treatment at the hospital were struggling to attend community rehabilitation sessions as well, since they were attending the hospital so frequently for scheduled appointments.

In 2013, a new cancer centre was built in the grounds of the hospital. With a new suite of consultation rooms for outpatient appointments, group meeting rooms and a gymnasium, it provided the opportunity to develop a new, innovative, highly flexible, palliative rehabilitation outpatient service. The model comprises a mandatory basic offer, with optional additional tailored elements. An initial consultation with a palliative care physician and a nurse specialist and a second consultation with the palliative care nurse are offered to all patients. Patients can then opt to participate in a 12-week educational group programme led by members of the wider multiprofessional team, including physiotherapists, nurses, occupational therapists, dietitians, social workers, chaplains and psychologists. Sessions are provided for both patients and their caregivers and cover the management of common symptoms, sleep, rest and relaxation, maintaining nutrition and coping with living with the illness and treatment, as well as psychological and emotional concerns. After each educational session, patients are offered individually tailored physical exercise in groups. Tailored sessions with any member of the multiprofessional team are also offered on a one-to-one basis in the outpatient centre. Following the 12-week programme, people whose palliative care needs have been addressed are discharged, with the option for referral back to the service in the future. Those with ongoing rehabilitation needs are referred on to the community rehabilitation services.

A randomized controlled trial conducted between 2014 and 2017 found that this new model of palliative rehabilitation was effective in improving quality of life and emotional functioning (20).

A cancer centre with a steadily expanding rehabilitation team, Fondazione IRCCS Istituto Nazionale dei Tumori, Milan, Italy

The Fondazione IRCCS Istituto Nazionale dei Tumori, established in 1928, is a comprehensive cancer centre providing cancer therapy and care from diagnosis with multidisciplinary antineoplastic treatments including palliative care and rehabilitation for both adults and children. The institute is a national referral centre for Italy. Since the 1970s, rehabilitation was associated with the palliative care and pain therapy services providing support for people receiving cancer surgery or oncology treatment at any stage of cancer, as either inpatients or outpatients. Today the department includes physical medicine and rehabilitation specialists, palliative medicine specialists, neurologists, physiotherapists, psychometrists and palliative-care nurses. Psychologists are also available on demand. Hospice beds are available for patients at the end of life.

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In the early days, the team focused mostly on pain management and motor and respiratory rehabilitation for people receiving surgery and oncology treatments. Over the years, a greater focus was placed on the care of people with advanced disease approaching the end of life, and a multiprofessional palliative care approach was developed. The rehabilitation team now includes two physical medicine and rehabilitation specialists, 15 physiotherapists – two of them dedicated to palliative rehabilitation in the hospice – and one psychometrist who treats paediatric patients. Palliative rehabilitation interventions provided by the physiotherapists include lymphoedema management, mobility training, provision of walking aids and prescription of physical and respiratory exercises where indicated. The physiotherapists also support patients and their caregivers in functional activities to improve their quality of life.

Rehabilitation is provided for inpatients and outpatients. Connections with local palliative and rehabilitation services are improving, which facilitates ongoing provision of palliative care and rehabilitation after the persons are discharged home. Occupational therapy services are underdeveloped in Italian cancer services and currently there are no occupational therapists at the institute. Occupational therapy is an additional area that the palliative care, pain therapy and rehabilitation team is hoping to develop in the future, to improve and extend the care they provide for people with advanced cancer receiving palliative care at the institute.

Building rehabilitation into palliative care services in Czechia

The provision of specialist palliative care in Czechia is growing more quickly, with European indices showing intermediate levels of integration within the wider health system. However, provision of integrated physiotherapy and other professions delivering rehabilitation within palliative care services is lagging behind.

Currently, there are only a few physiotherapists working as core team members in hospital or hospice palliative care services. People receiving palliative care in hospital settings may be provided with physiotherapy from other specialities. They are more likely to obtain access to physiotherapy if clinicians in their palliative care team know a physiotherapist personally.

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As a profession, physiotherapists understand that their interventions may provide valuable support for people living with serious illness, and palliative care teams and patients want rehabilitation. But there are no national referral criteria, guidelines or resources to indicate the persons who may benefit from physiotherapy provision, and this limits that provision. In addition, there is uncertainty about potential benefits and harms. Clinicians may underestimate the possible benefits, such as improved independence in mobility and daily activities, and may have a perception that physiotherapy may harm patients, for example, through provision of harmful vigorous exercise. A lack of detailed guidelines and educational resources published in the Czech language contributes to this uncertainty.

The lack of a formal curriculum for education and training in qualifying health care professional programmes on the provision of rehabilitation and physiotherapy in palliative care services limits the development of professional competency frameworks.

Both inpatient hospice services and home care palliative services are required to have specified levels of staffing, including a physician on the staff team, if they are to get funding from the national insurance scheme. The focus is on end-of-life care, and the inclusion of physiotherapy in the multiprofessional team is not currently a requirement for funding. This situation is exacerbated by a national shortage of physiotherapists within the health system.

Community paediatric hospices are more likely to employ physiotherapists, but the service they provide is likewise constrained by a lack of guidance and systematic provision. Occupational therapy services are better developed.

Nationally, conversations are taking place between palliative care providers, physiotherapists with an interest in palliative care and policy-makers to advance the integration of physiotherapy in palliative care services but, to date, no guidelines have been developed. Policy and clinical guidelines are urgently needed, supported by professional development programmes and the provision of undergraduate/preregistration education modules.

A palliative care centre with inpatient, outpatient and home-based specialist rehabilitative care, St Christopher's Hospice, London, United Kingdom

In terms of the allied health professional workforce and the provision of rehabilitation, St Christopher's Hospice provided physiotherapy and occupational therapy from its early days. Speech and language therapy and dietetics came later, initially under service-level agreements with local health care providers and later, from 2019 onwards, by professionals employed directly by the hospice.

Around 2008, a modern ground-floor gymnasium was built and classes were introduced, with an emphasis on group exercise circuits and other nonpharmacological interventions for people approaching the end of life, including a fatigue and breathlessness group (later developed into a holistic breathlessness management service (21)). The recognition of the allied health professionals as the "rehabilitation team" came in 2013, alongside a drive to articulate and promote rehabilitation and make it central in the services offered by the multiprofessional team at St Christopher's Hospice.

A living-well-at-home team was established within the rehabilitation team in 2016. This service used volunteers to help deliver community-based palliative rehabilitation to people in their own homes, for people previously not able to access rehabilitation at the hospice sites.

In 2018, the rehabilitation service became the Rehabilitation and Wellbeing team. This superseded day care, day support and day hospice services, moving towards an innovative model of goal-focused therapeutic outpatient services. This shift has increased the use of time-limited interventions and signposts people back out to local community services and support where available. Following discharge, people can self-refer again to services if they have new needs that meet the hospice referral criteria. This model of working benefits from the added support of a community action team and the compassionate neighbour movement. Most recently, psychosocial services came under the Rehabilitation and Wellbeing team – including social work, cognitive behavioural therapy, art and music therapy, psychotherapy and welfare support.

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