Cancer in the Long Term Plan for the NHS

Evidence from the Chartered Society of Physiotherapy (CSP) and the Association of Chartered Physiotherapists in Oncology and Palliative Care (ACPOPC)

About the Chartered Society of Physiotherapy

The CSP is the professional, educational and trade union body for the UK's 57,000 chartered physiotherapists, physiotherapy students and support workers.

The contribution of the physiotherapy workforce can be seen throughout a cancer care pathway. This may include leadership of multi-disciplinary teams, case management, prehabilitation before and during medical intervention, and rehabilitation within acute, palliative care and community settings. Physiotherapy supports people living with and beyond cancer.

Registered physiotherapists are autonomous, independent practitioners. They give expert advice and support to patients before, during and after cancer treatment. They aim to optimise health, regain function and mobility and manage long-term consequences of cancer and cancer treatment.

Support workers work with people directly on rehabilitation exercise. They provide care and support for people through individual and group moderate intensity physical activity programmes. They also support carers.

About the Association of Chartered Physiotherapists in Oncology and Palliative Care

The Association of Chartered Physiotherapists in Oncology and Palliative Care (ACPOPC) is a professional network of the Chartered Society of Physiotherapy.

ACPOPC's members are physiotherapists working in cancer and palliative care. We actively develop and promote high standards of physiotherapy practice for patients with cancer and/or palliative care needs. We inform and influence healthcare policy on behalf of members, strive to modernise service model delivery and support and champion education and research.

1. What are your top three priorities for improving cancer outcomes and care over the next 5 and 10 years?

With the number of people living with and beyond a cancer diagnosis increasing in the last decade and set to increase over the next 10 years, more importance needs to be placed on provision of, and equity of access to, high quality rehabilitation. This needs to be the next big area for research and development in cancer care.

As cancer services develop, there needs to be an emphasis on rehabilitation interventions that are multimodal and multi-professional, as part of a rehabilitation continuum that spans

the cancer care and survivorship pathway. There also needs to be better communication and integration across other long-term condition pathways.

Rehabilitation is an essential element of care to achieve the best possible outcomes with patients before, during and after cancer. High quality rehabilitation for anyone living with or recovering from cancer needs to be personalised, holistic and universal.

There is now a good evidence-base for prehabilitation.. Prehabilitation is a type of specific rehabilitation based intervention, delivered earlier in the pathway to prepare people, mentally and physically, for their cancer treatment. There is growing evidence of the positive impact n treatment outcomes that optimising physical function through moderate intensity physical activity before and during treatment has. The evidence for prehabilitation is evolving, and there is research currently underway to better understand regimes for different tumour groups, all of which should be used to inform the development of services.

The rehabilitation needs of people living with and beyond cancer need to be considered in the long term. People need ongoing support to manage the long term consequences of cancer and its treatment. Because of medical advances in cancer care, it is now a long term condition. Ongoing needs are not currently met which results in greater levels of disabilities and other long term health problems. These impact negatively on the lives of individuals and cause ongoing demands on the health and social care system.

7 out of every 10 people with cancer are living with at least one other long term condition. With better survival rates this is likely to become a growing challenge. There is therefore a need or rehabilitation staff to work across condition boundaries. This requires work to upskill the wider workforce in cancer care.

We suggest that the three top priorities are:

1. **All specialist cancer centres and hospices should include a rehabilitation team with the capacity to provide tailored support for all patients. These teams should provide screening and assessment of rehabilitation needs, stratified according to need. This would have a substantial effect for patients in terms of optimising outcomes and improving quality of life.**

The decision to organise cancer services into fewer centres of excellence has improved the quality of medical treatment for patients. However, the rehabilitative care within these centres is inconsistent. Some cancer units having access to physiotherapists and other allied health professionals in both their outpatient and inpatient services. Yet others have very little or no access in some settings, such as outpatients. There is inequity of access to rehabilitation services between cancer types, particularly in the acute sector.

Similarly, provision is unequal within palliative care and hospices. Now that people can routinely expect to live for several years, they require ongoing palliative support to optimise function, quality of life and reduce the need for care in the last months or years of life. However rehabilitation within palliative care services for people with cancer has not always kept pace with the change.

Commissioning of rehabilitation teams need to be standardised across settings

In five years
All specialist cancer centres, including acute secondary care and tertiary referral centres, need to have an adequate workforce of specialist cancer physiotherapy and allied health professionals to develop sustainable cancer service delivery models and pathways.

Palliative care services should be encouraged and supported to have established rehabilitation workforce provision. This needs increased capacity to provide in-service training, advice and outreach support to community based general rehabilitation services and primary care. This is a key aspect of integrated care, often overlooked but central to supporting more and more people to live well with incurable cancer diagnoses and multi-morbidity.

The significance of rehabilitative care within cancer centres and palliative care services will need to be reflected within senior healthcare leadership. Multi-professional management structures needed to truly inform progressive service development and sustainability.

In ten years
Rehabilitation services should work across the boundaries of sector and settings. Specialist teams would work in a more integrated way with community services. We would follow patients across the pathway through digital monitoring and follow up.

Evidence is growing to support the need to 'front-load' rehabilitation services. These should be provided earlier in the cancer pathway in order to equip people for the increasing intensive cancer treatments required to improve survival. This has become particularly evident in people who receive neoadjuvant chemo prior to major surgical resections.[1-3]

ACPOPC and the CSP are supportive of NHS England Cancer Transformation bid funding initiative to develop and evaluate a 'fit for surgery' prehabilitation programme. This includes fitness testing, exercise intervention, behaviour change support and psychological support. Based on emerging evidence as it develops, in ten years time this needs to have been implemented both for patients pre surgery and patients before other forms of treatment.

2. Establish a common set of rehabilitation outcomes to support better commissioning and service improvement

There is a lack of good quality data on rehabilitation services to inform commissioning decisions and allow decision-making about need and unmet need for people living with and beyond cancer. For example, the Transforming Cancer Services Team in London has reported there is no existing database of cancer rehabilitation metrics that can support the needs of commissioners in London and help inform their decision making.

The lack of data is a feature of all areas of rehabilitation services delivery, and most of the outcome data requirements are common across rehabilitation pathways.This urgently needs addressing in the long term plan for cancer care and all rehabilitation services. This requires upfront investment in piloting standardised data collection to test that this can be collected at scale.

In five years time
There should be a standardised dataset for cancer rehabilitation, integrated with the new mandatory community data set. A full roll out to all cancer rehabilitation services in England should be informed by a pilot to test what can be collected at scale. This has the potential to be aligned with national cancer registries to contribute to the longitudinal data required to continuing improving outcomes for people living with and beyond cancer.

In ten years time
The learning from this should have been used to establish a common rehabilitation data set across all long term conditions, focused on symptoms not diagnosis, integrated with the new mandatory community data set but spanning sectors.

3. Community-based rehabilitation services need to be available for all people with rehabilitation needs, relating to a range of conditions, including those living with and beyond cancer.

Cancer symptoms such as fatigue, deconditioning and pain are common to a range of long-term conditions. Many people with cancer have co-morbidities, such as cardiovascular disease, mental health conditions or osteoporosis. This adds to the complexity of their rehabilitation needs, and puts a burden on individuals, society and the health and care system in terms of their health and care needs.

Capacity and capability in general community rehabilitation services needs to be significantly developed to meet rehabilitation needs arising from patients with multiple long term conditions, frailty and complex symptoms. There is also a need to consider the number of people with a history of cancer, living longer and the emerging evidence that more people are living long enough to receive a second diagnosis of cancer later in life.

Community rehabilitation services should be organised around GP networks but with strengthened links to specialist rehabilitation teams in cancer centers. Using local leisure and voluntary services where appropriate should be part of an enhanced community rehabilitation model. Consideration should be made towards co-locating services from different sectors in easily accessible community locations.

In five years time
Community rehabilitation services should be part of the cancer pathway, with capacity in the system to enable timely and effective transition of care from acute care.

Following an assessment of need, as part of the overall management of their survivorship rehabilitation programme, all patients living with and beyond cancer with rehabilitation needs should be referred to their local community rehabilitation team.

Community based rehabilitation services should be readily available for people living with and beyond cancer whose needs emerge later, through self-referral and referral from primary care.

In ten years time,
Physiotherapy staff should be able to work flexibly across acute, community and primary care sector boundaries. They will be providing outreach and in-reach services to meet patient needs and ensure continuity of care. This may mean community rehabilitation team staff coming into hospitals to working with people in the latter stages of hospital-based rehabilitation and working with them following transition to the community sector. It could equally involve acute sector staff following patients into the community, as part of an integrated service.

2. What more can be done to ensure that more cancers are prevented, more cancers are diagnosed early and quickly, people can maintain a good quality of life during and after treatment, and people with cancer have a good experience of care.

2.1 Six month rehabilitation programmes as part of the cancer care have a proven benefit to patients physical fitness levels.[4] This results in better outcomes, secondary prevention, and increases for patients in their confidence, function and mobility.

2.2 Prehabilitation physical activity interventions for people with cancer focus on cardiovascular health and/or muscle strengthening before and during treatment or surgery. For example, for abdominal cancer, improving physical fitness and having

pulmonary physiotherapy is effective in reducing pulmonary complications.[5] For patients with bladder cancer, strength and endurance exercises prior to radial cystectomy showed improved mobilisation and ability to perform daily tasks.[6]

2.2 Rehabilitation supports people to; manage health conditions and disabilities caused by cancer and its treatment, reduce disease progression. They increase people's ability to manage health conditions and disabilities caused by cancer and its treatment. This enables them to regain confidence, function and mobility. For example, the progression of prostate cancer was reduced by 57% among men who engaged in three hours a week of moderate intensity exercise.[7] There is similar evidence for breast and colorectal cancers.

2.3 Common impairments and side effects of breast cancer include lymphoedema, shoulder disfunction, fatigue and pain. People who receive physiotherapy from the day after breast cancer surgery can have improved shoulder mobility and function, lower rates of lymphodema and lower rates of referral for outpatient physiotherapy after 6 months.[8]

2.4 Radiation therapy causes decreased bone density, muscular atrophy and fibrosis, muscle spasms and pain. These have both an immediate impact on recovery and long-term health. Loss of bone density is linked to a high risk of osteoporosis and fragility fractures. Rehabilitation exercise is required during and immediately after treatment, and later on. There is a wealth of evidence to show how physiotherapy supports people to strengthen their bones and reduce their risk of falling through strength and balance exercises.[9]

2.5 Half of all people diagnosed with cancer annually are of working age. The current number of people of working age with cancer is 890 000.[10] People living beyond cancer are 1.4 times more likely to be unemployed. Exercise, combined with counselling and patient education nearly doubles the likelihood of a person surviving cancer returning to work.[11]

2.6 All cancer patients need to have an expert assessment of rehabilitation needs. This should stratify patients for continuation of rehabilitation within an oncology department, referral to community rehabilitation or to support for self-care from professional trainers, voluntary organisations or leisure services.

2.7 Community services need to be in place for oncology departments to effectively handover patients for ongoing rehabilitation. Community rehabilitation services are over-stretched and coverage is uneven. This can often result in acute teams delaying referral of patients to community services or not referring them at all.

2.8 In the future services should not be delineated by sector and setting (ie acute and community) but rather operate much more flexibly across pathways, to improve the continuity of care for patients and better share expertise.

2.9 Physical inactivity is a major public health concern, directly linked to increased risk of developing many long-term health conditions, including cancer. Cross-sector collaboration is required to provide accessible, structured exercise programmes and behavior-change support to increase levels of physical activity. This is key to improving health outcomes and has a strong role in secondary prevention, regaining the confidence, function and mobility people need to resume active live. Physiotherapists have a particular role to play supporting people with long term conditions or disabilities to become more physically active.

3 How can we recruit, train and retain the workforce to deliver the changes we need and the priorities you have shared?

3.1 Modelling work for the Department of Health by the Centre for Workforce Intelligence demonstrated the need to growth of the rehabilitation workforce, including registered physiotherapists, other AHPS and physiotherapy and AHP support workers.[12]

3.2 The registered physiotherapy workforce is going through a period of growth, with over 40% increase in the number of pre-registration training places available in England since 2015/16. Unlike some other clinical professions there is a strong demand to train and a low drop-out rate. There are strong indicators from education providers that further growth can be anticipated. This should be utilised to improve cancer rehabilitation and community rehabilitation services more broadly.

3.3 A physiotherapy workforce with skills in cancer care and assessing rehabilitation needs of people with a range of long term conditions needs to be expanded and further utilised. In particular, developing advanced practice roles in both acute and community teams would enhance care pathways, enable stratified assessment of rehabilitation needs.

3.4 The physiotherapy support worker workforce could be providing more one to one support with therapeutic exercises and delivering group exercise classes. They could perform delegated duties at a higher level of independence if structured, standardised development opportunities are provided and appropriate clinical governance structures are put in place.

3.5 Contracts should build in time for NHS staff to share expertise and new developments in cancer care across disease specific and generalist rehabilitation services, regardless of employer. This should include a call on employers to support physiotherapists to lead and engage in high quality research activity and analysis of rehabilitation datasets, as part of their job plans, to further prove the efficacy and cost-effectiveness of cancer rehabilitation.

3.6 Exercise professionals in leisure and voluntary services have an important role to meet low rehabilitation needs, and supporting people to self-manage. Their contribution needs to be part of the rehabilitation pathway for those living with and beyond cancer. Physiotherapists have a particular role in developing activity suitable activity programmes for delivery by non-clinical staff, and advising such staff on the ongoing suitability of programmes.

3.7 The role of the clinical nurse specialist (CNS) in cancer is well established and is associated with improved satisfaction of people having cancer treatment. The desire to increase the CNS workforce has been hampered by the shortage of adequately trained nursing staff .This is resulting in unfilled vacancies. Allied health professionals, especially physiotherapists, could be a solution if these roles were developed to focus on the required capabilities, not on a single profession. Many of the needs identified as part of Macmillan cancer support holistic needs assessment (HNA), predominately carried out by CNSs, are specifically related to the expertise that physiotherapists are trained to assess and manage. Wider use of the AHP workforce to provide high quality, person centered, named key worker input, like that of CNSs could allow all people with cancer better access to the holistic care they need during cancer treatment. This role could also develop to include integration of patient care across all parts of the pathway – enabling greater sharing of expertise across sectors.

4 How can we address the variation and inequality to ensure that everyone has access to the best diagnostic services, treatment and care?

4.1 There is significant variation and inequality in rehabilitation for people living with and beyond cancer, but this is impossible to address without a shared rehabilitation data set and agreed outcomes to measure need, impact of services or identify gaps.

4.2 Those who do not get the support they need to regain function and mobility are more likely to develop lasting disabilities and debilitation despite an improved life expectancy post cancer treatment. This can lead to socio-economic disadvantage, disability and social exclusion.

4.3 Health Equality Assessments should be mandatory for all cancer service planning and delivery. The mandate should include: a minimum dataset for monitoring all cancer services and includes inequalities measures; health equity audit (HEA) as part of routine monitoring for all cancer services and reporting on actions taken to address inequalities identified through HEA.

4.4 To address variation the palliative care service delivery model and funding needs specific attention. The current system is out of step with the reality that many people with a terminal cancer diagnosis will live for several years, with an accumulative symptom burden from repeated cancer treatments. The services need to be developed to meet these need. There needs to be less reliance on voluntary donations to fund palliative care.

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Service examples

The PREPARE programme at Imperial College Hospital in London is a pre-habilitation programme for patients undergoing surgery for oesophago-gastric cancers which started in 2013. The MDT includes physiotherapists, dieticians and psychological professionals.

Impact includes: reducing average post-operative length of stay from 12 to 8 days, for patients also receiving chemotherapy it prevented deterioration in physical function and quality of life, it reduced rates incidence of post-operative pnueumonia from 60% to 29%.

South East London Community Head and Neck Cancer Team provides seamless care from hospital to home following cancer treatment. Physiotherapists are 'tracheostomy competent' team members who help rehabilitate people who need to breathe through a hole in the neck, either permanently following removal of the voice box (laryngectomy) or following temporary tracheostomy. Along with speech and language therapists and clinical nurse specialists, CHANT physiotherapists provide 'airway visits' within 24 hours of discharge from hospital to support patients and their families become competent and confident in managing tube breathing at home.

Impact: Prior to providing this intervention, patients sent home would commonly 'bounce back' into hospital within a couple of days either because they were not confident managing their tracheostomy in the home setting or because they could not get their equipment to work. The new service delivered cost savings and improved patient experience because it allowed the AHP or CNS to deliver active clinical interventions in the home, it reassured patients and their families, and eliminated hospital re-admission for tracheostomy-related problems.

The **Abertawe Bro Morgannwg University Health Board lymphoedema service** started in 2004 and initially focused on cancer-related lymphoedema before opening up the service to non-cancer patients. The service employs 14 staff members including physiotherapists, nurses and administration support.

Impact includes: reduced cellulitis episodes for lymphodema patients from 58 to 9%, and through preventative care have reduced breast cancer related lymphodema from 1 in 3 breast cancer patients to 1 in 12. It has also reduced appointments with GPs and community nurses for cellulitis, 'leaking' legs and reduced mobility, and reduced referrals to other specialities including vascular and plastic surgery.

Guy's and St Thomas' Cancer Physiotherapy team support patients at all stages of the cancer journey - pre-treatment, during treatment, post treatment, palliative and end of life.

The team provide educational and expert support to patients, health care professional and leisure providers within the local boroughs through health and wellbeing talks.

One of the services they provide is The Active You physical activity and exercise pathway – run in part collaboration with Macmillan Cancer Support, the service consists of physical activity and exercise support through one to one or cancer exercise group classes, information and advice on leisure services through one-to-one reviews and follow-up to support long-term behaviour change.

Impact includes: patients who complete the physical activity pathway have improved weight, exercise capacity, physical activity levels and overall quality of life.

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