

WE ARE
MACMILLAN.
CANCER SUPPORT

ALLIED HEALTH PROFESSIONALS

Who are they?

Allied Health Professionals (AHPs) are a diverse group of professionals who deliver high-quality care across a wide-range of health and social care pathways and across a variety of different settings, from people's own homes to hospitals. AHPs have a significant positive impact on the lives of people living with and beyond cancer in many areas including quality of life, physical fitness, wellbeing, mental health, fatigue, communication, mobility, function, nutritional status and pain. AHPs provide a connection between many services including community, primary care, social care and healthcare services through a range of services offered. Cancer rehabilitation, delivered by AHPs, empowers patients living with and beyond cancer. Rehabilitation aims to maximise patients' ability to function, to promote their independence and to help them adapt to their condition. AHPs working with cancer patients include occupational therapists, physiotherapists, dietitians, speech and language therapists, lymphoedema therapists and radiographers amongst others. They provide personalised advice and support to patients and also act as a vital assessment, coordination and referral point. These services improve patients' satisfaction and help the NHS save resources.

'During my transplant the physiotherapist arranged for an exercise bike to be put into my isolation ward so I could pedal away and watch the trains from my window.'

Cancer patient

Need



Early assessment and intervention by AHPs can prevent avoidable ill health and are effective in avoiding conditions becoming more complex and costly to treat later on.



30% of cancer patients report unmet needs after treatment for cancer which could benefit from additional interventions from AHPs providing a range of services including rehabilitation services.²

Reach



The average Macmillan AHP helped 189 patients across 2014.¹



Macmillan AHPs delivered help to **135,135 people** in 2014.¹

Impact



For every £1 spent on lymphoedema treatments by limiting swelling and preventing damage and infection provided by AHPs, the NHS saves an estimated **£100** in reduced hospital admissions.⁶



About 40% of cancer patients have been found to have significant protein-energy malnutrition which can be corrected by AHPs.⁶

This Impact Brief is part of a suite of Impact Briefs which provide evidence about the impact of Macmillan's direct and indirect services, available at www.macmillan.org.uk/impactbriefs

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INTRODUCTION

Macmillan has helped to fund or adopt almost 800 specialist Allied Health Professional (AHP) posts across the UK. These professionals can lead as well as form part of multi-disciplinary teams in hospitals, community services or work in partnership with healthcare providers such as hospices.

Specialist AHPs provide personalised advice and support to clients and also act as a vital assessment, coordination and referral point. The rehabilitation services designed and delivered by AHPs are vital in promoting well-being, independence, self-management and maximising quality of life throughout the cancer pathway. Cancer and its treatment may have a strong impact on people and these consequences can be better addressed with a multidisciplinary approach offered by AHPs. Interventions by AHPs improve patients' quality of life, physical fitness, wellbeing, mental health, communication, mobility, function, nutritional status. Interactions by AHPs can also reduce fatigue and pain.

SUMMARY OF KEY FINDINGS

- **Cancer's impact on daily activities**
Cancer and its treatment can have a major impact on a patient's ability to carry out usual daily routines. Activities most people take for granted, such as moving, speaking and eating can be severely impaired. All cancer patients are likely to need rehabilitation at some stage in the cancer journey.
- **Rehabilitation**
Rehabilitation, delivered by AHPs, empowers patients living with and beyond cancer. Rehabilitation attempts to maximise a patients' ability to function, to promote their independence and to help them adapt to their condition.
- **Addressing unmet needs**
30% of cancer patients report unmet needs after treatment for cancer which could benefit from additional interventions from AHP-delivered rehabilitation services during the survivorship stage of their illness.²
- **Interventions to improve quality of life**
AHPs are vital members of any multidisciplinary cancer team, supporting people living with cancer. Interventions by AHPs improve patients' quality of life, work and vocational rehabilitation, strength and fitness and reduce fatigue.
- **The National Cancer Survivorship Initiative (NCSI)**
NCSI is a partnership between NHS England and Macmillan Cancer Support which highlights unmet needs of cancer survivors including medical, psychological, social, spiritual, financial and informational requirements. This programme focuses on support from the point of diagnosis, promoting and sustaining recovery, managing the consequences of treatment and supporting people with active and advanced diseases. AHPs deliver key recommendations highlighted by the NCSI.

DETAILED FINDINGS

1. What is the issue?

i) Why are rehabilitation services required by people living with cancer?

Cancer and its treatment can have a major impact on a patient's ability to carry out usual daily routines. Activities most people take for granted, such as moving, speaking, eating, drinking and engaging in sexual activity, can be severely impaired. **Cancer rehabilitation** aims to maximise physical function, promote independence and help people adapt to their condition; empowering patients living with and beyond cancer with supported self-management. A range of AHPs provide rehabilitation services and, through developing self-management skills, patients can take an active role in adjusting to life with and after cancer.³

AHPs are a diverse group of professionals who deliver high-quality holistic care across a wide-range of health and social care pathways and across a variety of different settings – from people's own homes to hospitals.⁴ AHPs providing rehabilitation for cancer patients may include occupational therapists, physiotherapists, dietitians, speech and language therapists and lymphoedema therapists, amongst others.^{5,6} Due to a range of services provided, AHPs often become a link between social care, community, voluntary services and medical institutions allowing patients to feel less lonely and abandoned. They are the only healthcare professionals whose primary qualification is in rehabilitation.⁷ AHPs are autonomous practitioners and as such may well be the only person at a point in time supporting a patient.

Cancer-related symptoms which can require such therapeutic intervention from AHPs include anorexia, breathlessness, fatigue, weight loss, asthenia, pain, lymphoedema, loss of mobility and function or impairment in activities of daily living, communication difficulties, supporting those with altered body image, continence, pain, swallowing difficulties and anxiety management.⁴ The symptoms vary according to the stage of the cancer journey and cancer type.

For example, cancer cachexia or 'wasting syndrome' is a complex condition which can develop in many types of cancer, more commonly lung cancer and cancers affecting the digestive system. It is most common in advanced cancer, occurring in up to 60% of patients, however it can also appear at any stage of the cancer pathway. Symptoms include severe loss of weight, loss of appetite, nausea, feeling full after eating small amounts, anaemia, weakness and fatigue. Dietitians are the only qualified health professionals who assess, diagnose and treat diet and nutrition problems at an individual and wider public health level and have the ability to provide safe and effective therapeutic dietary advice.⁸

All cancer patients are likely to need rehabilitation at some stage in the cancer journey. For example, swallowing difficulties, or dysphagia, are experienced by people who have been treated for head and neck cancer and the seriousness of these effects depends on the type and nature of treatment, size and location of tumour. Speech and language therapists may be able to provide appropriate help to these patients.

In addition, AHP's specialist knowledge of cancer, treatments and the cancer journey means they are able to treat the variety of issues that could be hindering the rehabilitation process; these often go beyond purely physical based problems. Difficulties swallowing, for example, can also be due to a patient who has not come to terms with their prognosis.⁹

Patients' needs differ according to their individual cancer and may require assistance from AHPs during active treatment, in advancing disease, during remission, long after treatment has ended or at end of life.¹ Rehabilitation requires **a multidisciplinary team approach** because of the variety of potential problems patients may face during the course of illness.

Patients' rehabilitation needs should be assessed as early as practical. Early rehabilitation can prevent avoidable ill health and is more effective in avoiding conditions becoming more complex and costly to treat later on.¹⁰

Cancer rehabilitation attempts to maximise patients' ability to function, to promote their independence and to help them adapt to their condition. It aims to maximise dignity and reduce the physical, psychosocial and economic effects of cancer.¹ Rehabilitation brings added value to supportive and palliative care during the cancer journey and is not an optional extra.¹¹

However offering **continued rehabilitation** at various stages during the cancer pathway is also important, including at the end of active treatment, survivorship and end of life, to ensure that the appropriate rehabilitation service is identified and provided as circumstances change.² In a 2004 study to examine rehabilitation goals of cancer patients, participants emphasised that reviewing goals at different stages of their 'cancer journey' was crucial, because their needs and wishes changed throughout the trajectory of their illness. Results also showed that 65% of rehabilitation goals were related to **self-management**.^{12,13}

The concept of rehabilitation in cancer requires a much better understanding by the wider health and care workforce, commissioners, service planners and people with cancer as it can fundamentally improve the life of the person if their needs are identified and met.¹⁴

There are over 2 million people living with cancer in the UK. This number is increasing due to improvements in early diagnosis and treatments. It is expected that by 2030, 4 million people in the UK will be living with cancer.

A 2008 survey revealed that 78% of people living after cancer said that in the last 12 months they had experienced at least one of the physical conditions that can occur as a result of cancer.¹⁵ A later survey of patients' supportive care needs beyond the end of cancer treatment revealed that 30% reported unmet needs¹⁶ and therefore may benefit from additional interventions during the survival stage of their illness. Recent estimates suggest that 5-10% of those with common cancer types over a 20-year period will have complex problems requiring specialist multi-disciplinary management.^{17,18} In addition, a 2013 National Cancer Survivorship Initiative report advises that patients who continue to survive, with cancer complications, may be better supported through access to a **Multi-Disciplinary Team** (MDT) at the point of diagnosis, and with subsequent on-going MDT support.¹⁰

ii) Why are people living with cancer not receiving effective rehabilitation services?

Patients and clinicians agree that people with cancer are not getting access to the rehabilitation services they need. This may be because patients do not always receive assessments of their needs and front line staff may not recognise patients' needs for rehabilitation.

There may be a lack of AHPs available to provide services, or those who do exist may not be trained in cancer specific rehabilitation needs.¹

Research by the National Cancer Action Team (NCAT) in England has revealed that there are several barriers to the delivery of good quality rehabilitation services. These include a lack of understanding of the complexities as a whole and in relation to various cancer sites, and the misconception that rehabilitation is additional and not integral to patient care, meaning that it may not be valued as a service by patients and professionals.¹⁹ The need to provide rehabilitation services for cancer patients is also recognised in Wales, Scotland and Northern Ireland. National

strategies have been developed to support rehabilitation through Multi-Disciplinary Teams across the cancer care pathways.[†]

Additionally cancer care pathways do not always explicitly reflect cancer rehabilitation as part of the process.²⁰ To help address this NCAT have developed 9 tumour specific and 10 symptom specific evidence[‡] based pathways for cancer rehabilitation. Each pathway highlights the potential AHP interventions needed by people with cancer at various stages of the cancer journey and are considered by experts to be best clinical practice and evidence based.¹⁹

There are few integrated MDTs that include AHPs with rehabilitation expertise in cancer and palliative care, and a lack of training opportunities for AHPs who would like to specialise in cancer care.² Research in Wales has demonstrated that not all hospitals have specialist AHPs for oncology and palliative care.²¹ This is also the case across many health and care organisations in other parts of the UK.

A significant proportion of people with advanced cancer experience a range of complex problems that cannot always be dealt with effectively by generalist services.[§] However, many hospitals do not have full MDTs who can provide advice on a 24 hour, seven days a week basis and community specialist palliative care services vary considerably in their ability to provide services at weekends and outside normal working hours.²

2. What is Macmillan doing to address the issue?

Macmillan has helped to fund or support almost 800 AHP posts across the UK to promote well-being and independence and maximise quality of life at all stages of the cancer pathway.²² These professionals delivered high quality **preventative, restorative, supportive and palliative cancer rehabilitation** to over 127,680 people in 2013 and to 135,135 in 2014.^{23,24,†} Macmillan AHPs can form part of multi-disciplinary teams in hospitals or work in partnership with other health and care providers such as social care and hospices.

Macmillan AHPs also provide liaison and a range of services to people affected by cancer including prioritising referrals, assessment of individual needs, liaison with other agencies as appropriate, and co-ordinating, planning and implementing individuals' requirements as needed. AHPs also provide specialist advice and support to clients and are an expert resource to colleagues. Macmillan AHPs feedback to specific teams and organisations as necessary, thus improving the care pathway for patients and their families. A substantial element of the role is in promoting the service, educating colleagues and using resources already available to maximise the potential of the AHP role.

Macmillan worked with the Department of Health (DH) in England and NHS Improvement to conduct pilot schemes across the UK** to identify models of care and best practice for post treatment support for cancer patients, including assessment and care planning, post treatment support transition and supported self-management.

[†] Welsh Assembly Government (2010) *National Standards for Rehabilitation of Adult Cancer Patients (supported by individual cancer network strategies)* Scottish Executive (2007) *Co-ordinated, integrated and fit for purpose: A delivery Framework for Adult Rehabilitation in Scotland (Cancer is noted as a specific priority long term condition to target)*

[‡] The NCAT evidence report can be access here:

<http://www.mccn.nhs.uk/userfiles/documents/NCAT%20mapping%20report%20-%20final.pdf>

[§] One example of such a complex problem is lymphoedema, an incurable condition which can develop as a result of cancer treatment, the symptoms of which can be eased with specialist input from AHPs or specialist lymphoedema nurse.

** Two National Cancer Survivorship Initiative (NCSI) test centres to develop new pathways of care and support for patients post treatment are based in Wales

According to a recent National Cancer Survivorship report¹⁴, a key to good survivorship is creating a shared understanding between patient and healthcare professionals about what to expect during recovery, and identifying any needs to be addressed. AHPs work within this framework by the very nature of their training. Three interventions have been identified to best achieve this as part of a 'recovery package,' this includes Macmillan tested models of '**Health and Wellbeing clinics**'. These are post treatment multidisciplinary clinics that provide information and signposting for people with cancer in all areas of health including lifestyle, exercise and diet. The clinics also help to encourage and support patients to self-manage their condition. In combination with the two additional elements, of **Assessment and Care Planning** and creating a **Treatment Summary**, the clinics have been identified as the most important building block for achieving good survivorship outcomes.¹⁰

A second area where new models of care are being piloted is around **Vocational Rehabilitation** to help cancer patients return to work. A 2010 Macmillan study in Manchester indicated that savings in the region of £170,000 could be released annually to the wider economy through saved benefit payments and increases in tax contributions, if half of the sample of lung and breast cancer patients, who currently return to work and then leave, were more effectively supported through vocational rehabilitation.²⁵

Macmillan is also working with the Department of Health (DH) in England to increase physical activity of cancer patients during and after treatment. The evidence suggests that being physically active during and after cancer can improve physical and psychological well-being, reduce the risk of consequences of treatment, improve overall survival rates and reduce the risk of recurrence and co-morbidities.^{26,27}

3. What is the impact of effective AHP rehabilitation?

The impact on health and wellbeing of cancer patients

Effective rehabilitation interventions have a significant positive impact for the lives of people living with cancer in many areas including quality of life, physical fitness, mental health, fatigue and pain. Attendances at outpatient services provided by AHPs have risen rapidly since 2005-6. This compares to a 39% increase in all outpatient attendances over the same period.²⁸

i) Preventative interventions

Evidence suggests **early physiotherapy** to be an effective intervention in the prevention of secondary lymphoedema in breast cancer patients after surgery.²⁹ Physical exercise is also important for enhanced recovery for Upper GI and Colorectal cancers.

A 2005 study in the United States showed that rehabilitation intervention by means of **nutrition education** could improve both physical and emotional wellbeing in breast cancer patients post treatment.³⁰

'Without my Macmillan Consultant Dietitian I really and truly wouldn't have known what to do. Because of radiotherapy, my mouth was full of ulcers and blisters. I couldn't really talk or swallow. She gave me some supplement drinks that helped tremendously. She is a lovely, lovely person who listened to all my needs'

Cancer patient

AHPs, such as dietitians and speech and language therapists, who take on the responsibility of recommending (but not prescribing) medicines can reduce treatment delays and reduce patients' exposure to safety risks.¹⁹

Patients receiving physiotherapy immediately following neck dissection reported better wellbeing.³¹

Case Study: Cancer rehabilitation and support team Clatterbridge Centre for Oncology³²

Jenny attended six Occupational Therapy sessions, to explore her appearance assumptions and understand the impact of these beliefs on her functional (physical and psychological) ability.

Jenny said:

'It helped to know that someone was with me, understood how I was feeling and shared my deepest fears and it was OK, nothing bad happened. My confidence improved and family and friends started to respond differently to me, because I was responding differently to them, in a good way. I did try some wigs, but I prefer to wear headscarves and hats. My therapist was with me as it was the first time I had really had to look at myself in a mirror. She helped me to understand that what I think as I look in the mirror will affect how I feel. Changing what I think, will help me change how I feel. I still have a long way to go, sometimes people do stare but I am in a better position now to cope with it.'

ii) Restorative & supportive interventions

There is evidence that **physical activity interventions** by professionals including physiotherapists, occupational therapists, and nurses improve patients' quality of life, strength and fitness and reduce fatigue.⁶

A study on the effects of **nutritional management** in cancer patients demonstrated that nutritional support intervention led to significant improvements in energy levels, exercise capacity and weight gain.³³ Evidence suggests that intervention related to diet leads to improvements in body weight and survival for people living with cancer.⁶

Occupational therapists can develop and implement care plans to help patients remain independent and have a significant role in the management of long term conditions, including older people in the community.

Case Study: Macmillan Nottingham lung cancer care service³⁷

Patient A was suffering breathlessness, fatigue, pain, loss of weight and appetite, loss of independence and anxiety after potentially curative surgery for non-small cell lung cancer.

She was seen by all members of the Macmillan CARE team. The dietitian supported her nutritionally with supplements and her weight and appetite improved. The occupational therapist and physiotherapist worked together to optimise her independence at home through the provision of equipment and advice on strategies to help her regain her daily routine, and manage her breathlessness and anxiety.

Five months after surgery she returned to her previous levels of activity and independence.

AHPs play a key role in helping patients to remain in or return to work more quickly. Occupational therapists undertake vocational assessments and support people back to return to and stay in work with reasonable adjustments, for example, using interventions to build confidence and self-esteem.³⁴ Many AHPs routinely cover work as part of an initial “holistic needs assessment” with each patient.³⁵

'I feel safer and more confident. I'm able to get on with life. Not being independent got me down.'

Cancer patient

iii) Palliative interventions

For patients who receive **palliative care**, the focus of rehabilitation is improving quality of life, irrespective of its length.³⁶ Comments from patients receiving treatment from Macmillan Occupational Therapists at Farleigh Hospice in mid Essex highlight the positive impact of providing specialist palliative care services for people with cancer.

'Yes it (staying at home) has kept me going. I want to stay at home. I think most people in this situation do.'

Cancer patient

The Macmillan Nottingham Lung Cancer CARE service has shown that interventions from **supportive and palliative rehabilitation care services** including dietitians, occupational therapists and physiotherapists improved survival, decreased length of hospital stay and had a positive impact on place of death. Between 2006 and 2009 the number of patients who died within a six month period of follow-up fell from 74% to 58%, average survival increased from 52 days to 109 days and there were fewer deaths in hospital. The total number of inpatient days decreased from approximately 1,500 to 650 days.³⁷

Case Study: Macmillan Somerset Mouth cancer care service³⁷

Patient B was diagnosed with throat cancer, his intensive treatment plan had some devastating side effects and temporarily left him unable to eat or talk properly. Patient B felt well supported by the Macmillan AHP team – which for him included a radiographer, dietitian and speech therapist who constantly assessed progress and made relevant recommendations to enable the patient to get through the treatment. The patient also chatted to other people affected by cancer through Macmillan's Online Community to share experience and get relevant advice. After the treatment the patient still had some sore throat but there was much more flexibility in what could be consumed.

The National Cancer Survivorship Initiative

The National Cancer Survivorship Initiative (NCSI) is a partnership between NHS England and Macmillan Cancer Support. Its aim is to ensure that those living with and beyond cancer get the care and support they need to lead as healthy and active a life as possible, for as long as possible. National Cancer Survivorship Initiative Vision (2010) document listed key recommendations to improve cancer patient experience. Macmillan's AHP fulfil NCSI's recommendations in the following five key areas:

- Self management
- Greater focus on recovery
- Personalised Care Plan
- Early recognition of consequences
- Measuring patients to self-manage.

The impact on local health and social care economies

The knowledge, skills and experience of AHPs improve productivity, reduce hospital admissions and length of stay and prevent ill health.⁶ Macmillan occupational therapists benefit from being able to access funding for their own development and patient grants, which enhances the service they are able to provide.³⁸ Improving knowledge and skills of AHPs at all levels encourages movement into specialist posts at a higher level.¹ Therefore the support that Macmillan AHPs receive saves the NHS the cost of training professionals to develop specialist rehabilitation skills.

Occupational therapy interventions can bring cost benefits to the NHS by providing **preventative advice and treatment** to avoid complications which may lead to further referrals and admissions. Accident and emergency admissions can also be reduced by improving the physical wellbeing, for example by helping lymphoedema patients preventing limb injury or teaching patients breathing techniques to cope with panic attacks.³⁹ NCAT recognises that addressing the provision of cancer rehabilitation is cost-effective: a patient that returns to work and/or lives independently saves money to invest elsewhere. Well-resourced cancer rehabilitation teams can reduce excess bed days and possibly readmission rates.²⁰

Dietitians play a major role in reducing obesity, which is a significant risk factor in the cause of cancer. 8.7% of breast cancer cases are attributable to being overweight and obese and this rises to 24% in oesophageal cancers. Dietitians also provide nutritional assessments in preparation for the patient under-going cancer treatments. Appropriate nutritional screening and timely intervention can also limit weight loss. This potentially has direct cost benefits both financially and in terms of the quality of life of the patient and carers. A five day reduction in length of stay, from 15 days to 10 days, as a result of minimising malnutrition provides an annual saving of £266 million.

Lymphoedema practitioners assess physical movements to improve and manage the impact of any treatments (surgical/radio/chemotherapy) and optimise recovery time. For every £1 spent on lymphoedema treatments by limiting swelling and preventing damage and infection, the NHS saves an estimated £100 in reduced hospital admissions.⁶

By facilitating early discharge AHPs enable patients to die at home, reducing the number of days in hospital for patients. This can also result in a considerable saving to the NHS in terms of bed days.

It is estimated that the English economy lost £18 billion in 2008 due to cancer of which £5.5 billion were lost due to problems associated with productivity. Studies have shown that in order to achieve good quality cancer care, outcomes such as quality of life, functional status, living well and individual care experience should be considered. More healthcare professionals recognise that patients need to be looked at during their whole journey providing tailored support throughout according to individual needs. Research suggests that systematic preparations for cancer treatment and aftercare can significantly improve quality of life for cancer patients.² It is important to encourage people to continue educating patients, through AHPs, to self manage and live well which can reduce treatments costs and allow people to return to work earlier.

CONCLUSION

As the number of people living with cancer in the UK rises from two million to four million by 2030, so the need for effective cancer rehabilitation services will also rise.

Macmillan can help to fund and support AHP posts across the UK to ensure that people living with cancer have the rehabilitation support they need to improve their quality of life. Effective rehabilitation support can enhance physical fitness, reduce fatigue and pain and facilitate early discharge from acute care.

Macmillan continues to fund and support cancer AHPs and urgently needs more charitable donations to keep these services supporting cancer patients and their families. Go to www.macmillan.org.uk/donate or call 0300 1000 200 to make a donation.

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