

Exploring the Role of Allied Health Professionals in the Care of People Affected by Cancer: The Patient and Practitioner Voices project

June 2019

“

It is important that practitioners recognise that each day is important to a cancer patient – ensuring each day is as worry free as possible. Otherwise, cancer takes away what you have today, and may not have tomorrow.”



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Contents

Introduction	3
Section 1 - Background	5
Section 2 – Patient and practitioner voices.....	7
Section 3 – Additional resources	36
References.....	38

Introduction

Allied Health Professionals (AHPs) are a diverse group of clinical practitioners who work in multidisciplinary teams (MDT) alongside medical, nursing and scientific healthcare professionals.

In total, AHPs make up the third largest professional group in the NHS workforce and as such, they make a significant contribution to the care of people affected by cancer.

With the addition of osteopaths and operating department practitioners (in April 2017) there are now 14¹ Allied Health Professions (Box 1).

Box 1: The 14 Allied Health Professions



¹. There are 14 AHP roles. Radiography has two professional branches.



NHS England provides overarching [descriptions](#) of the roles of the 14 allied health professions. The aim of this project was to build on these descriptions and highlight the particular contributions AHPs make to the care of people affected by cancer.

The project was triggered by Recommendation 70 of [Achieving World Class Cancer Outcomes: a strategy for England 2015 – 2020](#): that HEE supports a national review of the cancer rehabilitation workforce and promotes the role of AHPs in multidisciplinary teams (NHS England, 2016).

As our starting point we took existing work that showcased and promoted the role of AHPs and supported the development of AHP competencies in cancer care. This project report presents further work undertaken by Health Education England (HEE) to explore the roles of AHPs that provide care within multidisciplinary cancer care teams and to explore the experiences of people affected by cancer who have received care from AHPs.

HEE continues to work with NHS and other partners in response to the Cancer Taskforce recommendations and to deliver the ambitions of the NHS Cancer Strategy.

We hope that by sharing the outputs of this project we can help:

- raise public and professional awareness of AHP roles across the entire cancer care pathway
- stimulate interest in AHP careers and help expand the AHP training pipeline
- inspire existing AHPs to develop the knowledge, skills and behaviours (competencies) required deliver high quality care for people affected by cancer
- inspire local NHS service leaders to consider further how AHP roles and multidisciplinary teamworking can help meet the needs and expectations of an increasing number of people being diagnosed with and surviving cancer.

Overview of report

In **Section 1** we provide a brief summary of the context of this work and an overview of the methods used to collect information from AHPs and people affected by cancer.

Section 2 describes the role of each of the 14 AHPs from the perspectives of AHPs themselves and people affected by cancer who participated in our project. This section showcases the range of care interventions AHPs can deliver and the impact these can have on the lives and health and care experiences of people affected by cancer.

Using the words of our practitioner and citizen participants we have included an illustrative description

of the scope of practice of each AHP in the care of people affected by cancer followed by patient and practitioner 'stories' of real-life AHP care experiences.

The information we present in this project report reflects AHP contributions to cancer clinical pathways across prevention, screening, diagnosis and treatment and during rehabilitation, remission, palliative and end-of-life care.

In **Section 3** we list HEE and other resources that can help support the provision of an adequate supply of new AHPs into the cancer workforce and resources that can help existing AHPs who meet people affected by cancer to develop the skills, knowledge and behavioural competencies required to deliver high-quality care.

Section 1 - Background

In January 2017, the Chief Allied Health Professions Officer published '[Allied Health Professionals into Action](#)' (NHS England, 2017) - a framework document describing the wide and diverse nature of AHP contributions to the NHS.

[AHPs into Action](#) identified that AHPs help to increase NHS capacity by streamlining patient pathways which accelerate diagnosis, improve survival and offer a better quality of life for people affected by cancer. Seven of the 53 case studies included in [AHPs into Action](#) mention cancer specifically (Table 1).

Table 1: Cancer cases studies in AHPs into Action (NHS England, 2017)

Case study	Patient pathway	AHP	Care intervention
24	Head and neck cancer survival	Dietitian	Dysphagia – management of swallowing difficulties.
32	Diagnosis, staging and monitoring - all cancers	Diagnostic radiographer	Interpretation and reporting of clinical images.
35	Breast cancer – rehabilitation	Physiotherapist	Exercise programme; lymphoedema management.
36	Breast cancer – radiotherapy	Therapeutic radiographer	Non-medical consultant treatment planning and review.
37	Prostate cancer – radiotherapy	Therapeutic radiographer	Prostate cancer specialist radiographer treatment review.
39	Head and neck cancer – rehabilitation, survival	Physiotherapist, Dietitian, Speech and language therapist	Safe 'at home' management of airway and breathing.
40	Head and neck cancer – rehabilitation, survival	Dietitian, Speech and language therapist	Education and support for social aspects of eating and drinking.

The aim of our project was to supplement the case studies identified in [AHPs into Action](#) by identifying further contributions that AHPs are making to the care of people affected by cancer.

Methods

On 3 October 2017, HEE held a workshop that brought together ten people who had been affected by cancer and 17 AHP practitioners who work in cancer care. At this workshop we started to explore the roles of AHPs who care for people affected by cancer and identify the knowledge, skills and behaviours that they considered to be important in this clinical context.

In the first session of the workshop we asked people affected by cancer to tell a story about being cared for by an AHP and we asked AHPs to tell a story about caring for someone affected by cancer - we collected 24 new patient/practitioner 'stories'.

In the second session, we asked participants to start to use the [Macmillan Allied Health Professions Competence Framework](#) to identify the skills, knowledge and behaviours that AHPs had demonstrated in the stories that enabled them to deliver high-quality care to people affected by cancer. We have included some examples of these in this report even though they are not comprehensive profiles of the full range of competencies

required to fulfil the relevant AHP roles in the cancer care pathway.

The people who attended the workshop told us about being affected by the following cancer types: bowel, breast, gynaecology, head and neck (brain, eye, face, tongue, throat), melanoma (skin), metastatic (spread), penile and prostate. They told us about the care given by the following AHPs: art therapist, chiropodist and podiatrist, diagnostic radiographer, dietitian, paramedic, orthoptist, speech and language therapist and therapeutic radiographer. The experiences described by the people at the workshop occurred along the care pathway during: screening, diagnosis, treatment, rehabilitation, palliative and end-of-life care.

Following the workshop, we also explored published literature to identify further examples of AHP care for people affected by cancer and additional AHP interventions in cancer care pathways. We mapped these across the professions and across clinical cancer and patient care pathways and approached targeted AHP individuals, specialist groups and professional organisations to generate further illustrative material for our project.

During the consultation that followed publication of the Phase 1 [Cancer Workforce Plan](#) (HEE, 2017), HEE held a series of stakeholder seminars. We shared an early draft of this project report at the nursing and AHP seminar in May 2018 and invited comments and further contributions. Nine service lead and oncology (cancer) special interest group member AHPs responded to this request by suggesting edits and supplying additional patient and practitioner stories. This final project report is the culmination of this iterative process.

The project report offers a snapshot of the contributions of AHPs to the care of people affected by cancer. It uses the personal experiences and recollections of a self-selected group of people who participated in and contributed to the project to highlight the knowledge, skills, behaviours and practices that are important in this clinical setting.

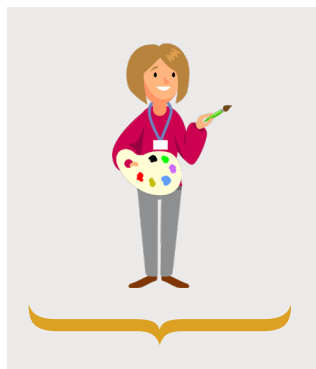
Unreservedly, we would like to thank all the people who generously recounted their experiences and described the practices of AHPs in the care of people affected by cancer. To preserve contributor anonymity, we have used pseudonyms throughout this report.



Section 2 – Patient and practitioner voices

Art therapist

Art therapists use their psychotherapeutic knowledge and training, plus their creative skills to work with people who have difficulty communicating and relating to others.



Working with individuals or using their skills to manage therapy in a group setting, art therapists create safe and secure therapeutic spaces across multiple environmental settings to help people express their feelings, explore their potential and achieve a sense of personal development and fulfilment.

Art therapists help people affected by cancer by supporting them through the difficult mental and social aspects of their diagnosis and treatment and during survival when they are living with and beyond cancer.

Art therapists often care for people over extended periods of time, for example to support them whilst coping with aggressive treatment for cancer and to help them with their recovery. During this time art therapists might develop long-term relationships with people affected by cancer and their families and work as a team to support an individual's return to independence and restoration to a sense of wellbeing.

Art therapy helps people affected by cancer feel a sense of control and strengthens their sense of identity, so it is not dominated by their cancer diagnosis. Completing artwork can give a sense of achievement – this feeling can be transferred to a feeling of success in other areas of life – assisting people to cope when living with and beyond cancer.



Art therapists may be employed in the NHS or may provide their services through a voluntary organisation. Interagency working and inter-dependency between professions is important to foster better understanding of the art therapist's contribution to care and to improve referral practices for art therapy support.



A patient's story

"Cancer treatment was hellish. Cancer itself was, and is, terrifying. Art therapy made it into something different:

something I could survive and learn from.

"The experience (of having breast cancer) forced a giant pause in my life. My year and a half of treatment included 'trying out' many of the hospital machines to make a diagnosis, followed by mastectomy, implant insertion, removal of lymph nodes, six rounds of chemotherapy, two surprise hospital admissions, 25 days of radiotherapy and a year of three weekly Herceptin infusions. I needed help just to keep going; to keep showing up and taking it and swallowing down the side effects. At its worst, I wasn't able to work or be a mother or sometimes just be a person and eat or leave the house or have a conversation. For this year and a half, I wasn't me. Art therapy helped me survive the experience and 'keep hold of me', or at least keep hold of 'my new me and new normal'.

"In a situation where I had very little control over my body art therapy became vital. At its peak every time I visited the hospital I was harmed: an injection, a needle, cut (surgery), poisoned (chemotherapy), burned (radiotherapy), adverse reactions, indignities (hospital gowns, prodding, poking). Art therapy was at the hospital but within it my body was my own; art therapy didn't hurt or harm me; I was fully clothed and not manhandled.

"The timeliness of the session was essential. With hospital appointments, I would frequently lose hours waiting for doctors or nurses or drugs to arrive. I would be sent off to other departments or told to wait for other professionals. Art therapy was at the hospital but it started and finished on time, every time, as expected. There was no uncertainty – I could choose to attend or not. I could talk or not talk. Draw or not draw. Stay or leave. Share or not share. It was part of my treatment but a part that I had some control over and that had some kind of respect for me."



A patient's story

"Alan sat next to my hospital bed with me and my bottles of blood in a carrier bag draining my wound, the morning

after surgery: I painted gowns and tubes.

"Alan sat next to me in the art therapy room with my sick bowl under the table; I'd thrown up in the park on the way here, I was trying to sit very still, to not vomit again: I painted a vomit picture with my hands.

"Alan and a small changing group of cancer 'affecteds' gathered in the Macmillan kitchen over and over again: I decorated sick bowls, sellotaped hospital name bands.

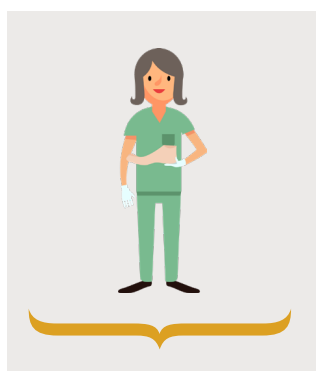
"We shared our stories and secrets and thoughts and silences and tears in the work we created. Too often I was vaguely delirious with exhaustion or pain or nausea; I was bald and bruised or dripping with sweat, clinging onto my chair and shivering...

"We drank tea; eventually, many months later, I was well enough to make the tea."



Chiropodist/ Podiatrist

Chiropodists and podiatrists assess, diagnose and treat disorders of the bones, skin and soft tissue of the foot and lower limb to help keep people mobile. They have an important role in helping people to remain independent and have a wide-ranging role in helping people affected by cancer throughout the entire care pathway.



During routine treatments, which can last for between 30 – 60 minutes, chiropodists/podiatrists have a health promotion role to try to improve a person's lifestyle choices and prevent their ill health. For example, they might offer education and advice to reduce a person's risk of getting skin cancer. They also have a screening role – monitoring moles to diagnose skin cancer, monitoring changes in nails and skin and monitoring verrucas and ulcers which can turn cancerous.

During oncology treatment cycles repeat appointments with the same chiropodist/podiatrist provides continuity of care; this helps professionals identify any changes that chemotherapy treatments are having on the foot/ lower limb. Chiropodists/podiatrists may highlight early

signs of palmo-plantar syndrome, peripheral neuropathy or lymphoedema. They can detect new side effects, for example from innovative combinations of chemotherapy drugs. Chiropodists/podiatrists will report these effects back to a patient's oncologist or signpost the patient to other appropriate colleagues in the multidisciplinary care team.

Chiropodists/podiatrists provide routine wound care and treat acute foot issues that arise during cancer treatment to reduce the risk of infection, a particular problem of chemotherapy associated immunosuppression.

Managing walking difficulties and prevention of falls, in the presence of treatment-associated osteopaenia or peripheral neuropathy, managing lower limb lymphoedema caused by cancer or its treatment and optimising function after lower limb surgery (amputation), including making decisions about the best types of orthotic that might be useful, are all within the chiropodist/podiatrist scope of practice.

People recovering from cancer, may have ongoing problems with nail health, fungal nails or skin issues (after palmo-plantar syndrome) that can be treated by chiropodists/podiatrists.

In addition to physical treatments during and post treatment, repeat appointments over an extended period of time offer the opportunity for chiropodists/podiatrists to develop therapeutic relationships with people affected

by cancer and to contribute to psychological aspects of their support needs.

During survivorship, general chiropody/podiatry care helps to keep people comfortable. Late foot/lower limb effects of cancer, palliative and end-of-life care offered by chiropodists/podiatrists include management of pain due

to fissuring, peeling skin, infection, ulceration and the effects of co-morbidities, e.g. vascular disease, diabetes, to reduce the risk of infection and try to avoid the need for amputation. Chiropodist/podiatrists in Advanced Clinical Practice roles may be able to provide analgesia, or other pharmaceutical treatments, as independent non-medical prescribers.



A practitioner's story

"A 65-year-old lady who had suffered with an ulcer on her foot for several months attended my outpatient podiatry clinic. Her journey had been long, visiting at least four other clinics in the preceding months, e.g. tissue viability, rheumatology and orthotics.

"After assessing the ulcer she was referred immediately to dermatology and diagnosed with a melanoma (skin cancer).

"Subsequently, I spoke with dermatology and highlighted the variability of clinical appearances

of melanoma of the sole of the foot, and how they frequently failed the 'ABCDE' acronym for diagnosing melanoma.

"We subsequently developed a new acronym (CUBED) for podiatrists to use within clinics to raise suspicion of diagnosis. This was published and has been downloaded over 40,000 times."

See: Bristow, I. R., de Berker, D. A., Acland, K. M., Turner, R. J., & Bowling, J. (2010). Clinical guidelines for the recognition of melanoma of the foot and nail unit. *Journal of Foot and Ankle Research*, 3, 25.

<http://doi.org/10.1186/1757-1146-3-25>

Professional competencies demonstrated by an Advanced Specialist Podiatrist

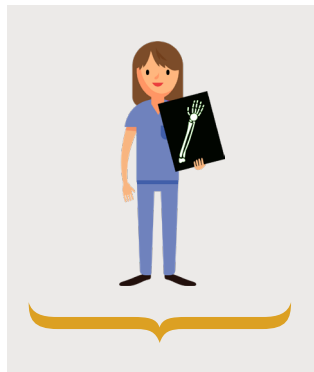
Clinical practice	Has a good understanding of oncology.
Personalised care	Discuss each level of the body with the patient and create a care pathway based on a 10-level assessment of their problems.
Leadership and Team working	Provide templates for summarising information and facilitate communication between all therapists involved with the patient.
Supporting independence	Deliver patient education days where they can meet members of the multidisciplinary team from NHS and independent providers.
Communication	Maintain continuity of care through use of secure email, picture sharing and teleconferencing between patient and care providers.
Professional practice	Engage with postgraduate learning packages and offer mentorship to AHP colleagues across frontline services.

N.B. This is not the full competence profile of an advanced specialist podiatrist.



Diagnostic radiographer

Clinical imaging is a large and growing area within modern healthcare and is based mainly in hospitals and health centres. Clinical imaging services are delivered by a multidisciplinary team of medical specialist doctors (radiologists), non-medical allied health professionals (radiographers) and non-registered assistant practitioners.



Diagnostic radiographers operate highly sophisticated equipment, using x-ray, ultrasound and magnetic resonance imaging technology to capture detailed clinical images of the inside of the body. Diagnostic radiographers produce images that are often crucial to detecting the first signs of disease and making a correct diagnosis.

People without any symptoms of cancer might meet diagnostic radiographers when they participate in screening programmes, e.g. when they have a mammogram (breast x-ray examination) in the NHS Breast Screening Programme, or when they are referred for a diagnostic imaging test or scan after visiting their General Practitioner. Clinical images are also used to plan and monitor treatment and in surveillance (follow up) programmes to look for recurrence or spread of cancer - chest radiography can detect lung metastases, ultrasound and computed tomography (CT) scans can detect liver metastases.

In addition to obtaining images, the role of the diagnostic radiographer has evolved over time to include interpretation and reporting of x-ray images and of CT and ultrasound scans. Radiographer reporting of chest radiography is contributing to redesign of the lung cancer pathway and improving lung cancer outcomes (Piper et al., 2014; Woznitza et al., 2014a, 2014b).

Diagnostic radiographers are contributing to managing increases in workload generated by the bowel cancer screening programme by performing and reporting a range of gastrointestinal examinations, for example CT colonography (Meertens et al., 2013; Law et al., 2005; [AHPs into Action](#)- Case study 51 - CT colonography & biopsies, Peterborough & Stamford NHSFT) and sigmoidoscopy ([AHPs into Action](#), Case study 52).

Diagnostic radiographers are stepping into the breach caused by a shortage of radiologists in breast cancer imaging (through imminent retirements and expanding service demand) by interpreting mammograms (Moran & Warren-Forward, 2016), performing and interpreting breast ultrasound examinations and carrying out minimally invasive (percutaneous) tissue sampling (biopsy) procedures in breast cancer screening, diagnostic and surveillance services (see [AHPs into Action](#) Case study 38 – Consultant breast radiographer, Shrewsbury and Telford Hospitals NHST). Consultant sonographers at Peterborough and Stamford NHSFT perform ultrasound guided fine needle aspiration and biopsy procedures which help diagnosis of thyroid (head and neck), liver, prostate and breast cancer ([AHPs into Action](#) – Case study 51).



A patient's story

"From my mid-30s I had been under the care of our local breast unit, where I had been treated for benign conditions.

I had my first mammogram at the age of 40 and first met Mandy (specialist radiographer) then. From the outset she demonstrated empathy, concern, skill, kindness and professionalism.

"I have had many mammograms over 27 years as I have a family history of breast cancer and have screening every year. Mandy has been my practitioner for most of them.

"In 2003 when 'a problem' was seen on the imaging – she knew I was going on holiday the following day and so she communicated in the best possible way – to permit me to go and not be worried. I was subsequently diagnosed with multifocal breast cancer and had a mastectomy, chemotherapy and Arimidex treatment. I now live with severe and disabling lymphoedema, complicated by lipoedema.

"The continuity I have had with Mandy as my radiographer over 25 years is remarkable. This relationship has helped me, during the very difficult time of having each mammogram."

Professional competencies demonstrated by a diagnostic radiographer

Clinical practice	Highly specialised knowledge of mammography technique to accommodate my lymphoedema.
Personalised care	25 years' continuity; she understands my personal needs and fears.
Leadership and Team working	In a senior position, she is confident with other members of the team and they rely on her; she knows where to refer me for further help and support.
Supporting independence	Her department offers me self-driven review appointments – I am usually seen within 2-3 weeks of my request.
Communication	She acknowledges the difficulties of the examination and succeeds in mitigating my worries and concerns.
Professional practice	Use of the latest equipment requires training and continuing development to keep up-to-date.

N.B. This is not the full competence profile of a specialist radiographer.



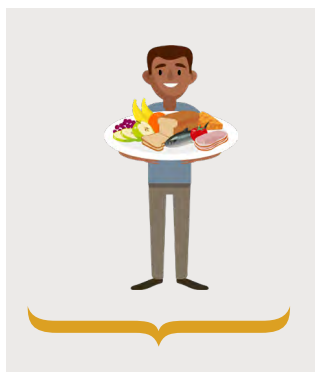
Dietitian

Dietitians are experts in food and nutrition. They are the only health professionals that assess, diagnose, support and treat health conditions with food and nutrition.

Dietitians translate the science of nutrition into advice about food and eating; they work in a variety of settings including hospitals, the community, health centres and specialist clinics as well as in people's homes.

Dietitians offer support to people affected by cancer throughout their care journey to optimise nutritional wellbeing and quality of life. Dietitians use counselling skills and motivational interviewing to enable people to optimise their nutritional status. Advice is tailored to individual need, taking into account clinical, psychosocial and nutritional factors, to create achievable patient-focused goals.

Dietitians help people to stay well by promoting good health at population and individual levels. There is good evidence that healthy eating can help reduce risk of developing certain cancers. The work of dietitians also involves promoting public health messages aimed at reducing obesity and diabetes for example, as well as working with individuals with special dietary needs to help them achieve their personal goals.



Dietitians have a vital role in providing nutritional support for people affected by cancer before, during and after treatment using their knowledge and understanding of the complex metabolic changes seen in some types of cancer e.g. head and neck, lung and upper GI (gastro-intestinal) cancers. For example, people affected by head and neck cancer and its treatment can have problems eating, drinking and swallowing normally because the structures required for these activities have been removed or because they are experiencing pain or change in taste. People who have undergone gastrointestinal surgery, for stomach or bowel cancer for example, may experience difficulties with eating, digesting and absorbing sufficient nutrients. The work of the dietitian in cancer care can be wide-ranging, from giving advice about provision of artificial nutrition support to lifestyle advice about secondary prevention.

Dietitians work closely with speech and language therapists (see later section) to support people who need rehabilitation of swallowing function, to optimise safe swallowing and to ensure their nutritional needs are met. Swallowing impairment can be long-lasting and it is often not possible to rehabilitate swallowing back to normal function. For patients who cannot take enough or any nourishment by mouth, dietitians support people with 'tube' feeding.

Dietitians have an important role to play in enabling people affected by cancer to optimise their enjoyment of food and maintain their nutritional status as far as possible and for as long as possible; they help alleviate anxieties about food intake towards the end of life, as illustrated in the quotation: "I might not be able to eat much, but you've helped me enjoy what I can eat."



A practitioner's story

"A 36-year old woman, who had been diagnosed with pelvic cancer 10 years ago and treated with pelvic

radiotherapy, presented with change in her bowel habit, reduced food intake and loss of weight, in addition to urinary urgency/incontinence, which was causing her to take time off work.

"The woman was referred to the 'late effects' clinic where she was seen by an experienced dietitian, a gastroenterologist and an oncology nurse. Following further diagnostic investigations to rule out neoplastic or recurrent disease, her symptoms were managed with diet, medication and referral to a psychologist.

"A motivational interviewing technique was used to encourage and support the woman to self-manage her symptoms and nutritional status."



A practitioner's story

"I run 'Eat Well Feel Better Cookery Skills' workshops in the Macmillan Horizon Centre at Brighton and Sussex

University Hospitals Trust. Making healthy choices about food, weight and being active can improve overall health and wellbeing. Cancer treatments can increase the risk of health conditions such as cardiovascular disease, type 2 diabetes and osteoporosis and maintaining a healthy weight might also lower the risk of some cancers and cancer recurrence.

"We invite people at the end of their cancer treatment to give them simple cooking skills to incorporate into their everyday life which will help them live with and

beyond their cancer healthily. There are three sessions; - healthy breakfasts, eating a rainbow (of fruit and vegetables) and positive protein (plant based alternative sources to meat). Alongside a chef, I provide people with practical, evidence-based information on healthy eating and we use easy healthy recipes with fresh ingredients, demonstrating simple processes and techniques.

"People can ask specific questions about how they can apply the healthy eating messages to suit their own circumstances, for example longer or lasting effects of treatment such as managing a stoma or having altered swallowing. People that come to the workshops get the recipes, a cook book and information based on the World Cancer Research Fund Cancer Prevention Recommendations."



A patient's story

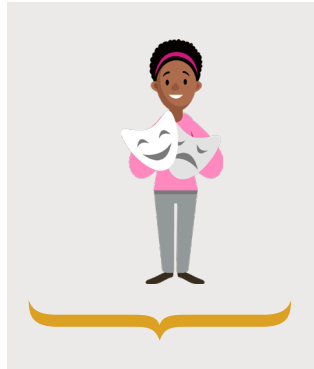
"I had a wonderful cookery class today overlooking the blue sea. The dietitian and chef are so sensitive to our needs and so professional, it is a complete

joy and lovely to be mixing with other people affected by cancer. Because of them I am getting over my concern that I am not a good cook and I am having a go. I loved the colours of the fruit and vegetable dishes we cooked today – very appetising. I'm looking forward to next week."

Drama therapist

Drama therapists work in a variety of settings using role play, movement and storytelling to help people explore and solve personal and social problems.

Therapy sessions can be in a group or individual setting according to people's individual needs.



Drama therapy includes role-playing, game-playing, improvisation and other techniques. Proven benefits include reduced anxiety, less pain, more social interaction and greater sense of control over one's life.

Drama therapists can support people coping with aggressive treatment for cancer and can help with recovery and restoration of wellbeing. Drama therapists can also support people affected by cancer and their families during palliative care and during the pre and post bereavement period, offering help with memory making, distraction techniques and building emotional and psychological wellbeing.

Drama therapists may be employed in the NHS, the charity sector or may provide their services through a voluntary organisation. Drama therapists often work as part of a multidisciplinary team making referrals and recommendations to other professionals where needed.



A practitioner's story

"Pauline came to see me for support after treatment for cervical cancer.

She was depressed and anxious with constant feelings of fatigue – she said she felt as though she had lost control over her body.

"I set up an individual one-to-one session with her initially – and used this to help her express difficult emotions in an animated way. The session helped her

laugh and have fun, relieved some of her anxiety and started to build her self-confidence again.

"Eventually we moved on to group sessions where she could work with other people who were having similar problems.

"After a few months of drama-based psychotherapy, Pauline was able to go back to full-time work and felt like she had restored her quality of life."



A practitioner's story

"John, who is 10 years old, was referred to me because of behavioural challenges which included outbursts,

along with concerns about his emotional and psychological wellbeing, following a diagnosis of leukaemia and an on-going programme of treatment.

"I work for a charitable community-based children's hospice and after an initial assessment I began one-to-one sessions with John in the family home. His high levels of anxiety surrounding his diagnosis and treatment often brought a 'fight or flight' response – with him displaying levels of both outburst and isolation – his behaviour was affecting both John and his family.

"In one session I brought some cardboard along and with John leading the play we created a gun. When I asked John what he was shooting he said 'cancer'. From a previous session we had created a character of 'what cancer would look like'. Using this we began some role

play of shooting the cancer 'creature'. John spoke of his enjoyment and observing him it appeared to be an emotional release for him. Afterwards his mood seemed to have improved and he appeared calmer.

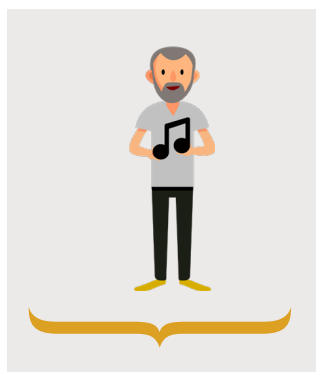
"Following further sessions John has become less anxious and happier, his mother now reports that his behaviour is better and that his outbursts have decreased significantly.

"I am currently in the process of ending my therapy sessions with John. I will be supporting him before, during and after this last treatment – due in a couple of months' time. Drama therapy has been an effective creative psychological intervention for John – he has now established a wide group of friends, is enjoying going to school more and his overall wellbeing has improved – positive outcome measures.

"The drama therapy service will continue to be available for John during his remission period if required."

Music therapist

Music therapists work in a variety of settings and use people's natural musicality to help explore and solve personal and physical problems. They may be employed in the NHS or may provide their services through a voluntary organisation.



Music therapists use a wide range of musical styles, including free improvisation, to help people, particularly those who find their emotions are too confusing to express verbally.

Music therapists can offer appropriate, sensitive and meaningful help to people coping with treatment for cancer and during their recovery. Therapy goals include promoting wellness, managing stress, alleviating pain, supporting physical rehabilitation and expressing feelings. Music therapy can help enhance people's memory and deepen their relationship with themselves and the world around them.



A practitioner's story

"I started seeing Melissa just after she had completed her treatment for head and neck cancer.

"The diagnosis and treatment had made her very withdrawn - the surgery and what she perceived to be facial disfigurement making her feel like she couldn't 'face the world'.

"Melissa loved playing the piano so we used her playing ability for psycho-therapeutic benefit. We used the vibrations from her personalised music to penetrate into areas that physical therapy (hands/massage) are unable to go. Through music she was able to restore her body's own natural rhythms for health and wellbeing. The sessions allowed her an opportunity to be herself, promote her physical rehabilitation and express her feelings - altogether making her more confident to face the world."

Occupational therapist

Occupational therapy is a wide-ranging role that links health with social care and the surroundings in which people live, encapsulating the interplay between occupation, health, recovery and wellbeing.



Using the Person-Environment-Occupation (PEO) model to guide their assessments and interventions, occupational therapists help people with physical problems to be more independent in the home, at work and in social settings. Occupational therapists assess what people are able to do for themselves and support people with mental health issues, enabling and encouraging people to find practical solutions which empower them to take control and manage their health state transition.

Occupational therapists help people with cancer 'assimilate' their new health status into their daily lives. They offer help to manage anxieties and concerns through prehabilitation (preparation) and rehabilitation (recovery, adaptation, restoration) of function. Occupational therapy support enables people to return to and maintain meaningful occupation for as long as possible.

Occupational therapists:

- teach people new ways of doing things to adapt when function has been lost because of a cancer diagnosis or its treatment
- give advice on how the home environment can be changed to help people cope with physical problems caused by their cancer diagnosis or treatment
- teach people with cancer how to conserve energy for daily living when their stamina is reduced
- reduce the need for care packages by improving equipment-supported moving and handling.



Peer-reviewed evidence

The ability to carry out activities of daily living (ADL) is essential for maintaining independent living.

Grov, Fosså and Dahl (2010) demonstrated that older people with cancer have more problems with

both personal (e.g. personal hygiene, dressing and eating) and instrumental (e.g. household activities, managing finances, shopping and administration of medication) ADL than older people who do not have cancer, and highlighted the importance of primary care assessments of ADL in older cancer survivors.



Peer-reviewed evidence

NICE-recommended gold standard treatment for palliative care includes three quality statements that support occupational therapist-led interventions:

- 1. comprehensive holistic assessment.
- 2. timely personalised support for social, practical and emotional needs.
- 3. care coordinated and delivered in accordance with a personalised care plan including rapid access to holistic support, equipment and administration of medicine. (NICE 2013, cited in COT, 2016).



Evidence review case study

The Royal Marsden Hospital employs seven full-time equivalent occupational therapists. They help people recovering from cancer to increase their independence in daily tasks and routines and to use coping strategies to maintain involvement in roles and occupations, including return to work.

A typical patient experience of four sessions with an occupational therapist to target fatigue management and learn relaxation techniques costs £152. One patient helped by an occupational therapist is thought to have benefited by almost £13,500 due to being able to make a planned and phased return to their previous occupational role.

“Simple techniques gave me the ability and confidence to get back on with my life. I am living with cancer rather than dying from it.” (COT, 2016: p.23)



Evidence review case study

A specialist palliative therapy team based at Heart of England NHS Foundation Trust comprises a dedicated team of senior occupational therapists and therapy support workers working across three hospital sites, seven days a week. The team deploys holistic, specialist interventions with over 5,000 people with cancer per year; 20% of these are new diagnoses. The interventions include functional and goal-oriented assessments, in addition to complex discharge and advanced care planning.

As a result of the service, people with cancer leave hospital more quickly, anticipate deterioration and thus reduce

crisis re-admissions and have reduced anxiety and fear. With the support of this specialist team of occupational therapists and support workers, people nearing their end of life are more able to continue with valued occupations and are more confident remaining in their homes.

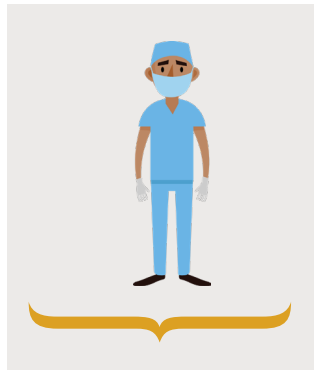
This service has enabled 90% of their palliative patients to die in their place of choice, 60% being discharged home to die. The Trust attributes the service with a reduction of 45 inpatient bed days per year; in addition, four readmissions per month are avoided and prescriptive equipment provision has been reduced through early emergency department intervention or crisis intervention in the community.

(COT, 2016: pp .23,24)



Operating department practitioner (ODP)

ODPs are members of the operating theatre team, working with surgeons, theatre nurses and anaesthetists to ensure that operations carried out to treat disease are as safe and effective as possible. ODPs provide care for people immediately before, during and after operations - their role being separated into three categories - anaesthetic, surgical and recovery.



During the anaesthetic phase, ODPs assist in looking after the patient and preparing equipment and drugs for use during operations.

During the surgical phase, ODPs have an important role in maintaining health and safety – in ‘circulating’ or ‘scrubbed’ roles their duties might include following aseptic technique and infection control procedures and making sure equipment and surgical instruments are clean, prepared and available during the operation.

Once the operation is finished, patients are moved to ‘recovery’ where ODPs assess their condition, observe physiological measurements and provide support, intervention and treatment until the patient is stable and well enough for transfer to nursing care on a ward.



Evidence review case study

Breast cancer, the most frequently diagnosed cancer in women, can spread to other areas of the body along the lymphatic system. If this is suspected, lymph nodes in the armpit can be removed during breast cancer surgery to see if they have been affected by the tumour. One of the ways of identifying the first lymph node affected, the sentinel lymph node (SLN), is to inject radioactive fluid into the breast and see which lymph node it goes to first.

See: <http://snmmi.files.cms-plus.com/docs/Final%20Breast%20Sentinel%20Node%20Guideline.pdf>

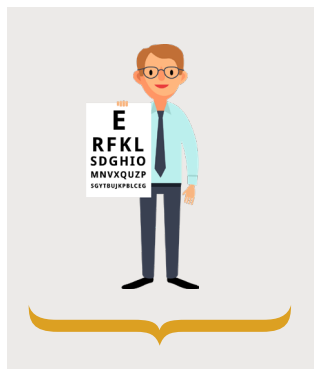
ODPs who work with breast surgeons need to be aware of the special procedures carried out to do this and of the additional safety precautions that need to be observed when radioactive material is present in the operating theatre. For example – timing of the patient’s arrival in theatre needs to be carefully co-ordinated within 2 – 30 hours after their radioactive injection; the ‘gamma probe’ used to detect radioactive lymph nodes must undergo strict quality control procedures to make sure it is working correctly; radioactive waste from the operating room is a biohazard and has to be collected and disposed of in accordance with radiation safety regulations.

ODPs working in this environment will need additional training in safe handling and disposal of radioactive materials.



Orthoptist

Orthoptists assess, diagnose and treat problems relating to binocular vision that may arise from defects in eye movement, alignment and coordination. In children, this can include squint (strabismus) and 'lazy eye' (amblyopia).



In adults, orthoptists investigate, support and provide non-surgical treatment for people with double vision and other visual symptoms due to conditions such as stroke, thyroid eye disease and diabetes.

People affected by head and neck cancers e.g. retinoblastoma (eye cancer), glioma and cytoma (nerve/brain tumours) can have vision problems related directly to the position, size and nature of the cancer or related to surgical or radiotherapy cancer treatments. This might be picked up with routine vision screening tests or through symptomatic referral for specialised diagnostic tests.

Orthoptists use specialised eye tests to help diagnose cancers such as retinoblastoma and optic nerve glioma and provide a baseline measurement of a person's visual function. Regular review to detect any deterioration

in vision allows the orthoptist to implement corrective therapies or initiate a surgical pathway.

Presenting symptoms of vision loss do not always fit precise diagnostic criteria so orthoptists need to exercise their professional judgment to localise lesions and differentiate between other neurological causes of vision disturbance. Orthoptists must balance all information available against a spectrum of diagnostic variables and make clinical decisions about suitability for established treatment protocols, the need to provide an individualised care plan and referrals to other multidisciplinary team members, e.g. endocrinologist, neurologist, neuro-ophthalmologist and ENT (ear, nose and throat) surgeon. If a tumour is related to a genetic condition, the orthoptist role can include liaising with colleagues in other parts of the country to arrange screening eye appointments for other family members.

Orthoptists sometimes assist during surgical operations and, as members of the multidisciplinary team, will liaise with neuro-oncologists.

Both before and after surgery, during longer term rehabilitation and into palliative and end-of-life care, the orthoptist will advise and counsel patients and their families providing support, reassurance and information. Orthoptists continue to monitor vision stability, provide vision aids (prisms, occlusion), provide certification of sight impairment and advise on capability for driving.

Throughout the cancer care pathway, the orthoptist has a key role in signposting patients to appropriate social, educational, welfare and charitable services for people with vision loss.

Over an extended period of time, individual orthoptists might continue to see the same patient and develop

strong trusting relationships. In the case study below, both the patient and his wife were very anxious at the initial consultation but became much more relaxed over serial appointments with the practitioner. This made them more willing to accept the dynamic and unpredictable nature of his condition and how this affected his surveillance vision assessments.



A practitioner's story

"Paul, a 63-year old male IT manager with a Grade 3 pleomorphic pineocytoma and drop metastases

was referred to me because of double vision after ventriculostomy and tumour debulking surgery.

"He also had Parinaud's syndrome and skew deviation – a defect of vertical eye movements and a squint causing double vision and tilted images; disruption to otolithic pathways caused a perception of a visual tilt when his head was straight; he was unable to join double vision.

"I saw Paul with his wife – but found it difficult to gain their trust as I was unable to give an exact prognosis due to the dynamic effects of radiotherapy. I had to break the bad news to Paul that he would be unable to drive because of the inability to join up double vision –

this had a significant adverse impact as it meant he had to retire from work. His future appointments had to be juggled around his wife's (carer's) work time as he had to rely on her to drive him to the appointments.

"I showed Paul how to use compensatory head posture to minimise his symptoms for certain tasks. He was given prisms, once suitable, for distance and reading, alongside exercises for reading. He now walks with a stick and is coping better with his visual impairment symptoms.

"Following the counselling and advice I gave, Paul has agreed with his oncologist not to have frequent imaging scans to look for metastases or tumour regrowth - thus reducing the cost of his care. As subtle changes in his visual status may indicate disease progression, the orthoptist needs to be able to recognise any change in vision and act accordingly."

Professional competencies demonstrated by a specialist orthoptist

Clinical practice	In-depth knowledge of neuro, skull and facial anatomy, specific brain and facial tumours which may affect vision and ocular motility and specialist knowledge of localising signs.
Personalised care	Select most appropriate treatment and understand potential limitations due to condition, ensure patient and carers are fully aware of this too.
Leadership and Team working	Ability to differentiate between other neurological causes of symptoms and act on this/ refer accordingly.
Supporting independence	Recognition and patient centred understanding of symptoms and of impact of assessment and treatment on quality of life.
Communication	Communicate effectively and calmly in different situations. Anticipate barriers to communication and take action to improve communication.
Professional practice	Development to higher/advanced practice level - ability to adapt to difficult/complex/ atypical presentations.

N.B. This is not the full competence profile of a specialist orthoptist.



Orthotist/ Prosthetist

Orthotists assess, design and provide orthoses (custom-designed external devices such as splints, braces and specialist footwear) to modify the structural or functional characteristics of the neuromuscular and skeletal systems. These can help mobilise people, reduce their pain or discomfort and facilitate healing.

Prosthetists use their skills to provide the best possible replacements for people who have lost limbs through the disease process itself or as a result of treatment; their



work helps restore function that has been lost through amputation and includes design, fitting and helping people adjust to life with artificial limbs.

Orthotists and prosthetists work in hospitals, clinics and community health centres both as autonomous practitioners and as part of multi-disciplinary teams. Working alongside physiotherapists, prosthetists and orthotists can help people affected by cancer to optimise function using prosthetic devices after limb amputation or to help manage lower limb lymphoedema caused by cancer or its treatment.

Splints and spine bracing are used by orthotists to help manage musculo-skeletal instability in people affected by head and neck cancer and to manage the risk of spinal cord compression in people with secondary (metastatic) cancer.



Peer-reviewed evidence

People affected by the advanced stages of cancer may suffer from metastatic disease – their cancer has spread from its original site. A common site for metastatic disease in people with lung, breast or prostate cancer is the bones in their spine for example.

Orthotists can provide spine bracing equipment to relieve and reduce the effects of spinal cord

compression (pain, impaired mobility and/or paralysis) in cases of late stage diagnosis and/or during palliative/end-of-life care.

Orthotists can support people affected by metastatic cancer to achieve a comfortable and balanced combination of spine bracing, positioning therapy and bed rest to minimise their risk of vascular complications (deep vein thrombosis and pressure sores) in the final stages of their life.

(Lee et al. 2015)



A practitioner's story

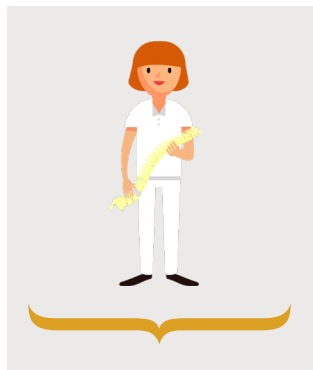
"I work with cancer patients who have had amputation or limb loss due to either their diagnosis or treatment. My professional training allows me to assess and advise on the best orthosis to use and ensure that it is comfortable

during use. One example of a recent patient is a young boy with bone cancer. I saw him in clinic after he had had his leg amputated and fitted him with an orthosis to help him walk again. Over time I reviewed him in follow up clinics, making adjustments to the 'artificial limb' so that he was able to walk in comfort."



Osteopath

Osteopaths are knowledgeable about pathology and skilled in differential diagnosis. They can use their knowledge and problem-solving skills to relieve the side-effects of conventional surgical, chemotherapy and radiotherapy cancer treatments.



Musculoskeletal osteopathic treatments aim to improve the alignment and movement capacity of the body and provide relief of pain and muscle stiffness. In addition to alleviation of specific tensions and pains, osteopathy can also have systemic benefits – relieving stress, fatigue or nausea and improving a person's general sense of feeling better.

The holistic osteopathy intervention, involving detailed consultations and repeated physical treatments over a period of time, provides an opportunity for exploration of complex health problems. The dynamic of touch and body work can, for example, help people affected by cancer to come to terms with an altered body image and encourage them to talk openly about their anxieties.



Evidence review case study

Three years after being diagnosed and treated for gastric cancer, an elderly male received eight osteopathy consultations over a period of 10 months. Osteopathy interventions included manual treatments to improve his musculoskeletal mobility and cranial osteopathy to release deep fascia tension. The osteopathy consultations and interventions also provided space and time to discuss diet and give information and advice

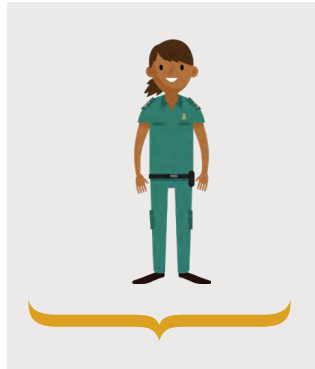
about symptoms related to his initial treatment with total gastrectomy and chemotherapy.

Following the osteopathy intervention, the man's physical symptoms (neck pain) reduced, the nausea and discomfort he felt after eating disappeared and the frequency of the diarrhoea, breathlessness and fatigue he was experiencing improved. As a result, he gained weight and resumed social activities.

(Leach, 2008)

Paramedic

Paramedics respond to 999 and 111 calls and are trained in urgent and emergency care ranging from problems such as cardiac arrest (heart attack), stroke, major trauma and minor illness/injury.



In the past, paramedics provided emergency treatment at the scene, stabilising and then transporting patients to hospital. Modern day paramedics provide a comprehensive mobile healthcare service which may include assessing patients, diagnosing problems and providing treatment in a range of primary care settings such as 'at the scene', in 'out-of-hours', GP surgery or minor injury settings and in people's homes. Paramedics can help people manage long-term conditions such as cancer and support planned dying in a place of choice.

Paramedics may be involved in looking after people undergoing palliative care and end-of-life care. They may be called by carers who are in distress when someone deteriorates suddenly or unexpectedly, or when someone is in the phase of imminent death. Paramedics also provide care in non-emergency situations when people affected by cancer are transferred between care settings (Rogers et al., 2015).



To enable them to manage the complex physical and psychosocial needs of palliative patients and their families, paramedics need enhanced awareness of ethical issues, end-of-life communication needs and knowledge of structured patient care pathways - clinical decisions made by paramedics in these situations may set the trajectory for subsequent care of their patients.



Evidence review case study

In their description of how a multi-professional team provided end-of-life care to a person with learning disabilities who had been diagnosed with cancer, Marriott et al. (2013) provide additional insight into a 'good practice' exemplar in end-of-life planning and palliative care highlighted by the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (Improving Health and Lives, 2013).

Keith, a man in his 50s with mild learning disabilities, lived alone in a supported-living complex. He was receiving

palliative care following a diagnosis of lung cancer. One day, sudden deterioration due to bronchopneumonia prompted one of the other residents in the complex to call an ambulance. The paramedics who attended Keith were able to avoid hospital admission because Keith's express wish to stay at home was well documented in his care plan. Keith was discovered passed away in his chair the following day by the district nurse.

This case study illustrates the role of paramedics in caring for and supporting people to die in their place of choice, highlighting their place in the collaborative multidisciplinary team that supports individuals with terminal cancer.



A practitioner's story

"A 69-year-old man, who had recently received treatment for throat cancer was visited by a neighbour after they realised that they hadn't seen him for some time. The neighbour found the gentleman to be looking very unwell so called 999.

"Paramedics were called and arrived on the scene to find an unkempt gentleman in a dirty bed who hadn't been eating and drinking. The man's blood pressure was low and he had a rapid pulse (tachycardia). He was experiencing unpleasant side-effects from his treatment

and was dehydrated from not being able to eat or drink - he was also in significant pain. He insisted that he no longer wanted further treatment - he had had enough and wanted to die."

This story is used as a training case study - challenges for the paramedics include the need for an appropriate documented history to determine where this patient is on the illness trajectory. There is a risk that, as correctly established in the previous case study, he could be perceived to be at the 'end-of-life'. Correct questioning and history taking in this case identified recent onset dehydration and pain, due to difficulty eating and drinking, that was reversible.

Professional competencies demonstrated by a specialist paramedic

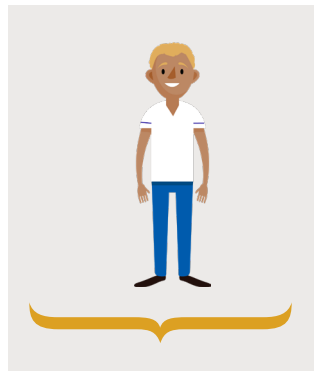
Clinical practice	Awareness of influences of contemporary drivers on cancer service delivery at local level and where to locate cancer plans. Awareness and understanding of health-related impact of medication used in cancer and end-of-life care and signposting patients to appropriate teams for management of issues.
Personalised care	Understand the issues facing individuals as they complete cancer treatment and are discharged from acute hospital care. Recognise and intervene when deviations occur from expected progress and take appropriate action including adapting it to the changing needs.
Leadership and Team working	Liaises between service users, relatives, carers as equal partners when making links to members of the multidisciplinary team involved in planning individual care pathways to optimise interventions.
Supporting independence	Acknowledges and respects the decisions made by individuals concerning their health and wellbeing in relation to cancer treatments, survivorship and late effects care. Explains the options available to individuals to enable them to make informed decisions about their care.
Communication	Crucial to the role, but very often has little formal training for this.
Professional practice	Access to appropriate sources of evidence to support own practice in cancer and palliative care. Aware of national guidance for rehabilitation related to cancer, palliative and end-of-life care; aware of policies and procedures relevant to own area of practice and supports service developments to improve patient outcomes.

N.B. This is not the full competence profile of a specialist paramedic.



Physiotherapist

Chartered physiotherapists work with individuals, their families and carers, from birth to end-of-life. They typically work in a range of large and small organisations across public, private and charitable sectors.



Physiotherapists use a flexible and holistic approach towards meeting the needs of people affected by cancer by working in partnership with and respecting their autonomy. They also play a key role in promoting and maintaining health and preventing disease.

Physiotherapists are experienced in the assessment and treatment of a wide range of physical problems that people can develop as a result of an oncology diagnosis. They can assist people affected by cancer throughout all stages of the care pathway. Prehabilitation prepares people during assessment, diagnosis and prior to their cancer treatment. Rehabilitation uses restoration and adaptation techniques during recovery and survivorship into living with and beyond cancer.

Cancer and its various treatments are associated with a wide range of distressing physical and psychological symptoms. Physiotherapists use a range of physical and psychological approaches, including movement, exercise and manual therapy, to optimise mobility, function and quality of life. Physiotherapists also help people to stay in or return to work as well as to remain independent for as long as possible.

Physiotherapy interventions include:

- assessment and treatment of physical problems such as weakness, balance problems and paralysis, which can be caused by brain and spinal tumours
- prevention and treatment of potential complications of major surgery, e.g. pre-operative individualised exercise programmes to optimise fitness
- provision of individualised exercise programmes to promote wellbeing and independence during and after treatment
- techniques to help manage breathlessness and management of respiratory complications including chest infection, sputum retention or atelectasis (partial or complete lung collapse)
- management of additional respiratory (breathing) support including oxygen therapy, traditional ventilation and non-invasive ventilation e.g. Optiflow™
- provision of exercises and advice following surgery or radiotherapy
- pain control – through therapeutic exercise, TENS (transcutaneous electrical nerve stimulation), acupuncture, manual techniques
- assessment for provision of equipment such as walking sticks, crutches, frames or splints to help promote independence
- outpatient services for musculoskeletal problems following cancer diagnosis or treatment
- contribute to health and wellbeing events to promote benefits of physical activity during and after cancer treatment.



A practitioner's story

"I saw Dennis when he was admitted to hospital following a diagnosis of lung cancer with metastatic spinal cord compression (MSCC). On initial assessment he had bilateral lower limb weakness and was unable to mobilise. In addition, he had significant sensory impairments with loss of bladder and bowel control. On admission Dennis needed a standing hoist to transfer and assistance from two people. His condition at the time meant that chemotherapy was not a feasible treatment option.

"I realised that if Dennis had been discharged home at this point he would have required a 'four times per day, double-handed' care package, specialist equipment and would have been wheelchair bound. Although it was possible to organise access to community-based therapy, the outcomes of this would be limited by his

home environment and reduced frequency of therapy sessions in a community setting.

"After intensive daily therapy input from the highly specialised physiotherapist, highly specialised occupational therapist and therapy assistant in the Macmillan neuro-oncology rehabilitation service team at St Bartholomew's Hospital, Dennis's condition improved such that chemotherapy became a suitable treatment option.

"When he was discharged from hospital Dennis could walk independently with a frame and only required assistance with personal care in the mornings – he told us how much his quality of life had improved as a result of his rehabilitation therapy. We estimated that the improvement in Dennis's functional status and his reduced dependency would save the healthcare system £25,636 annually."

Professional competencies demonstrated by a highly specialised physiotherapist

Clinical practice	In-depth knowledge of disease process and symptoms resulting from disease and treatment. Able to assess, apply clinical reasoning and formulate treatment plans for people affected by cancer. Able to evaluate effects of interventions and develop the service to enhance care and manage resources effectively.
Personalised care	Deliver person-centred care. Involve people affected by cancer in setting realistic personalised goals for treatment and adapt them for people of fluctuating ability.
Leadership and Team working	Lead teams to develop services and promote the role of AHPs. Provide holistic person-centred care within multidisciplinary team.
Supporting independence	Work with people affected by cancer, their supporters and other health and care professionals to assess individual needs and maintain mobility and functional independence, as appropriate. Help people affected by cancer to adjust to change of circumstances resulting from their disease.
Communication	Communicate effectively and calmly in different situations and adapt communication style to different situations and individuals. Anticipate barriers to communication and take action to improve communication.
Professional practice	Development to work at higher (advanced/specialist) levels of practice. Progress through clinical expertise and/or managerial/strategic routes to AHP leadership roles.

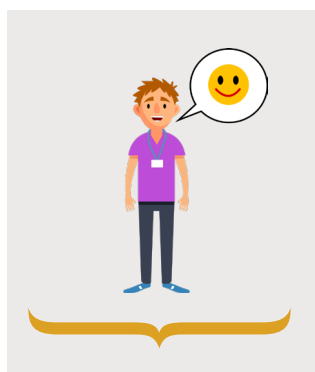
N.B. This is not the full competence profile of a highly specialist physiotherapist.



Speech and language therapist

The role of the speech and language therapist is to assess, diagnose and treat communication and swallowing difficulties (dysphagia) which arise as a result of a cancer diagnosis and/or as a result of cancer treatment.

The Speech and Language Therapy team undertakes communication and swallowing assessments and



therapy prior to, during and following cancer treatment, laryngectomy care and tracheostomy care.

In accordance with National Institute for Clinical Excellence (NICE) guidelines, the speech and language therapist is a named core member of the multidisciplinary team for head and neck cancer, neuro-oncology, critical care and paediatrics and young adults. Speech and language therapists provide specialist input regarding communication and swallowing, in particular for people affected by gastrointestinal, lung and breast cancer.

Speech and language therapists caring for people affected by cancer can work in a range of different settings including hospitals, outpatient clinics, community health centres, hospices and clients' homes.

The Speech and Language Therapy team at the Royal Marsden Hospital in London sees people undergoing curative treatment for head and neck cancer before treatment, during chemotherapy and/or radiotherapy treatment and post-treatment for ongoing rehabilitation. The team works very closely with their clinical nurse specialist, dietetic, oncology and surgical colleagues.

Pre-treatment assessment and counselling involves:

- multi-dimensional baseline assessment of communication and swallowing function
- provision of information on the potential side effects of proposed treatment on communication and swallowing function
- provision of prophylactic (preventative)/prehabilitative exercises
- liaison with a dietitian.

On-treatment review involves weekly monitoring of communication and swallowing function with provision of support, coping strategies and intervention when required.

Weekly on-treatment reviews are completed jointly with a speech and language therapist, dietitian and head and neck clinical nurse specialist.

Post-treatment review involves:

- multi-dimensional post-treatment assessment of communication and swallowing function
- post-treatment rehabilitation to maximise functional outcome
- optional instrumental evaluation of swallowing function using videofluoroscopy (x-ray imaging) or fiberoptic endoscopic evaluation of swallowing (FEES).



A practitioner's story

"I work as part of the Royal Marsden NHS Foundation Trust 'head and neck' team. On a weekly basis I attend the

MDT meeting with the consultant oncologists, surgeons, radiologists, pathologist, nurses and dietitians.

"Here, all the people newly diagnosed with 'head and neck' cancer are discussed and recommendations for

their management are made. I meet the patients with the 'head and neck' team and undertake preliminary baseline assessments to inform their definitive treatment plans. I then follow patients during and after their treatment for ongoing rehabilitation.

"My main aim is to promote functional outcome and maximise quality of life for people following their treatment for head and neck cancer."



A practitioner's story

"A lady aged 34 years, who had been previously treated for cancer of the tongue was referred to me with throat

cancer. She was reviewed regularly, supported during chemotherapy and seen for follow-up to aid and monitor her speech and swallowing. An urgent review was requested when her swallowing deteriorated.

"As a specialised speech and language therapist, working in a tertiary cancer centre, I diagnosed a 'late effects' swallowing problem and was able to differentiate this from recurrence of her cancer.

"I treated her with an evidence based innovative therapy – expiratory muscle strength training (EMST) and made appropriate referrals to psychology and complementary therapy colleagues."

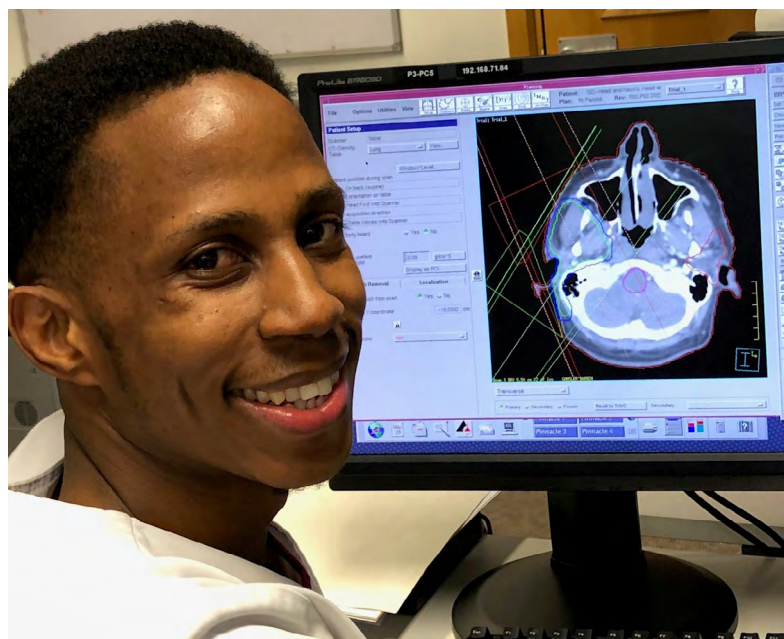
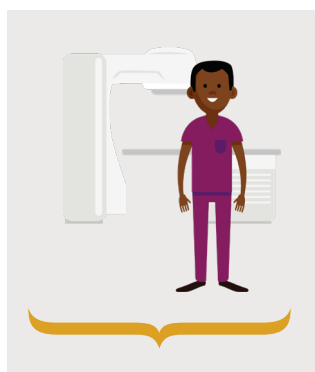
Professional competencies demonstrated by a highly specialised speech and language therapist

Clinical practice	In-depth knowledge of head and neck cancer and its treatment; expertise in the clinical and instrumental assessment of swallowing to guide information provision and rehabilitation; in-depth knowledge of the evidence base for swallowing rehabilitation in head and neck cancer.
Communication and personalised care	Information provision regarding likely functional status post-operatively to facilitate informed decision making. Relate patient's holistic needs to the importance of complying with (the EMST) treatment exercises.
Interagency and partnership working	Close working with surgical and dietetic teams. Referral to psychological care and complementary therapy.
Supporting independence	Returning home post-operatively on oral intake; survivorship goals including being able to eat out with friends and family, returning to work.
Leadership and professional practice	Exemplary pathway patient-centred MDT working; service improvement lead for introduction of new evidence based (EMST) tool via medical devices committee; dissemination of work at national conferences.

N.B. This is not the full competence profile of a highly specialised speech and language therapist.

Therapeutic radiographer

Therapeutic radiographers are based mainly in specialist hospitals and operate highly sophisticated equipment. They play a key part in the frontline battle against cancer by planning and delivering radiotherapy – high-energy ionising radiation to treat cancer. They provide specialist expertise, advice and continuity of support and are responsible for the wellbeing of people before, during and after their diagnosis and treatment.



Pathway	Role of Therapeutic radiographer
Pre-diagnosis	Give health promotion advice and raise awareness of cancer.
Pre-treatment: preparation and planning	Work with patients to enable them to make informed decisions about their treatment options; obtain patient consent for treatment. Use sophisticated equipment to scan patients and plan treatments. Prepare any required devices to ensure the accurate delivery of treatment.
Treatment delivery	Use a range of radiotherapy equipment to deliver external beam radiotherapy and brachytherapy (internal radiotherapy) treatments.
During treatment	Manage patients - regular assessment whilst undergoing treatment. May be qualified to prescribe drugs for patients to counteract side effects of treatment. Monitor psychosocial wellbeing of patients whilst attending for treatments.
Follow up	Responsible for ensuring continuity of patient management and care after treatment has finished.

Therapeutic radiographers, who specialise in a particular clinical pathway (e.g. breast or lung cancer) are responsible for streamlining and focussing care and support for patients across the radiotherapy pathway.

Skills-mix and new roles at advanced and consultant levels of practice for therapeutic radiographers have been highlighted as key to improving access to innovative and advanced radiotherapy treatments (CoR, 2014).

See case studies in [AHPs into Action](#)

Case study 36 – Consultant Breast radiographer, Leeds Cancer Centre (p.98-100)

Case study 37 – Advanced practice, Prostate cancer, Christie Hospital, Manchester.

See: https://www.sor.org/sites/default/files/document-versions/appg_a4.pdf



A practitioner's story

"For the past six years I have been the Advanced Urology Practitioner specialising in radiotherapy for prostate

and bladder cancers – a role developed to fill a gap in the quality of support available for these patients. I am the link between urology and radiotherapy and have contact with all patients undergoing radiotherapy for a urological cancer. I am responsible for writing our department patient information and I support the patients and their families during treatment after initially seeing them at a pre-treatment seminar.

"As well as inserting gold seed markers into the prostate to aid the accuracy of treatment, I provide continuity of care throughout the course of radiotherapy and I facilitate a monthly prostate cancer support group. As a non-medical prescriber, I can initiate treatment for side effects and provide a follow up clinic. Close working with colleagues in the multi-disciplinary team is crucial to ensuring the best care for the patient, enabling referral to other specialties such as andrology or continence nurses."

See: https://www.sor.org/sites/default/files/document-versions/appg_a4.pdf



A practitioner's story

We do all we can to offer the best possible treatments to patients. I work with a multi-professional team to set

the strategy and vision for our service, communicate to staff about the great work everyone is doing and acknowledge their successes. I ensure all staff have access to education and training opportunities to support them in their roles.

"Most importantly I have to ensure the service is staffed appropriately, which involves crunching lots of data and understanding how it relates to the number of staff we need and how many patients we're likely to treat in any one year."

See: https://www.healthcareers.nhs.uk/sites/default/files/documents/Careers%20in%20the%20allied%20health%20professions_0.pdf (p.19)



A patient's story

"Having cyber-knife treatment was something new, not the usual radiotherapy – it's not widely available.

Having metastatic breast cancer, I've had lots of radiotherapy – but this was a new type of treatment. The room was empty, just the treatment bed and the machine above it. I had to lie still for a long time, it was a scary environment.

"I had high quality care from the team of therapeutic radiographers and assistant practitioners. They were well prepared – they knew about the specialist

treatment. They were caring, they explained about the machine and explained why I had to be in the exact position. Doctors give you scientific information; the radiographers give you information on how to feel more comfortable, such as distractions to help keep you still - to bring a talking book for example. They helped me understand the benefit and how it was supposed to work. They gave me very clear information on side effects and how best to cope, to fit it all into my lifestyle and who to call.

"It felt like I had fully participated in the decision to have this treatment, and when and how it would be delivered – it was very much a team process, with me as a partner."



AHPs in multidisciplinary teams

Dedicated multidisciplinary teams of specialists were established to deliver cancer care in response to publication of the Chief Medical Officers' for England and Wales 'Calman-Hine' report 'A policy framework for commissioning cancer services' in 1995 (Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales, 1995), (NICE, 2002).

In parallel with this development, the NHS Cancer Plan introduced a four-tier skill-mix model to make better use of the skills of non-medical staff by expanding their

traditional roles and placing emphasis on competency, i.e. appropriate skills and experience, rather than specific (medical/non-medical) professional background (DH, 2000). AHPs are legitimate members of modern day multidisciplinary teams and are recognised for their critical contribution and participation.

Teamworking enables healthcare professionals to focus on patient needs throughout the cancer care pathway, such that the skills and competencies required to meet these needs are held within, and distributed across, the team – regardless of the individual job roles or professions of the individual team members.



Evidence review case study

In their 2002 guidance on improving outcomes in breast cancer, NICE suggested that expert care should be available locally for all patients (NICE, 2002). In order that sufficient expertise was always available, NICE recommended there were at least two individuals who had specialist qualifications and experience with breast cancer patients for each role in the core breast care team and that each of these individuals should have a substantial fixed time commitment, at least 50% of their time, to breast care (NICE, 2002). Initially, the (medically qualified) radiologist was identified as a core member of the breast MDT and (AHP) radiographers were identified only as having a supporting role to 'carry out the decisions' of the core team (NICE, 2002).

Guidance on organisation of symptomatic breast services was published by the Association of Breast Surgery, a division of the British Association of Surgical Oncology (BASO) which itself is part of the Royal

College of Surgeons of England in 2005 (BASO, 2005). This provided a template for reorganisation of symptomatic services in the UK. Both NICE (2002) and BASO (2005) advised that breast specialists from a range of healthcare professions should work together in MDTs and that clinical decision making should be democratic. BASO specifically identified both the specialist radiologist and the radiographer as 'diagnostic team' members (BASO, 2005).

The current Breast Cancer Service Specification (NCIN, 2012) reflects development in skills mix in the imaging service specifying that membership of the core MDT breast team includes two imaging specialists, without referring to any specific professional group. Kelly et al. (2008) describes the innovative role of the consultant breast radiographer at Countess of Chester Hospital, attending MDT meetings, participating in case discussions and advising the MDT about further imaging work-up of indeterminate, suspicious or discordant triple assessment (breast screening) cases.



Evidence review case study

The Leeds Head and Neck Cancer team comprises 23 healthcare professionals including dietitians and speech and language therapists. Effective team working helps provide holistic and seamless care across the extended cancer journey and across a variety of health and social care settings.

The Leeds team supports patients from the initial breaking of the bad news (diagnosis), through surgery, radiotherapy and chemotherapy (treatment) onto rehabilitation and adjustment, in inpatient, outpatient and community settings. Their ultimate goal is to help patients control their pain and manage their symptoms and avoid unnecessary hospital admissions.

Effective team working has enabled them to overcome the difficulties associated with working across three hospital sites.



A practitioner's story

"Working within a multiprofessional team offers a unique opportunity to learn from another specialty and helps make sure you are working in a holistic way, keeping what is most important to the patient at the centre of what you are doing."

Michelle, Specialist Dietitian in the Leeds Head and Neck Cancer team

LTHT Facebook post, May 2017

https://www.facebook.com/pg/LeedsTHTrust/posts/?ref=page_internal



Evidence review

Consultant radiographers have sustained direct contact with women in diagnostic breast clinics where they perform and interpret mammography (breast x-ray imaging) and ultrasound examinations and conduct tissue biopsy procedures. As a result, they develop rapport and empathy and are able to advocate in MDT

discussions, thus promoting patient-centred decision-making. Including the radiographer who has performed and/or interpreted the mammogram in MDT case discussions, and thus has first-hand knowledge of the patient and their images, helps to ensure that clinical decision making is based on synthesis of accurate and complete information.

Culpan, 2016

A final word

The participants in this project revealed the wide range of valuable contributions that AHPs make to the care and experience of people affected by cancer before, during and after treatment.

The information collected during the project has allowed us to map a spectrum of clinical interventions delivered across the full range of the allied health professions and across primary, secondary and community health and social care settings.

We have been able to illustrate how AHPs are at the forefront of caring for people with cancer, across the whole lifespan, across all cancer types and along the entire cancer care pathway.

In addition to generating the patient and practitioner stories presented in this report, the following key themes emerged from our citizen and practitioner engagement activities and discussions during the project.

Communication – although considered integral to all AHP roles, communication was a high priority for people affected by cancer and some of their communication needs were considered to be specific to the ‘cancer’ clinical setting.

Patient-focussed care – patients believed they were their own ‘experts’; our ‘patient’ participants would have liked more opportunity to talk and be listened to about their individual goals for living with and beyond cancer; they would have welcomed more involvement in making decisions about their care and more support to self-manage and be independent.

Continuity of care, sharing information, partnership working – patients said they and their carers built up relationships with the people who looked after them. Our participants valued being cared for by people who they knew and who knew them and ‘their story’. People affected by cancer pointed out that some of their care can be delivered by professionals who are not part of the NHS. They highlighted how good liaison, inter-

agency collaboration and access to care records across organisational boundaries was important to the quality of their care overall.

Practitioner education – both patient and professional participants felt they would benefit from greater recognition of, and support with, the emotional effects of cancer. In view of the growing number of people affected by cancer, they thought that specific content in all AHP training courses would be useful. Participants suggested that inter-agency collaboration between the education and charity sectors, e.g. such as use of the Macmillan AHP Competence Framework resource, could be helpful with this.

Raising awareness of the role of AHPs – AHPs, and their important contributions to the care of people affected by cancer, were not always easily recognisable to the public, patients and their families. This finding endorsed the value of our project to try to uncover and showcase the wide scope of practice of the 14 allied health professions across cancer care settings. It validates our plans to undertake further collaborative work to support AHPs to participate fully in MDTs through identification and support of leadership development roles for AHPs in cancer care.

Inter-dependencies – participants and the project team recognised that this stream of work had links to other HEE workstreams, for example mental health, children and young people; as a group we acknowledged that other agencies, e.g. NHS England, Macmillan Cancer Support and Cancer Research UK were also doing valuable work to help improve the lives of people affected by cancer and promote the role of AHPs – and that continued collaboration would align all this to national Cancer Strategy recommendations and ambitions.

Service user resource – the information gathered during this project has been used to create an associated publication: ‘Who else is on my care team? A guide to the Allied Health Professionals who care for people affected by cancer’ aimed at service users – people affected by cancer and their families and carers.



Section 3 – Additional resources

The Phase 1 [Cancer Workforce Plan](#) outlines a series of actions that HEE is taking, working with partners across other stakeholder organisations, to optimise the contribution of AHPs to the care of people affected by cancer. The following resources are available to support delivery of the Cancer Workforce Plan ambitions for AHPs:

[Health Careers](#) – provides information and resources on all AHP roles, including role descriptions, routes to study and information for overseas practitioners and those wishing to return to practice after a career break.

[RePAIR project](#) – a series of initiatives to reduce avoidable attrition from pre-registration training programmes; includes development of a toolkit for use by higher education institutions, service providers and policy makers to help improve retention in pre-registration clinical education programmes and support newly qualified staff during the first two years of their clinical practice.

[Return to Practice programme](#) – attracting experienced AHPs back into the workforce. It has a target to return 300 AHPs back onto the Health and care Professions Council register and into the NHS by 2019. The scheme offers financial support for out-of-pocket expenses and course fees and helps to facilitate clinical placements.

[Advanced Clinical Practice \(ACP\)](#) - advanced clinical practitioner AHPs are able to expand their role to encompass a wider scope of practice than that associated with their original unique skill set. In ACP roles AHPs can enhance the capacity and capability of the multiprofessional teams within which they work; they are able to improve clinical continuity and provide more patient-focused care for people affected by cancer. HEE led development of the ACP definition and the ACP competence framework and facilitated development of the ACP apprenticeship.

[STAR tool](#) – resources to support workforce transformation activity under the headings of:

- supply
- upskilling
- new ways of working
- new roles
- leadership.

Macmillan Cancer Support offers the following resources to support AHPs working in cancer care:

[Macmillan Explore](#) – an e-learning programme, supported with telephone mentoring. Four modules (increase your knowledge about the cancer pathway; Macmillan services to help you, your patients and their carers; managing yourself; increase your knowledge about key elements of the specialist role) to increase knowledge of cancer care and/or enhance skills and confidence in caring for people affected by cancer. Aimed at nurses and AHPs considering a cancer specialist practitioner role or Clinical Nurse Specialists and AHPs newly appointed to oncology roles.

Macmillan Allied Health Professions Competence Framework

– an up-to-date resource endorsed by all 14 AHP professional bodies. It is a freely available tool that can help organisations and individuals identify how AHPs might develop the knowledge, skills and behaviours that will enable them to fulfil existing and new roles and function effectively in current and new models of cancer care.

In addition to individual profession-specific core and specialist clinical competencies, the framework sets out the knowledge, skills and behaviours that AHPs need to demonstrate in the clinical context of providing care for people affected by cancer at three levels of practice:

- competent
- specialised
- highly specialised.

Along with communication and leadership competencies, it articulates five clusters of 'cancer' competence:

- clinical practice
- care coordination
- supporting independence
- interagency and partnership working
- professional practice.

NHS England's Quick Guide: the role of allied health professionals in supporting people to live well with and beyond cancer provides practical advice and case studies highlighting how AHPs are contributing to implementation of the cancer strategy and improving both cancer outcomes and quality of life.



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