

Who else is on my care team?

A guide to the Allied Health Professionals who care for people affected by cancer

June 2019



It felt like I had fully participated in the decision... it was very much a team process, with me as a partner."



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Allied health professionals

Teamwork is important when it comes to cancer care.

So it's important that everyone involved in the care of people affected by cancer works together to address the needs of individuals and their families in the best way possible.

In addition to doctors and nurses, allied health professionals (AHPs) provide a range of care for people affected by cancer.

Considered together, AHPs are the third largest workforce group in the NHS (after doctors and nurses).

With their range of individual specialist knowledge and skills they bring a unique perspective to your care and can be a crucial bridge – helping people to find their way within what is often a complex and bewildering system of care.

AHPs play an essential part in every aspect of the clinical pathway – from cancer prevention, diagnosis and treatment – through to supporting people during survivorship and end-of-life care.

AHPs provide key support when and where it is needed most, being able to look for and emphasise the links between physical and mental wellbeing.

This booklet has been produced to raise awareness of the roles of AHPs and provide an overview of their important contribution to the care of people affected by cancer.

Clinical psychologists work alongside AHPs and with music, art and drama therapists they provide essential support for people affected by cancer. So, we have also included information about their role in this booklet.

The last section of the booklet illustrates the role of teamworking in managing childhood cancers and the critical role of AHPs in such teams.



Acknowledgements

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Fictitious names are used in the stories in this booklet to protect the identities of the people who kindly contributed.

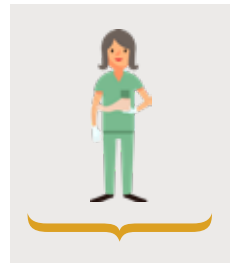


Chiropodists and Podiatrists

Chiropodists and podiatrists assess and treat problems of the bones, skin and soft tissues of the foot and lower limb to help keep people comfortable and mobile.

They play an essential role in prevention of cancer, for example, by giving information and advice on reducing the chances of getting skin cancer and monitoring moles, skin and nails as well as checking verrucas and ulcers, to spot any cancerous changes.

During cancer treatment chiropodists and podiatrists provide routine wound care and treat acute foot issues. They monitor risk of infection and on-going problems such as fungal nails or skin issues. They can also identify changes that occur over time, report these changes to oncologists and/or signpost people to relevant members of their healthcare team for additional care or therapy.



Podiatrists looking after people affected by cancer help to manage walking difficulties, prevention of falls and optimise function for people who have treatment-associated bone problems or those who are suffering from lymphoedema (swollen limbs), a common side effect of cancer treatment. In rare cases, where people have had lower limb amputation, they have a vital role advising on the prosthesis of choice.

During palliative and end-of-life care chiropodists and podiatrists offer care to help people manage pain due to fissuring, peeling skin, infection, ulceration and the effects of co-morbidities such as vascular disease and diabetes, and help people reduce the risk of infection to avoid the need for amputation.



A chiropodist/podiatrist's story

"A 65-year-old lady who had suffered with an ulcer on her foot for several months attended the podiatry outpatient clinic. She had visited several other clinics (tissue viability, rheumatology, orthotics) in previous months. After assessment of the ulcer by the podiatrist she was immediately referred to a dermatologist and was diagnosed with melanoma (skin cancer)."



A patient's story

"I had a painful ulcer on my foot for a few months and had originally seen my family doctor about this. It caused me a lot of discomfort and I struggled to walk with it. I was referred to different clinics with no solution to the problem and was getting quite upset and frustrated.

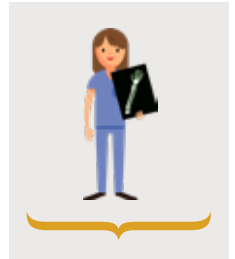
"The solution finally came when I visited the podiatry clinic where this nice practitioner saw to my leg. She managed to diagnose the problem straight away and sent me immediately to the skin clinic, where I was told I had skin cancer.

"The professionalism, skill and the empathy of the podiatry practitioner made the whole experience a lot easier and I felt I got some answers."



Diagnostic radiographer

Diagnostic radiographers work mainly in hospitals and health centres operating equipment that uses X-ray, ultrasound or magnetic resonance imaging technology to obtain detailed images of the inside of the body. These images are often crucial to detecting the first signs of disease and making a correct diagnosis.



People without any signs that they might have cancer might meet diagnostic radiographers if they participate in a screening programme. For example, in the NHS Breast Screening Programme, diagnostic radiographers perform breast X-ray (mammogram) examinations.

People who are referred for tests after visiting their General Practitioner (GP) with unusual or troubling symptoms might meet a diagnostic radiographer if they are sent to have an X-ray or scan.

Diagnostic radiographers also obtain images to help doctors plan and monitor cancer treatment and to follow up patients who have had cancer in the past (surveillance), to look for recurrence or spread (secondary cancer).

As well as obtaining images, some diagnostic radiographers are also trained to interpret and report on X-ray images and (computed tomography, magnetic resonance and ultrasound) scans and some contribute to the bowel cancer screening programme by performing and reporting imaging examinations such as endoscopy.



A diagnostic radiographer's story

"I have been a mammographer (a specialist radiographer working in the breast screening programme) for over 15 years and routinely see women who are in the breast screening programme.

"They can be terrified when they come for the procedure (the fear or the unknown). It is my responsibility to ensure that I can make the procedure as easy as possible by being empathic and kind and work with the highest standard of professionalism. In some cases, as I work within the breast screening programme, I see the same women regularly and I develop a relationship with them. I feel that this is an essential part of supporting them through a difficult journey. It is nice to be able to support the women in my care."



A patient's story

"I've been treated for a number of benign conditions by my local breast unit since I was 30 years old. I had my first mammogram at the age of 40 with the specialist radiographer, a mammographer. From the outset she displayed empathy, concern, skill, kindness and professionalism.

"Mandy has been my mammographer since then and when a 'problem' was seen on the mammogram she supported me in the best possible way.

"Over the years, with the need for repeat mammograms, the continuity I have had with Mandy is remarkable and this relationship has helped each and every step of the way during the difficult visits."



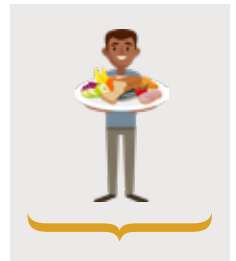
Dietitian

Dietitians are experts in food and nutrition. They are the only health professionals who 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 and in people's homes.

Dietitians have a vital role in providing nutritional support for people affected by cancer before, during and after treatment. People affected by cancer and its treatment can have problems with eating and drinking due to the side effects of treatment or the cancer itself. Some symptoms include poor appetite, taste changes, nausea and pain on eating.

Cancers affecting the head and neck region and their associated treatment can cause problems eating, drinking and swallowing normally because the structures required for these activities have been removed or damaged by treatment.



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. For patients who cannot take enough or any nutrition by mouth, dietitians may recommend and support people with ‘tube’ feeding. Tube feeding is the delivery of nutrients in the form of a liquid feed into the digestive tract via a feeding tube.



A dietitian's story

“Mr Green was having chemotherapy for pancreatic cancer. He was admitted with nausea and vomiting and had emergency surgery.

Following this he was referred to me due to a history of poor appetite and weight loss. He could only manage liquids and had difficulty eating due to chemotherapy side effects. His mood was very low, and his wife was anxious about the eating problems and weight loss.

“We decided as a team, with Mr and Mrs Green's agreement, to insert a feeding tube to try to help improve the situation. I worked very closely with Mr Green and his wife providing advice, guidance, reassurance and support on ways of improving nutritional intake that suited their needs and that Mr Green could adapt to suit himself at home.

“On discharge from hospital Mr Green was eating full meals and was taking oral nutritional supplements. He went on to gain 3.5kg, feel stronger, was able to mobilise; eventually he and his wife agreed that his feeding tube could be removed. It was rewarding to see the progress Mr Green made and how the couple's mood and anxiety improved – it was good to see him looking stronger and happier.”



A patient's story

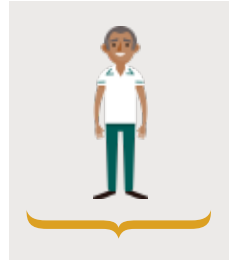
"I first met my dietitian Valerie when I was being treated for (head and neck) cancer during a consultation with my healthcare team. I had been struggling to eat after my surgery and had lost my appetite completely.

"Valerie spent a long time with me asking about what I liked eating and about my eating habits. Together we worked out a menu that combined food that I thought tasted good with food that gave me the nutrients I needed to maintain weight and get through the gruelling chemotherapy and radiotherapy. Despite this, I struggled so hard to eat because of the chemotherapy side effects that we decided I needed a feeding tube. This decision would have been harder had it not been for Valerie's support and patience. Once my treatment was completed, Valerie helped me regain my appetite and my wish to eat – I can now eat a full meal, have had the tube removed and I am looking forward to being able to eat a lovely three course meal at my big birthday bash."



Occupational therapist

Occupational therapists help people with physical and psychological problems to be more independent in the home, at work and in social settings by assessing what they can do for themselves.



Occupational therapists provide support and encourage people to find practical solutions that enable them to take control and manage changes in their health state.

Within this wide-ranging remit, the occupational therapist helps people affected by cancer to incorporate their new state of health into their daily lives, to manage any anxieties and concerns through rehabilitation and to restore function. They play a key role in giving advice on how the home environment can be changed to help people cope with physical problems caused by cancer diagnosis or treatment. They can teach people to conserve energy for daily living when their stamina is reduced and teach them new ways of doing things, allowing them to adapt, and thus maintain meaningful employment if they wish to do so, for as long as possible.

In cases where people have lost some function due to their cancer diagnosis or treatment, occupational therapists can teach adaptive techniques, with or without equipment-supported moving and handling, in the home. This allows people affected by cancer to be more independent and reduces or delays the need for formal care packages.



A patient's story

"I was diagnosed with prostate cancer when I turned 55. I was running my own business before this and thought that the gruelling treatment and side effects would mean that I would have to change my lifestyle. However, I have been supported by the occupational therapy team to use 'simple techniques' that give me the ability and confidence to get back on with my life. I am 'living' with cancer rather than 'dying' from it."



A occupational therapist's story

"I work within a specialist therapy team working across three hospital sites, seven days a week, with people affected by cancer, including those who are newly diagnosed.

"As part of my role, I review how people are managing in their daily living activities using goal-oriented assessments. For example, I ask them how they are managing to get dressed in the morning, and how independent they feel they are.

"I use this information to provide a care plan that can support them to continue to live as independently as possible, to continue to remain in meaningful work if desired, and thus reduce some of those anxieties and fears as well as problems managing numerous hospital appointments.

"A lot of my work is multi-disciplinary. I work with colleagues in a number of other professional disciplines to ensure that people affected by cancer can maintain the best quality of life they can."



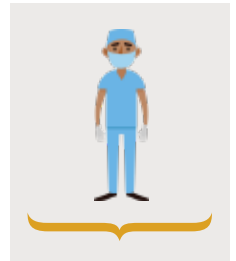
Operating department practitioner

Operating department practitioners are members of the healthcare team who look after people undergoing procedures carried out in operating theatres to diagnose or treat diseases.

Operating department practitioners care for patients immediately before, during and after operations in anaesthetic, surgical and recovery roles. As most patients are sedated (drowsy) or asleep (general anaesthetic) during operations, the only patients that see the care provided by operating department practitioners are those having procedures under local/spinal anaesthetic.

In their 'anaesthetic' role operating department practitioners help to look after patients and prepare equipment and drugs for use during the operation. During surgery they have an important health and safety role. Working in a 'circulating' role they make sure equipment and surgical instruments are clean, prepared and available during the operation; in a 'scrubbed' role their duties may include following aseptic (sterile) technique and infection control procedures.

Once the operation is finished and patients are moved to 'recovery', operating department practitioners assess their condition, observe physiological measurements (breathing, blood pressure and temperature) and provide support and care until patients are stable and well enough to be transferred back into nursing care on a ward.





Operating department practitioner's story

"I am a professional that works behind the scenes. By the time the patient is brought into the theatre, they are usually unconscious with the anaesthetic.

"My job is to support the surgeon with the procedure and help ensure that the patient is maintaining a constant airway and has stable vital functions.

"After procedures I look after the patient in the recovery suite continuing to check maintaining their airway and vital functions.

"I sometimes work with the breast surgeons. Breast cancer can spread to other areas of the body and one of the ways of identifying the first area it has spread to (the first lymph node affected or the sentinel lymph node), is to inject radioactive fluid into the breast and see which lymph node it goes to first.

"When I work with surgeons during this procedure, I have to be aware 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 by the surgeon to detect radioactive lymph nodes must undergo strict quality control procedures to make sure it is working correctly, and radioactive waste from the operating room is a biohazard and has to be collected and disposed of in accordance with radiation safety regulations."



Orthoptist

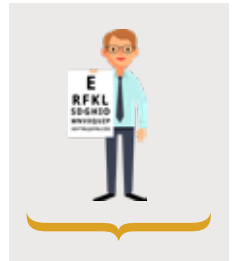
Orthoptists assess, diagnose and treat problems relating to vision that arise from defects in eye movement, alignment or co-ordination.

Cancer-related sight problems might be picked up early during routine eye tests or when people with symptoms are referred for specialised tests.

People affected by head and neck cancers such as retinoblastoma (eye cancer), glioma and cytoma (nerve or brain tumours) can have vision problems due to the position, size and nature of the cancer and/or related to surgery or radiotherapy treatments. Orthoptists use their professional judgment to help work out where a tumour is and help differentiate between other nerve-related causes of sight disturbance.

Orthoptists provide baseline measurements of visual function, review sight stability regularly to detect changes, provide vision aids and implement corrective therapies, provide certification of sight impairment and advise on driving capability.

During rehabilitation, palliative and end-of-life care, orthoptists advise and counsel patients and their families, providing support, reassurance and information about social, educational, welfare and charitable services for people with vision loss.





An orthoptist's story

"Over an extended period of time I tend to see the same patients and develop strong trusting relationships with them.

"Paul came with his wife, both were very anxious at the initial consultation, but they became much more relaxed with me over the course of several appointments. I think this made them more willing to accept the fact that Paul's eye sight was changing because of his tumour and treatment, and that it was difficult to predict what was going to happen.

"I showed Paul how to use different head postures to minimise his symptoms and gave him some vision aids and exercises for reading and distance vision.

"These interventions have helped Paul and his wife to cope better with this visual impairment and given him some independence and a better quality of life."



A patient's story

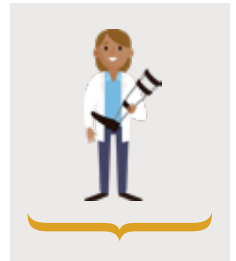
"I saw Katherine, the orthoptist, with my wife after I was diagnosed with an eye tumour. When she told me I was unable to drive as my vision was badly affected I was devastated, not only would I have to give up work, I would be reliant on my wife for my every need. It can be difficult to adjust when you are used to being so independent. With a lot of patience and empathic professional skill, however, Katherine gave me different exercises and postures to perform to allow me to maintain some vision.

"I was able to carry out small tasks, and walk around with a stick, making me feel more in control of the situation and that I wasn't reliant on someone. Best of all I was able to continue my hobby of reading – something I take great pleasure in."



Orthotist/prosthetist

Orthotists assess, design and provide devices such as splints, braces and specialist footwear (orthoses) which alter the structural or functional characteristics of the musculo-skeletal system. These devices help to keep people on the move, reduce their pain and discomfort and can help to heal nerve, muscle or bone damage.



Prosthetists use their specialised knowledge and skills to provide the best possible replacements (prosthetics) for people who have lost limbs through a disease process itself or because of treatment. Their work includes design, fitting and helping people adjust to life with artificial limbs to help restore function.

Prosthetists and orthotists work in hospitals, clinics and community health centres both independently and as members of multi-disciplinary healthcare teams.

Working with physiotherapists, prosthetists and orthotists can help people affected by cancer to optimise function using prosthetic devices after limb amputation and can help people suffering from lymphoedema (swollen limbs) caused by cancer or its treatment.

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



An orthotist's story

"As an orthotist I work with some people who have been affected by cancer and have had an amputation or lost a limb due to their diagnosis or treatment. I can assess for the best orthosis for a person to use and ensure that they can use it as comfortably as possible.

"One of my referrals was a young boy with a bone cancer that had required amputation of his leg. I saw him in clinic and fitted him with an orthosis that would help him walk.

"Over time I reviewed him in the clinic and made adjustments to the orthosis to ensure that he remained comfortable when walking."



A patient's story

"I saw Marion, my orthotist, after I had to have an amputation as a result of bone cancer.

"She was lovely, put me and my mum at ease immediately and calmed all our fears. She measured my leg and arranged for me to have an artificial leg to walk with.

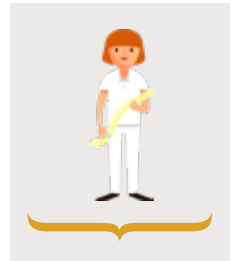
"Over time I have had a lot of visits to Marion and with her adjustments I was able to walk again, I even managed to play football with my brother and friends in the park again.

"The nice thing about seeing Marion regularly was I was able to share so many things with her, not just about the artificial leg but how I was feeling about life, school and home. She helped me but she also helped my family though a tough time too, especially my mum who came with me to the appointments."



Osteopath

Osteopaths use their knowledge about disease processes and their problem-solving skills to help people manage the side effects of conventional surgical, chemotherapy and radiotherapy cancer treatments.



Musculoskeletal osteopathic treatments are used to try to improve the alignment and movement of the body and provide relief of pain and muscle stiffness.

In addition, osteopathic techniques can also have more general benefits – relieving stress, fatigue and nausea, and improving a person’s general sense of feeling better.

Osteopaths carry out a detailed initial consultation with their clients and then often perform repeated physical treatments over an extended period. This long-term relationship provides an opportunity for them to explore health problems that are complex and might involve both physical and psychological triggers.

Through massage, manipulation and by giving psychological support, osteopaths can help people affected by cancer to come to terms with an altered body image and encourage them to talk openly about their anxieties.



An osteopath's story

"I was asked to review Mr Tucker three years after his diagnosis and treatment for gastric cancer and I scheduled him for eight osteopathic consultations.

"The consultations included manual treatments to improve his musculoskeletal mobility and cranial osteopathy to release deep fascia tension. In addition to this the consultations also provided him with space and time to discuss diet and for me to give information and advice about symptoms related to his initial treatment with total gastrectomy (removal of his stomach) and chemotherapy.

"Following the osteopathic treatments, Mr Tucker's physical symptoms, including his neck pain reduced, the nausea and discomfort he felt after eating disappeared and the frequency of his diarrhoea, breathlessness and fatigue improved.

"As a result, he gained weight and resumed some of his normal social activities."



A patient's story

"Three years after my diagnosis and treatment for stomach cancer, I kept having problems with stiff muscles and had difficulty walking. I was managing my daily life but that was it – I was just managing.

"After mentioning it at several follow-up and GP appointments, I was finally referred to an osteopath for support. Not only did my osteopath carry out a number of differing treatments at the consultations, he used the time to talk to me and discuss lots of different things, amongst these one of my biggest problems was with diet.

"At the time I couldn't understand why he was talking to me about this as it had nothing to do with his consultations, but I was glad of someone to talk too. Now I am better I can see in hindsight what he did – his treatment not only helped my physical wellbeing but my mental well being too, because I was able to share my difficulties with him."



Paramedic

Paramedics respond to 999 and 111 calls and are trained to care for people in urgent and emergency situations.

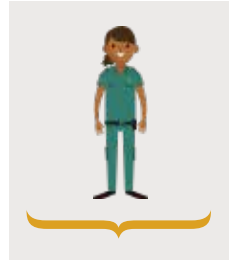
Modern day paramedics provide a full mobile healthcare service which includes assessing someone's overall condition, diagnosing specific problems and providing treatments. They can work in a range of primary care settings such as at the scene of an accident/emergency, out-of-hours in a GP surgery, in a minor injury clinic and in people's homes.

In non-emergency situations, paramedics are involved in transferring people affected by cancer between care settings, for example between hospitals, between hospital and home.

Paramedics help people undergoing palliative care and those at the end of their life by allowing them to die in the place of their choice. They also support carers and family members who are in distress when someone deteriorates suddenly or unexpectedly.

To enable them to manage the physical, psychological and social needs of palliative care patients and their families, paramedics need to understand ethical issues, end-of-life communication needs and know about patient care pathways.

Decisions made by paramedics in emergency situations can have a big impact on the subsequent care of their patients.





A paramedic's story

"Mr Stevens visited his neighbour George when he realised that he hadn't seen him for a few days. He found George looking very unwell, so called 999.

"My colleague and I arrived on the scene to find George looking unkempt, in a dirty bed and it was clear he hadn't been eating and drinking for a while. George's blood pressure was low and he had a rapid pulse (tachycardia). He was experiencing unpleasant side effects from his cancer treatment and was dehydrated from not being able to eat or drink – he was also in significant pain.

"At first, George insisted that he no longer wanted further treatment – he said he had had enough and wanted to die. We took some time to talk with George at length, concluded that his outlook on life was due to the onset of dehydration and pain, and then referred him on to relevant colleagues who intervened to improve his quality of life."



A carer's story

"My dad had been diagnosed with lung cancer and had just completed his treatment.

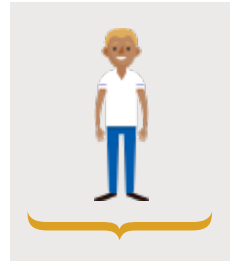
"One day he had a bad episode of breathlessness and mum needed to call for help. The call handler managed the call with great care and diligence, managing to keep my mother calm and providing basic care and support until the paramedic arrived.

"When I reached them, the paramedics were helping my father into an ambulance and I was allowed to accompany him to hospital. The paramedic and ambulance team were efficient and caring, giving us feedback every step of the way. Not only were they looking after my father they were making sure mum and I were OK as well. They were amazing."



Physiotherapist

Chartered physiotherapists assist people affected by cancer during diagnosis, treatment and rehabilitation and when living with and beyond cancer. They help improve quality of life by relieving pain and preventing loss of, or regaining, function.



Many physiotherapists work with patients in hospitals and in outpatient clinics, but they also work across a wide range of community settings, in people's homes and can provide advice and support over the telephone or over the internet.

Working with occupational therapists, physiotherapists help people maintain their independence, so they can carry out activities of normal daily living and, where desirable, return to employment both during and after treatment.

In some cases, physiotherapists also support patients with 'prehabilitation', getting them to be better prepared for the gruelling and often difficult treatment to come, enabling and empowering them to have good quality of life after treatment.

Physiotherapists may provide people with an individual exercise 'prescription', run education and supervised group exercises programmes and keep in touch over several months to support people after cancer treatment to maintain positive health and fitness behaviours.

Supervised and supported exercise 'interventions' help people to manage cancer-related fatigue (tiredness), improve health and wellbeing, and help people get back to work more quickly.



A patient's story

"I was referred to the lymphoedema clinic when I started noticing that my whole arm was swollen when I used to carry heavy equipment for millinery to and from college. Having been warned that this was common after breast surgery and treatment for the cancer I had, I contacted my cancer nurse straightaway. I was fitted with garments to wear and the physiotherapist discussed the need for three weeks of daily treatment. I was worried about how this would affect my work, especially my ambition to be successful in my new passion of millinery.

"The team were very professional and understanding and made it possible for me to manage everything so well that it did not impact on my work.

"Since taking up my new career I now use my experience as a cancer survivor who now has lymphoedema to inspire my creations and I include features of lymphoedema treatment in a series of hat designs."



A physiotherapist's story

"Mr Morris is a 77-year-old man with non-Hodgkin lymphoma (cancer of the lymphatic system) – he had been confused for about four days since being admitted to hospital. He was managing quite well at home, was independent in the home and had no history of falls.

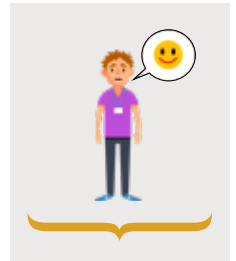
"In hospital, Mr Morris initially required the assistance of two therapists for mobility. However, after ongoing rehabilitation with strengthening exercises and mobility practice, he improved and only needed one of us for assistance – over time, Mr Morris transformed back to his usual self – becoming more interactive and appearing much brighter.

"Seeing this over the course of several weeks, watching him change from being acutely unwell to getting close to discharge home, made me feel more passionate about being a physiotherapist, using my clinical skills to assist getting a patient back to former pre-admission levels of mobility."



Speech and language therapist

Speech and language therapists assess and manage communication, for example voice and speech problems, as well as swallowing difficulties. They work with people affected by cancer from the point of diagnosis, throughout their treatment and rehabilitation into survivorship.



Speech and language therapists play a key role in supporting and rehabilitating people with swallowing difficulties (dysphagia). Problems with muscles, nerves and breathing due to location of a cancer or due to cancer treatments such as surgery or radiotherapy can make it difficult to eat with food sometimes getting stuck or 'going down the wrong way' (aspiration) – eventually people might need to resort to 'tube feeding'. Speech and language therapists work closely with dietitians to address this together and maximise quality of life.

Speech and language therapists support people with communication too, for example those with voice and speech problems. These can occur after surgery such as laryngectomy (removal of the voice box), after radiotherapy or be due to worsening muscle, nerve or breathing function due to cancer or its treatment. Problems with communication can severely affect a person's ability to participate in normal life and communicate their wants and needs and can affect their identity and sense of mental wellbeing.



A speech and language therapist's story

"Barry came to see me during the first week of his treatment for cancer at the base of his tongue. He was eating and drinking without any issues and openly stated that he did not think he needed speech and language therapy.

"Barry was adamant that he would continue to eat and drink 'no matter what' throughout his treatment. I explained to him how his swallowing function might change due to the radiotherapy. He was then able to make a more informed choice about having a feeding tube fitted before any treatment side effects kicked in – in reality, Barry's swallowing function deteriorated quite quickly during his radiotherapy.

"I did weekly reviews alongside the dietitian to help him realise how things were changing, and he began following our recommendations about daily swallowing exercises and mouth care. I assessed Barry's swallowing regularly and advised him to change his food textures and use the feeding tube accordingly. This was to help prevent him getting a chest infection from food going down the wrong way. He successfully made it through treatment and has now started to rehabilitate his swallowing."



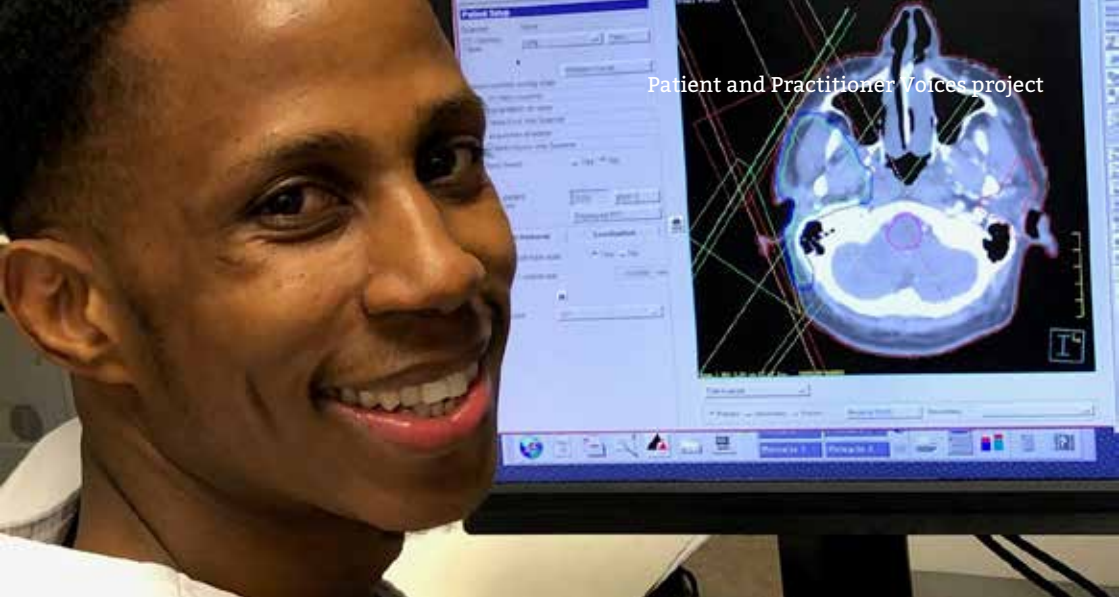
A patient's story

"I always thought speech and language therapists helped patients with talking. When I first got diagnosed with tongue cancer I was eating and drinking fine – I didn't understand why they were asking me about swallowing.

"Throughout my radiotherapy they checked my swallowing every week and showed me how to do lots of swallowing exercises. Then it got really difficult to swallow very quickly – it was hard to eat because everything made me choke.

"I started using my tube to feed and actually started doing the swallowing exercises. This made me feel a lot better and it started to make sense to me why swallowing was so important. I am now 6 months post treatment.

"It took a lot of hard work (and swallow exercises!) to get where I am now but last week I reached my goal of having my first roast dinner with my family!"



Therapeutic radiographer

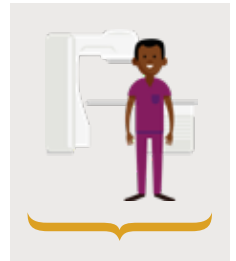
Therapeutic radiographers operate highly sophisticated equipment, using it to plan and deliver radiotherapy treatments (which use high-energy ionising radiation).

In addition to their specialist technical role, therapeutic radiographers have the knowledge and skills to give advice and support to people diagnosed with cancer before, during and after their treatment.

Their role in the delivery of treatment means that they often see people over an extended period. This allows them to build a relationship with their patients and enables them to provide support for all aspects of their care.

Some therapeutic radiographers work in a more specialist advanced care setting. After undertaking further study, they work in advance practice roles in multidisciplinary teams closely alongside oncologists. Therapeutic radiographers offer support to help people identify and manage the long-term side effects of radiotherapy treatment such as skin, limb, urinary (passing water), bowel or fertility problems.

In some places therapeutic radiographers (consultant practitioners) have their own review clinics where they obtain consent for treatment, prescribe medicines or offer continuity of care after treatment is over; this service is provided in the hospital setting or via telephone if necessary.





A therapeutic radiographer's story

"When John was told of his cancer diagnosis by the oncologist he was understandably very upset and shocked – to the point where he was unable to retain information, so was invited back to see me in the clinic. We discussed his radiotherapy treatment plan in depth and together completed the consent form.

"On the day of the radiotherapy planning scan we talked through different relaxation techniques he could use to help him cope with the treatment mask. Throughout his radiotherapy treatment I saw him on a weekly basis, reviewed his side effects and prescribed appropriate medicines. He did very well throughout treatment and I now see him every three months in the follow-up clinic."



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 scary. 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 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, about distractions to help keep you still, to bring a talking book. They helped me understand the benefits and how it was supposed to work. They gave me very clear information on side effects and how best to cope, how to fit it all into my lifestyle and who to call if I needed. 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."



Psychosocial therapists

Psychological distress is not unusual in people affected by cancer – it is an understandable and natural response to any traumatic and threatening situation.

During the year after cancer diagnosis, approximately one-in-10 people have symptoms of anxiety or depression that are severe enough for them to be referred to specialist psychological or psychiatric services.

A similar number of people with advanced (secondary or metastatic) disease experience severe symptoms of anxiety and depression. The need for psychological support for anxiety and depression is also significant in people who care for people who have been diagnosed with cancer.

Appropriate psychological treatment of anxiety and depression in people affected by cancer helps improve their quality of life and extend the length of their life. Identification and treatment of psychological problems can reduce the rate at which symptoms worsen, reduce the number of times people want to see their GP or need to access community services, reduce admissions to hospital and reduce the number of people who are unable to work or support themselves.

Some of the work covered by psychologists with specialised expertise in cancer includes dealing with a change in body image on the patient's sense of 'self'.

Where the treatment for the cancer has led to a loss of an organ, facial or body disfiguration such as a mastectomy or amputation, this can be very difficult to cope with and can have a debilitating effect on survival after treatment. In some cases, people who have had breast or prostate cancer for example, experience psychosexual anxieties which can also be quite debilitating. Support and treatment from a member of the clinical psychology team in such situations can improve someone's sense of self and worth, dramatically.

Psychological distress does not necessarily have to be managed by clinical psychologists. Art, drama and music therapist allied health professionals have a significant role in providing this essential service.

Art, drama and music therapists can use their creative and psychotherapeutic skills to bring out issues relating to change in body image, coping with treatments and side effects and psychosocial issues that patients face.

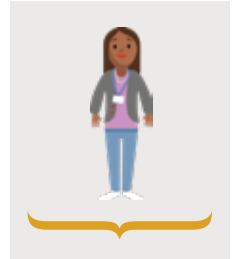
Although not registered as AHPs, play therapists are also often employed in healthcare settings – to support children undergoing treatment for cancer. They have a vital role in supporting children to understand the details of the treatment they are undergoing, especially during radiotherapy.

The next sections of this booklet outline the roles of clinical psychologists, art, drama and music therapists.



Clinical psychologist

Clinical psychologists working in oncology services support patients to cope with the psychological problems and effects that occur during detection, diagnosis and treatment of cancer. They can offer therapeutic interventions at every stage of the disease process to help people manage change and develop coping mechanisms to reduce anxiety and depression that might occur from a change in body image or adjusting to the news of the diagnosis.



Clinical psychologists support people during cancer treatment. Cancer treatments can be demanding both physically and mentally, with the role of the psychologist to provide the right type of support to deal with this. Support is not limited to solving mental issues such as anxiety about the treatment that might lead to refusal to have treatment, or worries about side effects, but also includes support in managing physical reactions to anxiety such as nausea and vomiting.

Clinical psychologists also work with families, both adults and children, of people who have cancer, to help them come to terms with their loved one's diagnosis.

Clinical psychologists also play a significant role in the physical and psychological rehabilitation of people affected by cancer. They support them to come to terms with long-term debilitating side effects of treatment, such as disfigurement, but also help them to manage anxieties related to self-management of their condition and their increased need to depend on others.



A patient's story

"I had been struggling to cope with the side effects of my punishing cancer treatment and in particular with the impact on my mental health. Aware of my plight my consultant and CNS (clinical nurse specialist) suggested psychological help which I have been receiving within the hospital setting.

"I liked the fact that my psychologist understood the system, had access to my notes and understood the procedures I had been through. I felt the psychologist was in the centre of things, part of the multidisciplinary team so my care was all joined up.

"My overall well-being has and continues to improve as a result of my sessions. I consider the support and help that I have been receiving from my psychologist an important and invaluable part of my treatment plan. The difference it has made to me is immeasurable and I really don't know where I would be without it."



A clinical psychologist's story

"When Alison refused upfront to have radiotherapy as part of her standard chemotherapy-radiotherapy treatment for cervical cancer she was urgently referred to me through the hospital psycho-oncology service.

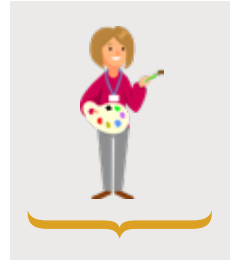
"During my initial assessment she revealed that she had been tortured in a South American country in her youth – whilst doctors were in attendance – and exposure to the radiotherapy machines and staff had triggered memories of this experience.

"I was able to offer her urgent Post-Traumatic Stress Disorder (PTSD) type treatment which allowed her to separate the two situations and undergo her radiotherapy, and importantly from our point of view, in time to comply with the national cancer waiting time standards."



Art therapist

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 are trained in psychotherapy and use their specialist knowledge and artistic creative skills to work with individuals and their families to help them to express their feelings, explore their potential and achieve a sense of personal development and fulfilment.

Art therapy can help restore a sense of wellbeing in people affected by cancer and support them to return to independence and 'normal' activities of daily living.

Arts therapists may be employed by the NHS or may provide their services through charitable or voluntary organisations. They work in hospital and community settings creating safe spaces for art therapy to take place.



A patient's story

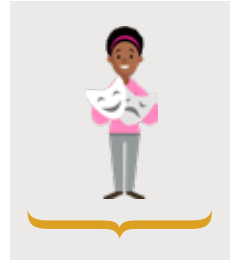
"Cancer treatment was and is terrifying, with some horrible side effects. At its worse I wasn't able to work, be a mother, or just be a person. Art therapy helped me survive the experience and 'keep hold of me' or at least keep hold of the 'new me and the new normal'.

"In a situation where it felt like I had very little control, art therapy became vital. It was at the hospital but it didn't hurt or harm me; it started and finished on time – there was no uncertainty. I could choose to attend or not; I could talk or not talk, draw or not draw, stay or leave. It was part of my treatment but a part that I had some control over and that had some kind of respect for me."



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. Drama therapists can support people coping with aggressive treatment for cancer, helping with recovery and restoration of wellbeing.



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

Drama therapists may be employed in the NHS or may provide their services through charitable or voluntary organisations. The therapy sessions can be in a group or individual, based on the needs of individuals.

Drama therapists often also form part of a multidisciplinary team making referrals and recommendations to other professionals where needed.



A drama therapist's story

"Pauline came to see me to obtain support after treatment to her cervix. She was depressed and anxious with a constant feeling of fatigue. She felt that she had lost control over her body.

"I employed an individual one-to-one session with her initially to give her the chance to air difficult emotions in an expressive way. It helped her laugh and have fun, relieving anxiety and building her self-confidence. We then moved to group sessions where she could work with other people affected by similar issues. After months of therapy, Pauline was able to go back to full-time work and feel like she had her quality of life back."



A patient's story

"I had had months of grueling treatment for cervical cancer that had made me depressed and anxious and always tired. After speaking to my cancer nurse specialist about this, she suggested I try a complementary therapy to see if that would help.

"My local cancer support centre ran some drama therapy group sessions which I decided I would try. I was initially very apprehensive about this and wasn't sure it would work. Being in the group however and being able to talk to other people in the same boat as me, made me feel better. I found that by being able to express my emotions in a fun way and laugh, I gradually built my self-confidence.

"As a result, I was able to go out, meet friends and get my quality of life back."



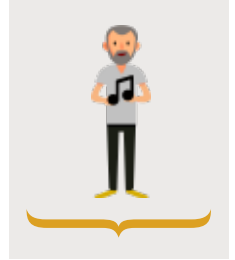
Music therapist

Music therapists use a wide range of musical styles, including free improvisation to help people coping with treatment for cancer and during their recovery.

Examples of music therapy goals for people with cancer and other illnesses are to:

- promote wellness
- manage stress
- alleviate pain
- promote physical rehabilitation
- express feelings
- enhance memory
- deepen relationships with self and others.

Music therapists may be employed in the NHS or may provide their services through a charitable or voluntary organisation.





A music therapist's story

"I started seeing Melissa when she had completed her treatment for head and neck cancer. It had made her very withdrawn and the surgery and what she perceived as facial disfigurement made her feel like she couldn't 'face the world'.

"Melissa loved playing the piano so we made use of her playing ability – encouraging her to let the vibrations from her personal music penetrate areas in which hands (conventional physical therapies) are unable to go, and in doing so help her to restore her body's own natural rhythms to promote health and well-being.

"The music therapy sessions allowed her an opportunity to be herself, they accelerated her physical rehabilitation and by enabling her to express her feelings, made her more confident to face the world."



A patient's story

"I have always loved music. Playing the piano helped me escape into a world of my own. After my diagnosis and treatment for head and neck cancer I lost all interest in playing. I couldn't face day-to-day activities let alone doing things I enjoyed doing.

"At one of my consultations after treatment, one of the team of health professionals asked if I would be interested in taking up music therapy to see if it would help me feel less withdrawn. I decided to give it a go.

"The therapist, Pamela, was lovely – she put me at ease. She started off asking me to play the music I enjoyed. With each session, I started noticing the change in how I felt. I started feeling stronger in myself.

"Seeing Pamela regularly, especially in a setting that was not clinical, without medicine in an environment I loved, helped me gain confidence. I started feeling better, less tired and ready to face the world."



AHP collaboration in multi-professional teams

AHPs often work together, providing a vital role to support people through tough and challenging circumstances on their 'cancer journey'. Working together in teams, from different professions and with different levels of specialisation AHPs coordinate

- prehabilitation – to prepare people for cancer treatment and recovery
- intervention – to cope with and manage planned and unexpected side effects, and complications during cancer treatment
- rehabilitation – to restore people back to activities of daily living or adjust to a permanent change in ability.

AHP roles extend to optimising nutrition and function throughout the whole care pathway, alongside supporting families through a distressing time.

The following case study highlights the role of teamworking involving a combination of allied health professionals caring for a young boy with a brain tumour.

Jake and the team of AHPs who cared for him

Jake was 18 months old when he was diagnosed with an 'ependymoma' – a tumour in the back lower part of his brain. Following neurosurgery to remove the tumour he was transferred to our hospital for a six-week course of radiotherapy.

Jake was part of a close-knit family and lived with his mum, dad and an older sibling who was at school. Immediately after his surgery, Jake was unable to walk, talk, eat or drink and a tracheostomy tube had been put into Jake's neck to support his breathing and prevent saliva going down 'the wrong way' into his lungs.

Planning Jake's care

All the people looking after Jake attend the multidisciplinary team (MDT) meeting regularly. It is at these meetings that all the various health care professionals have the chance to discuss all the patients receiving treatment and learn about other patients who will have surgery or treatment in the coming weeks. When we discussed Jake's case we confirmed which professionals would need to be involved in his care and began gathering information about him, so we could plan his care and therapies around his individual needs and his family's circumstances.

Getting to know Jake and his family

Once admitted into hospital, all the therapists who would be involved in Jake's care met him and his family to assess his needs, talk about any worries and determine their priorities for his care. Building relationships with children affected by cancer and their families and showing how AHPs work together as a team, is a vital part of our initial role.

Each therapist had their own area of specialist expertise and was keen to assess and understand Jake's needs.

- Sarah, the **physiotherapist** wanted to assess how the neurosurgery had affected Jake's ability to move and his posture. Jake could not sit up or crawl and had become much more dependent on his parents. Sarah also wanted to assess Jake's respiratory (breathing) function and understand how his tracheostomy tube worked.

- Sandjeev, the **occupational therapist** wanted to assess how well Jake could sit up, how much hand function he had and how this affected how he could enjoy playing. Importantly, Sandjeev was also keen to investigate Jake's home situation to help with planning for when Jake was discharged home from hospital. As it turned out, Jake's house was quite small and needed to be adapted to make it accessible for a wheelchair.
- With the tracheostomy tube in his neck, Jake couldn't swallow safely and had to take nutrition through a 'feeding' tube. David, the **dietitian** assessed Jake's size and growth profile, so he could calculate exactly what nutritional support he would need during his treatment. David developed a feeding plan that would help Jake's parents meet his nutritional needs. He worked with Karen and Brian the **therapeutic radiographers** and Jake's parents to make sure it was compatible with the radiotherapy treatment plan and to help ensure he could tolerate it.
- David worked with the **pharmacy team** to ensure Jake's medicine timings were coordinated to help him tolerate his feeding plan. During Jake's treatment, David monitored Jake's progress and adjusted the feeding plan whenever required.
- Andrea – a **speech and language therapist** worked on Jake's communication and swallowing. Jake could not talk or make any sound at all because of the tracheostomy tube. So, Andrea worked with Jake's parents to introduce other ways of communicating – including Makaton signing which reduced Jake's frustration and helped him feel understood. Andrea was also responsible for making sure when the time came that Jake could swallow safely. Her specialist knowledge helped her understand the impact of the tracheostomy tube and how to monitor swallowing safety. Jake missed not being able to actually eat anything and was pleased when Andrea came to check whether it was safe for him by giving him 'tastes' of food.

Whole team liaison

An essential part of AHP working is to work together as a seamless multiprofessional team and liaise with professionals from other disciplines. Here are some examples from Jake's care:

- **Therapeutic radiographers**, Karen and Brian, were responsible for giving Jake his radiotherapy. Sue, the **play therapist** helped them prepare and support Jake and his family before and during the radiotherapy treatments. They showed Jake and his family the machines (linear accelerators) that would deliver the treatments and used play therapy to allay fears and anxiety about being underneath them and lying still. During Jake's course of treatment Karen and Brian made notes about any problems the family were having and followed these up with other members of the team.
- Sue, the **play specialist** and Andrea the **speech and language therapist**, worked together to ensure Jake had plenty of developmental play and fun at the same time as working on his post-operative communication.
- Sarah, the **physiotherapist** and Sandjeev the **occupational therapist** took Jake out of the hospital, with his parents, to build their confidence about managing the tracheostomy outside of the clinical environment and to ensure Jake was comfortable and well supported in his wheelchair.

As Jake prepared to leave hospital once his cancer treatment was complete, **all the therapists** agreed that he would benefit from further rehabilitation to meet his potential. Each therapist wrote a discharge report for their counterparts in the community to ensure Jake and his family could continue his rehabilitation journey and they collaborated to make a **joint referral** to the **specialist neuro-rehabilitation** service.



Got more questions?

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