

Quick Guide:

the role of allied health professionals in supporting people to live well with and beyond cancer

Transforming health, care and wellbeing with allied health professionals



Foreword

In my travels across England I see at first-hand how Allied Health Professionals (AHPs) are leading changes that create equitable and efficient services that improve peoples' lives and wellbeing. Cancer continues to be a priority for the NHS and the individual case studies included in this publication are examples of how AHPs' work supports people through their treatment and care, ensuring that a holistic, multi-professional approach is taken to maximise each individual person's quality of life.

I am therefore delighted to introduce this document 'Quick Guide: the role of allied health professionals in supporting people to live well with and beyond cancer.'

It is nearly two years since [AHPs into Action](#) was launched, in this time we have seen AHPs leading change, transforming care and improving health and wellbeing across the nation.

I hope that this document will inspire AHPs to create opportunities to lead further change, evidence practice development and share outcomes in cancer rehabilitation, treatment and care.

Suzanne Rastrick
Chief Allied Health Professions Officer
NHS England
October 2018

Introduction

In 2015, an independent expert group was commissioned to provide a [strategy](#) to improve outcomes for people affected by cancer in England. More people than ever before are surviving cancer but many need support to live well and enjoy life. The cancer strategy and subsequent transformation work recognise the importance of improving quality of life and patient experience alongside earlier diagnosis and faster treatment. People living with, or after, cancer may experience problems related to the disease or its treatment, in the weeks, months and years following diagnosis. Many of these people will have more than one condition and have care needs that are both complex and ongoing. AHPs have a central role in transforming cancer care and the cancer strategy specifically recommends that the role of AHPs in multi-disciplinary teams is promoted.

About this document

This is one of a series of online resources providing practical advice and case studies to support AHPs into Action.

This quick guide will support health and care staff who share an interest in making faster progress in improving outcomes for people living with or beyond cancer. This includes Cancer Alliances, cancer care teams, primary care teams, provider organisations, commissioners, third sector organisations, education and research institutions, alongside AHPs and the professional bodies that represent them. This quick guide is aligned with ongoing work by NHS England to promote equality and reduce health inequalities.

This quick guide aims to:

1. Support the improvement of care and services for people with cancer.
2. Raise the profile of the role of AHPs in leading the design and delivery of care and support for people affected by cancer.
3. Encourage, support and inspire AHPs to recognise their central role and to lead on this agenda.
4. Share examples of innovative AHP practice in cancer care.
5. Highlight the aspects of strategic transformation that are particularly relevant to AHPs and explain how this links to everyday AHP practice.

About the Allied Health Professions

AHPs are collectively the third largest professional workforce in the NHS, with more than 170,000 AHPs in England. The 14 AHPs are art therapists, drama therapists, music therapists, chiroprodists/podiatrists, dietitians, occupational therapists, operating department practitioners, orthoptists, osteopaths, paramedics, physiotherapists, prosthetists and orthotists, radiographers (diagnostic and therapeutic) and speech and language therapists.

AHPs into Action provides a framework to inform and inspire how AHPs can transform health, care and wellbeing. It sets out key priorities of evaluating, improving and evidencing the impact of AHPs' contribution. It includes a number of case studies that demonstrate how AHPs are transforming care. This quick guide builds on this work; it provides further examples of AHP cancer services and links them to strategic developments in cancer care.

The strategic context

AHPs have a key role in supporting people with cancer to live well. Their work supports many of the strategic aims of the NHS to transform cancer care and to improve quality of life. The personalised treatment and support provided by AHPs has a significant impact on improving the health and wellbeing of a person across the whole pathway from diagnosis, through active treatment, to living with and beyond cancer, and including any palliative and end of life care.

Timely, holistic and personalised care improves quality of life. It also benefits the NHS and wider society by ensuring health and social care resources are used more effectively and by helping people to return to activities that benefit the economy, such as work, education or spending money on holidays and socialising.

With survival rates at a record high, by 2020, everyone diagnosed with cancer will have access to personalised care and support, promoting their health and wellbeing before, during and after cancer treatment. AHPs have an important role in shaping and supporting personalised interventions, commonly known as the 'Recovery Package'. Personalised care and support planning should be provided based on a holistic needs assessment at specific points in a person's cancer pathway, including diagnosis and shortly after treatment. This ensures that a person's individual needs and concerns can be fully addressed at the earliest opportunity. Later, a structured treatment summary provides both the individual and their GP with valuable information and prompts for action, so that health and wellbeing can be optimised in the years after treatment.

Cancer care reviews provide an opportunity in primary care to ensure that an individual's holistic needs are being met and to promote the ongoing management of cancer as a long term condition. Every individual, their family and friends, and all parts of the health and social care system, should know what is available to help them achieve their goals after treatment. Comprehensive health and wellbeing support across health, community and charity sectors will support the move to greater self-management.

The 19 [Cancer Alliances](#) in England are the main vehicles for local service improvement and accountability. Cancer Alliances bring together providers, clinical and managerial leaders from different hospital trusts and other health and social care organisations to plan cancer services for their local population and design care pathways. Alliances also measure outcomes and provide improvement support, as well as engaging with the public. Cancer Alliances and their partners are an extremely important part of cancer transformation as the key decision makers that set the local strategic direction for cancer care. It was recommended in the cancer strategy that Cancer Alliances include AHPs within their work and plans, alongside other key stakeholders.

AHPs' role in supporting people to live well with or after cancer

The Recovery Package interventions ensure that a person's needs are identified, recorded and communicated in a timely way. This will facilitate onward referral to specialist rehabilitation services, often AHP-led, which provide crucial support to prepare people for future treatment, restore functional ability, manage ongoing symptoms and optimise future wellbeing.

This is particularly important for people who have more than one health condition and have complex rehabilitation and care needs as a result. AHPs understand these complex needs and can redesign services around them, creating links between primary and secondary care, across specialties and across health, public health and social care.

By intervening in a timely, proactive way AHPs can optimise health, support people through treatment and minimise the downstream consequences after a cancer diagnosis. They support people to live the life they choose for as long as possible.

Putting this guide into action

This quick guide provides a snapshot of how AHPs are transforming cancer services and enhancing care for patients and carers, improving outcomes, and using resources effectively. It supports AHPs into Action in focusing system leaders' attention on the role of AHPs in supporting people to live well with and beyond cancer.

To support AHPs to transform care and improve services, leaders across the system will need to play a part:

- System leaders in Cancer Alliances, cancer care teams, provider and commissioning organisations, third sector organisations, education and research institutions.
- Regional and organisational AHP leaders.
- AHPs working in cancer care.

System leaders

System leaders working in cancer care should use this guide alongside AHPs into Action to:

1. Ensure explicit consideration of AHPs' contribution and ambition in local cancer care pathways; particularly their contribution to prehabilitation, recovery, rehabilitation and reablement, self-management and care, and return to work.
2. Ensure that AHP leads are involved in key clinical forums.
3. Support AHP services to evidence the quality and cost effectiveness of the care they provide, to support continuing improvement and innovation in service delivery.

AHP leaders and AHPs working in cancer care

1. Become familiar with the components of stratified follow-up and the Recovery Package and understand how these are implemented locally.
2. Find out about your local Cancer Alliance and the communication channels between your service and the Cancer Alliance Board, including representation of AHPs.
3. Find ways to raise awareness of your AHP service and AHP contribution to cancer teams. Opportunities include Trust communications teams, social media, professional bodies and networks, case studies and conferences.
4. Ensure you are able to evaluate and demonstrate the impact your service has on people's lives, experience of care, health inequalities, cancer outcomes and effective use of resources. Being able to demonstrate impact is critical for sustainability of services.
5. Consider how AHPs can move forwards together and the opportunities to work in partnership with AHP colleagues across cancer care pathways.

Case studies that demonstrate the role of AHPs in supporting people with or beyond cancer

Each organisation is responsible for the accuracy of the information shared. NHS England has not validated the published information.

Case Study 1:

Jigsaw: a pre-school developmental group for children hospitalised with cancer

About the service

Children who undergo cancer treatment, especially those who experience long inpatient stays, may have fewer opportunities to engage in the everyday activities that support healthy development.

During cancer treatment, opportunities to go to pre-school groups, school, trips to the park and parties are limited due to infection risks and other complications that come as a result of treatment. This can reduce social and peer interaction and be detrimental to a child's psychological and physical development.

Jigsaw provides play opportunities and therapeutic support for pre-school children undergoing cancer treatment, and for their families. Additionally, Jigsaw acts as a triage opportunity to proactively identify developmental difficulties or therapy needs.

"Jigsaw is such a valuable opportunity to encourage children to play freely during treatment and to help parents to understand that it is ok to hop, run and dance when children are attached to lines and tubes. Our aim is to highlight the importance of children's development and typical childhood experiences within the hospital setting, where developmental care can sometimes be under-prioritised."

Denise Pessoa, Paediatric Occupational Therapist at The Royal Marsden Hospital

How the service works

Jigsaw is a weekly drop-in group for all children under 5 years old who are receiving treatment at The Royal Marsden NHS Foundation Trust. It is run by an occupational therapist, a physiotherapist, a speech and language therapist and an assistant psychologist on a rotational basis. It provides holistic, multidisciplinary advice and support.

Jigsaw is a relaxed group with opportunities for free play with various toys, different shapes and textures, alongside soft play, messy play, singing action songs and music. These activities promote cognitive, motor and communication development, as well as social interaction and family support. Parents are actively encouraged to participate and to share their experiences with staff and each other. When appropriate, parents may use the session time to rest and reflect, and may take themselves away for a while for practical purposes such as eating and showering.

Jigsaw provides a vital opportunity for children to engage in typical play experiences whilst in hospital and highlights the importance of play to parents. Frequently, Jigsaw will be the first time a child is invited to play when attached to intravenous lines, central access

lines, feeding tubes and catheters. The group facilitates play under these circumstances and supports parents to manage lines and drip stands when their children are playing, hopping, climbing on soft play or dancing. This provides a starting point for parents and children to normalise play in the hospital environment.

Impact

In 2017, the team ran 45 sessions and saw 115 children who were either inpatients or attending the day care unit for outpatient treatment.

Following Jigsaw attendance, benefits have been informally reported via letters and comments from staff and families. Parents have reported they feel more confident to take their children to more activities within and out of hospital. They also report being pleased to see their children play again, and have the opportunity to play with others.

“She used to do this sort of stuff and I don’t want her to get out the habit. I see it leads towards school as well as being therapeutic. The soft play encourages her to move and it’s great having other adults engaging her in play.”

Parent

Tips from the team

- Building in flexible staffing helps to cope with variable demand.
- Engaging parents is critical to the success of the group.
- First attenders are usually scared and withdrawn, children need time to understand that the therapy room is a safe environment and the therapists will not do any painful procedures.

Cancer Alliance: Royal Marsden Partners

Organisation: The Royal Marsden NHS Foundation Trust

AHP contact: Maria Denise Pessoa Silva, Paediatric Occupational Therapist
mariadenise.pessoasilva@rmh.nhs.uk

Twitter: @RM_CancerRehab @royalmarsdenNHS

Case Study 2:

Development of a pre-treatment clinic for people with head and neck cancer

About the service

A multidisciplinary team based at Aintree University Hospital NHS Foundation Trust have developed a pre-treatment clinic for head and neck cancer patients prior to surgery. A substantial proportion of head and neck cancer patients are malnourished at diagnosis and likely to lose further weight during treatment. Other problems include swallowing difficulties, reduced jaw opening, respiratory and mental health issues.

The pre-treatment clinic helps support patients with these complex physical and psychosocial issues by offering assessments with specialists including a dietitian, physiotherapist, speech and language therapist, cancer nurse specialist and an emotional support therapist.

Prior to this service development, patients were not seen by an AHP until after their cancer surgery.

“The pre-treatment multidisciplinary clinic offers an outstanding opportunity for patients and AHPs to explore physical, functional, psychosocial, and behavioural aspects of proposed patient treatment. Patients have the opportunity to develop greater understanding of their treatment and planned rehabilitation all within a highly condensed pre-treatment phase of head and neck cancer care. The clinical interventions made by the multidisciplinary AHP team aid in the optimisation of patients prior to surgery in a variety of ways achievable only with the ‘joined-up’ approach of a combined multidisciplinary team clinic.”

Mr Andrew Schache, Honorary Consultant in Oral and Maxillofacial Surgery

How the service works

A comprehensive baseline assessment is completed for each patient prior to surgery. This enables timely and appropriate patient-centred interventions to be put in place, such as correction of nutritional deficits pre-operatively, assessment of swallow function and assessment of physical status and exercise tolerance. Proactively addressing these factors reduces the potential for further complications and delays to care which can cause discomfort and anxiety.

Patients also receive holistic needs assessments and are supported to improve their own wellbeing using the trust-wide Making Every Contact Count approach. This supports people to make positive lifestyle changes that will benefit their health, for example increasing physical activity or stopping smoking.

Impact

A comprehensive evaluation is planned, but early pilot data suggests that pre-treatment interventions can reduce the length of hospital stay. A substantial reduction in total bed days for head and neck cancer patients has been noted since the service began.

Feedback indicates that patients value seeing the same AHPs throughout their cancer journey and that they have increased confidence and reduced anxiety during their treatment and recovery. Patients have a better understanding of their post-operative journey and consistently report an improved quality of life.

"I found the process very helpful and reassuring. My wife was with me and remarked on how slick and joined up each member of the team were. I found it useful and felt well informed and much more relaxed about the treatment ahead. All of the processes and descriptions of how things were going to be were accurate. I didn't feel as anxious about surgery following the clinic and I've never had an operation before. My wife and I thought the team were remarkable and all our faith was placed in them. We also found the emotional intelligence of all the professions involved outstanding."

Patient

Tips from the team

- Making the case for increased administrative support has facilitated the smooth running of the clinic.
- Effective communication about this new service was critical to its success and some creative methods were needed. For example, providing laminated forms with pre-treatment criteria prompted consultants to make referrals into the clinic.
- Regular review and patient engagement has informed service development.
- Developing a database of all patients seen informs all professions of interventions/assessments done in pre-treatment clinic.

Cancer Alliance: Cheshire and Merseyside Cancer Alliance

Organisation: Aintree University Hospital NHS Foundation Trust

AHP contacts:

Ruth Price, Specialist Head and Neck Physiotherapist ruth.price@aintree.nhs.uk

Rachel Skelly, Advanced Head and Neck Dietitian rachel.skelly@aintree.nhs.uk

Lisa Houghton, Principal Speech and Language Therapist lisa.houghton@aintree.nhs.uk

Twitter: @AintreeHospital

Case Study 3:

Reduced hospital admission following speech and language therapy input

About the service

At Leeds Teaching Hospitals NHS Trust, the speech and language therapy team provide support for people with head and neck cancer from diagnosis to completion of acute treatment.

An increase in service demand, led the team to redesign their approach and to create a more resource-efficient service. An evidence-based model to predict the risk of swallowing difficulties throughout treatment was implemented. This is called a risk stratification model and it enables patients to be grouped according to the level of clinical need and risk.

“The risk stratification model allows our team to ensure the right patients are seen at the right time during their treatment which has optimised our efficiency and streamlined our workload. Taking a proactive, education approach has ensured our patients understand the role and know how to access our service promptly. This has helped to ensure early identification and management of swallowing problems.”

Sally Scudamore, Speech and Language Therapy Lead in Radiation Oncology

How the service works

This new service identifies high, medium and low risk patients in a timely manner which enables resources to be allocated accordingly.

Resources have been developed to provide education and support for patients to manage their symptoms, including swallow education and exercise interventions. Proactive, self-surveillance of swallowing difficulties and aspiration, a common and potentially serious complication in this population, has also been promoted.

Impact

The new approach has enabled the team to manage the substantial increase in service demand. It also has the potential to reduce unwarranted variation by using a consistent, transparent and equitable approach.

Evaluation is ongoing but early findings include a 22% reduction in unplanned hospital admissions for patients undergoing chemotherapy and/or radiotherapy and a 28% reduction in length of hospital stay. In addition, feedback from patients and carers has been extremely positive.

"It's all been seamless, from the diagnosis to the planning meeting to the commencement of treatment all through, and everything just happened...I'm getting appointments before I've had the previous one so I know when the next one will be, there's no uncertainty...you're not in that period of wondering what's happening, what's the next stage and I think that's huge because you don't know what's happening with your body...to put it bluntly, you don't know whether you're going to live or die...you are living with so much uncertainty.... but knowing there's a path that's there and it's structured...is fantastic because it's a very scary time."

Patient

Tips from the team

- Prioritise team resilience and well-being to enable staff to deliver the best care they can.
 - Administration support is essential to reduce administrative burden on clinicians.
-

Cancer Alliance: West Yorkshire Cancer Alliance

Organisation: Leeds Teaching Hospitals NHS Trust

AHP contact: Emma Taylor, Macmillan Clinical Manager, Speech and Language Therapy Cancer Team emma.taylor61@nhs.net

Twitter: @lthTrust @ltht_slt

Case Study 4:

Advanced practitioner diagnostic radiographers perform procedure that reduces waiting times and improves patient experience

About the service

In this workforce development project, two advanced practitioner diagnostic radiographers, with an interest in gastro-intestinal imaging, were trained to perform ultrasound-guided drain insertion for ascites, an abnormal build of fluid in the abdomen. This procedure can provide relief from the discomfort associated with a distended abdomen, improve mobility, reduce shortness of breath, reduce fatigue and improve bowel function.

A procedure historically only performed by radiologists can now be performed by the advanced practice radiographers as the result of the implementation of a local training package in 2016, led by consultant radiologists. Since then, over 100 ultrasound guided ascites drains have been performed by the radiographers.

"Our advanced practitioner radiographers perform, on average three to four paracentesis a week, mostly cancer patients, this equates to 200 patients a year (return of investment within three months). Their service is invaluable it takes pressure of hospital bed requirement especially with good use of the Radiology Day Case Unit. This model should be duplicated across other Trusts."

Dr. Biju Thomas, Consultant Radiologist and Deputy Clinical Director for Imaging

Impact

This service improvement has reduced the burden on radiologist colleagues and reduced patient waiting times. Audit data demonstrates a reduction in average waiting times for this procedure from six days to two days.

"The nurses were so kind, caring and reassuring throughout this scary experience. The advanced practitioner radiographer was brilliant and made me feel so calm; I have been in very good hands."

Patient

Tips from the team

- Build a strong case for AHP expansion of practice. Strengthen this case with the relevant clinical and managerial support, with the patient at the forefront of the service improvement.
 - Ensure a robust approach, involve patients at the start, consider training requirements and gain support from the relevant governance groups at both directorate and trust level.
 - Continually monitor the service through audit and patient feedback and act upon the results.
-

Cancer Alliance: West Midlands Cancer Alliance

Organisation: University Hospitals of North Midlands NHS Trust

AHP contact: Carl Bradbury, Advanced Practitioner Radiographer
carl.bradbury@uhnm.nhs.uk

Twitter: @UHNM_NHS

Case Study 5:

Multidisciplinary rehabilitation service for breast, prostate and colorectal patients provides evidence-based, holistic and personalised care

About the service

A co-production approach was used to bring together commissioners, providers, patients and charities in order to design Macmillan Next Steps Cancer Rehabilitation (MNSCR) to redress gaps in Gloucestershire cancer care. Traditionally, the diagnosis and treatment of cancer was the dominant focus, with less attention placed on aftercare, healthy lifestyles, prevention and rehabilitation. A robust model of care was developed which demonstrates commitment by all involved to create a cultural shift towards integrated, restorative and preventative cancer rehabilitation and support.

"Involving patients centrally in the design of this service has enabled us to create a flexible service that really meets people's needs. No two patients have the same experience of cancer and our service can provide personalised care that addresses all their concerns."

Clare Lait, Macmillan Specialist Cancer Physiotherapist, Gloucestershire Care Services NHS Trust

How the service works

As part of the recovery package, this specialist service offers holistic, personalised rehabilitation following a breast, prostate or colorectal cancer diagnosis. The team is led by a consultant radiographer and clinical team members include specialist physiotherapists, a specialist dietitian, health trainers, an exercise professional and a therapy assistant.

A three-step model blends the clinical skills of AHPs with the behaviour change/coaching skills of healthy lifestyle specialists and volunteers.

Step one: Recovery - Using one-to-one clinics MNSCR clarify and address patients' main concerns and recovery needs, reducing the potential consequences of treatment by addressing physical, psychological, spiritual or practical areas of concern in a proactive manner.

Step two: Prevention - A suite of interactive programmes and workshops are offered, including positive psychology programmes, and health and wellbeing workshops. These allow groups to work together to make positive changes to improve physical activity, diet, sleep and stress. The service also supports carers and healthcare professionals through "mindful compassion" courses.

Step three: Maintenance – Patients are supported to maintain positive changes through delivery of innovative group programmes such as ballet, mindfulness and Nordic walking. Maintenance programmes make use of digital technology and collaborate with community partners.

Impact

In the last two years, MNSCR has supported over 750 patients and their families through the programme, and trained over 4000 health and social care professionals. The team routinely measure a range of clinical outcome measures, including measures of fatigue, fitness, strength, grip strength, waist circumference, weight and confidence. They measure nutritional status and eating behaviours and patient activation is also assessed and monitored. These are all measured at baseline, at the end of programme and 12 weeks later, and show sustained change. The team report that initial evaluation shows positive changes in strength, cardiovascular fitness and patient activation measures. This is being further evaluated by the University of Gloucestershire.

"I welcome this opportunity to tell you about the fantastic support and outstanding service I have had from Macmillan Next Steps. Put simply they have given me my life back. I am now fitter, healthier both physically and importantly mentally than I think I have ever been."

Patient

Tips from the Team

- Ensure that there is involvement from patient representatives in all aspects of the service.
- Never assume that someone has 'done it before'.
- Be prepared to think outside the box and in an innovative manner.
- Be open to criticism and ways to learn but be prepared to challenge 'old ways' of practising.
- Be open and honest at all times.

Cancer Alliance: Somerset, Wiltshire, Avon and Gloucestershire (SWAG) Cancer Alliance

Organisation: Gloucester Care Services NHS Trust

AHP contact: Communications team gcscomms@glos-care.nhs.uk

Clare Lait, Macmillan Specialist Cancer Physiotherapist clare.lait@glos-care.nhs.uk

Jo Pain, Macmillan Specialist Cancer Dietitian jo.pain@glos-care.nhs.uk

Nikola Hawkins, Consultant Cancer AHP nikola.hawkins@glos-care.nhs.uk

Twitter: @ClareLaitPhysio @jypain82 @Glos_careNHS @gloshospitals @macmillancancer

Case Study 6:

Advanced practice radiographers lead innovative clinic to address consequences of cancer treatment

About the service

When cancer treatment finishes some people may continue life with few or no health problems, but for others there will be ongoing physical and emotional challenges that they experience every day for the rest of their lives. We are curing more patients with cancer and need to follow them up long enough to identify long-term effects. When these problems develop a patient is likely to be referred by the GP to someone who may not have the specialist knowledge of how to manage them. This has been the frustrating experience of many people when trying to get help for cancer treatment-induced consequences.

The service at Nottingham University Hospitals NHS Trust provides specialist care for cancer patients who experience ongoing, adverse effects from their cancer or its treatment. Any patient can be seen regardless of tumour site, as long as they are at least six-months post-treatment. Initially funded by Macmillan Cancer Support, the team made a case for funding to be continued and a local funding agreement is now in place.

How the service works

The service is run by two advanced practice therapeutic radiographers and a supervising oncology consultant. They provide specialist advice and management techniques across a range of areas including bowel and bladder training, pain management, fatigue management, simple lymphatic drainage massage and interventions to support sexual dysfunction. The radiographers developed their skills before starting the service through an education package.

New pathways into a variety of pre-existing services have been developed for patients who need higher levels of input; these include pain acceptance clinic, dental clinics and orthotics service. The majority of patients at the consequences of cancer treatment clinic have problems related to radiotherapy; advanced practice radiographers have an in-depth knowledge of radiotherapy and its potential impact.

"This project has completely changed our current practice. These silent, long-suffering patients that attend clinic with heart-wrenching stories gave us the motivation and determination to provide this unique service."

Liz Stones, Advanced Practice Radiographer

The service forms part of the recovery package and integrates national initiatives, for example, all patients complete a holistic needs assessment with a radiographer. The aim is to provide a personalised, holistic and cost-efficient service and the team believe that this service model could be easily adopted in other areas.

Impact

Reported outcomes include an improvement in psychological wellbeing demonstrated by a reduction in distress thermometer scores. Measured outcomes show that 75% of patients were managed with advice from within the clinic with additional information or referral to an AHP service (such as physiotherapy or the pain acceptance clinic). Only 25% of patients required referral to medical teams for ongoing investigations and formal review in medical clinics, thus reducing the burden on medical pathways that were historically the next step for these patients.

Patients who have been through the clinic have reported improvements in quality of life. The team also report positive feedback from patients, carers and relatives.

"Gave me hope that the ever-current problem may be able to be controlled."

Patient

Tips from the team

- Look at other services when designing your own. To date, seven cancer centres have visited with a view to adopting this service model.
- GP's receive an in-depth letter explaining the clinic discussion and outcomes along with a description of what the service is to help inform the primary care community about the consequences of treatment clinic.

Cancer Alliance: East Midlands Cancer Alliance

Organisation: Nottingham University Hospitals NHS Trust

AHP contact: Emma Hallam, Macmillan Radiotherapy Information and Support
Radiographer emma.hallam@nuh.nhs.uk

Twitter: @teamnuh @teamcas @nottsmacmillan

Case Study 7: “One-stop” multidisciplinary clinic for patients with painful bone metastases

About the service

The Rapid Access Multidisciplinary Palliative Assessment and RadioTherapy (RAMPART) clinic at University Hospital Southampton NHS Foundation Trust offers patients with painful bone metastases rapid access to palliative radiotherapy and multidisciplinary input. Using a ‘one-stop’ clinic format, the RAMPART clinic was initially set up using a Health Foundation grant because patients with cancer-induced bone pain often waited weeks to receive palliative radiotherapy treatment and to have an assessment by specialist palliative care and AHPs. During this time, patients continued to experience psychological distress and potentially debilitating physical symptoms.

A clear need for input from rehabilitation professionals was identified through 10 interviews with patients and a literature review. Patients with metastatic disease often did not see AHPs until the final few months of life, but there was significant potential for earlier and preventive rehabilitation interventions with a focus on improving quality of life within this patient group.

“It has been fantastic to see the impact of the RAMPART clinic. It is a clear illustration of how multidisciplinary assessment is more than the sum of its parts. We have not only been able to improve timely access to better pain control for our patients but through the holistic needs assessment and AHP intervention we have been able to address their wider concerns and needs. The patient and carer feedback speak for themselves and the shared learning and education benefit of the clinic is also a powerful resource.”

Dr Paul Fenton, Consultant Clinical Oncologist

The RAMPART Clinic project is part of the Health Foundation’s Innovating for Improvement programme. The AHP aspects of the project were also supported by Macmillan Cancer Support.

How the service works

Occupational therapy and dietetics input was implemented into the clinic from April 2017, with support from the Health Foundation and Macmillan Cancer Support. Patients are seen concurrently by a multidisciplinary team including a therapeutic radiographer, an occupational therapist, a dietitian, a clinical oncologist and a palliative medicine consultant. Patients then have their radiotherapy planning scans and if they require further AHP input, they will be seen later in the day whilst waiting for radiotherapy treatment.

Patients have a single fraction of palliative radiotherapy treatment at the end of the clinic day. The AHPs in the clinic work with individuals to complete a holistic needs assessment and develop a care plan. The personalised approach enables a holistic and patient-centred management approach. The AHP intervention involves:

- Assessment of impact of pain and other symptoms on function and daily life.
- Self-management support education that may include management of breathlessness, fatigue, pain, taste/appetite changes and weight loss and the promotion of physical activity.
- Provision of equipment or high calorie supplements.
- Signposting to other relevant services and sources of support.

At the end of the clinic day, patients are given a letter outlining the recommendations from all healthcare professionals which facilitates self-management. After one month, patients are given a follow-up phone call to collect outcome measures and ascertain whether they have any further needs.

Impact

Evaluation data has demonstrated that 77% of patients who attend the clinic have occupational therapy and/or dietetic needs. The most frequent patient concerns are pain (72%), fatigue (55%), changes in appetite/weight (40%) and breathing difficulties (31%). The most commonly identified patient concerns benefit from rehabilitative and self-management input.

Referral times to the RAMPART clinic are substantially less than those for the standard radiotherapy pathway. Other reported outcomes include a reduction in patients' global concern scores. All patients were 'very satisfied' (82%) or 'satisfied' (18%) with their experiences of the clinic. Reported qualitative feedback suggests patients feel informed, more confident and value the comprehensive nature of the assessment.

"If there was an option for 'over the moon' I would have ticked that box. I would have liked this five years ago when I was diagnosed. All the information was helpful and the people were nice. It was a clear pathway and I was given options. The opportunity to sit in front of five experts was good. The occupational therapy and dietetics information was good. It was very helpful being sent up to see Macmillan – there is a lot there which might help me get through treatment."

Patient

Tips from the team

- Focus interventions on patients' needs and concerns and supporting patients to actively self-manage their condition.
- Pathway redesign is a powerful tool to improve cancer patient experience; AHPs have great insight and should be central in this process.

- Collect both qualitative and quantitative data (before and after implementation) to evidence the need for and added value of AHPs working with people living with and beyond cancer. Macmillan's patient concerns checklists are a useful way of evidencing the need for AHPs.
-

Cancer Alliance: Wessex Cancer Alliance

Organisation: University Hospital Southampton NHS Foundation Trust

AHP contact: Dr Charlotte Brooks, Macmillan AHP cancer rehabilitation lead and teaching fellow, charlotte.brooks@uhs.nhs.uk

Lynsey Clode, Lead oncology dietitian, lynsey.clode@uhs.nhs.uk

Inga Driver, Advance practice therapeutic radiographer, inga.driver@uhs.nhs.uk

Twitter: @UHS_Therapy @UHSFT @LottyBrooks @drandrewjenks @CarolUHS

Case Study 8:

Transforming ambulance care for people living with cancer and those who have palliative or end of life needs

About the service

South Western Ambulance Service NHS Foundation Trust (SWASFT) covers an area of 10,000 square miles, with more than 5.3m residents and over 17.5m visitors. It has 96 ambulance stations and 3 control rooms. Collaborative work was undertaken to promote best practice in cancer palliative and end of life care when patients access urgent and emergency care via 999.

How the service works

This was a joint project between SWASFT and Macmillan Cancer Support. A team comprising a specialist paramedic and three specialist nurses undertook a comprehensive review of the urgent and emergency care needs of patients living with cancer, especially those in the palliative and end of life phases. A review of current services resulted in a programme of workforce development and a number of service and system improvements that have enabled frontline ambulance clinicians to better meet the needs of patients.

“What paramedics within SWASFT now have are options, they know who to phone, they know what their resources are in hours and during the out-of-hours and urgent periods.....they didn’t know that they had access to these things before. It doesn’t mean that we don’t take patients to the emergency department, it means that when appropriate we can we can treat people at home, or facilitate a referral to a more appropriate health setting”

Lynn Dunne, Nurse and Cancer Care Facilitator

Impact

In 2017, the SWASFT team saw approximately 103,000 patients living with cancer or with palliative or end of life care needs. All clinicians within the organisation now have access to revised guidance that includes:

1. scope of practice information;
2. specialist directories which include direct referral options and specialist guidance;
3. additional medicines protocols; and
4. guidance on best practice.

Over 1300 ambulance service staff received training to support the management of palliative and end of life cancer patients. All clinicians will now receive some education during their annual mandatory development day. External stakeholders have also had opportunities for education. Outcomes include:

- a workforce that is equipped with the skills and confidence to meet the care needs of palliative and end of life cancer patients;
- prompt conveyance and access to specialist advice and pathways when indicated;
- reduced inappropriate conveyance to emergency departments; and
- improved triage and response to this patient group ensuring our finite resources are used appropriately.

Feedback from patients and carers has been positive.

"I would like to thank the specialist paramedic for his assistance and support, not only to my father but to myself and my husband. We called for assistance as my father was struggling to breathe after undergoing radiotherapy on cancer cells in his nose. Within minutes of calling, an ambulance arrived and examined my father thoroughly. The paramedic was very understanding and soon reassured my father that he wasn't in any danger and suggested various ways to alleviate the breathing problem. The paramedic took time to explain the effects of the radiotherapy treatment not only to my father but to me as well."

Family member

Tips from the team

- Collaborate early and widely, link in with specialists and map local services and support.
- Introduce a feedback system to encourage stakeholders to share issues and opportunities for improvement and to share great practice. Collate and use this feedback to influence quality improvement.
- Understand the information and data needed to evidence outcomes.

Cancer Alliances: Peninsula Cancer Alliance, Wessex Cancer Alliance and Somerset, Wiltshire, Avon and Gloucestershire Cancer Alliance

Organisation: South Western Ambulance Service NHS Foundation Trust

AHP contact: Joanne Stonehouse, Macmillan Cancer Care Project Manager joanne.stonehouse@swast.nhs.uk

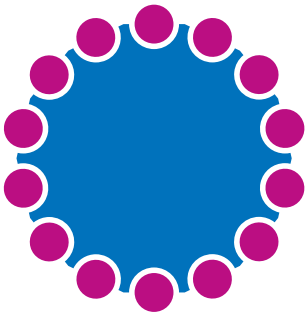
Twitter: @swasFTCCT

Acknowledgements

We would like to thank all the AHPs who shared information about their services.

This information can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request.

Please contact 0300 311 22 33 or email england.contactus@nhs.net.



This document is owned by the Allied Health Professions team (Medical Directorate). It has been produced in collaboration with the National Cancer Programme Team (Information and Operations Directorate).

Publications Gateway Reference 08425

First Published - 15 October 2018
Version 1.0

