Support Workers

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Introduction

Macmillan Workforce Engagement Advisor Jacqueline Goodchild on how support workers can help improve care for people with cancer.

The Macmillan support worker role was introduced in 2012, as part of a two-year project to pilot four new roles with 15 organisations across the UK. These roles were a complex case manager, a primary care nurse, a community care nurse and a support worker, all working together to give people with cancer One-to-One, tailored support.

The roles themselves were not new, but the pilots meant that, for the first time in cancer care, these roles could be tested and evaluated for their cost effectiveness and impact on patient experience and outcomes.

In recent years, there has been an increasing recognition of the different needs that people have following cancer treatment.

While we know that follow-up care often fails to address all these needs, Macmillan support workers are really starting to make a difference in this area.

The original specification for the support worker role within cancer care was to provide coordination of care to people identified as non-complex, who can be enabled and supported to self-manage their own care.

A 2014 evaluation report showed that in most of the pilot sites, the support worker roles were well received. The evidence suggested that support workers were helping cancer nurse specialists and other health professionals to manage a bigger caseload by taking on some of the less clinical and specialist areas of work, as well as offering people a single point of contact and continuity.

These roles evolved well at each site, working effectively in a range of different ways, such as:

- Supporting people with a cancer diagnosis after treatment – providing emotional and practical support as a first point of contact to help people navigate the health and social care system, and signposting to existing community support.
- Personalising care – identifying and addressing unmet individual needs through holistic needs assessments, helping people to take control of their own care.
- Implementing the recovery package and redesign of follow up procedures – creating capacity to implement elements of the Recovery Package and base aftercare on individual needs.
- Optimising resources – dealing with non-complex tasks to allow registered practitioners to dedicate more time to people that require their specific skills and expertise.

Adapting to meet local needs

Over the past three years, Macmillan has been working with partners to establish more support workers in hospital settings and to explore creating a new similar role in communities. By doing this, we want to continue improving care for people with cancer and alleviating some of the pressure on clinical specialists.

It has become clear that the support worker role can be adapted to address the specific needs of local populations.
Highlighting impact
However, an ongoing challenge for sites has been effectively influencing commissioners to pick up and support these roles in the future. This means that evaluating the impact of current support workers remains key to maintaining services and roles, and replicating success elsewhere in the country.

This edition of Sharing Good Practice showcases some of the fantastic work going on across the UK, highlighting best practice and the impact that support workers are having for people affected by cancer.

If you think your service could benefit from introducing a support worker role, our service development teams will be happy to share their expertise.

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Support workers

Building the support worker service in Bristol

Macmillan cancer support workers Gemma Wham and Racheal Williams on developing new ways of working to meet patient needs.

We were appointed as Macmillan cancer support workers at University Hospitals Bristol in October 2012 as part of the national Macmillan One to One Support Pilot. It was an exciting but on occasions difficult time, and continuation of funding was uncertain as we approached the end of our fixed-term funding from Macmillan.

During the first year, we spent time researching, contacting and meeting local and regional services that were imperative to the success of the support that we provided for people with cancer.

It was also important to develop new ways of working to meet the needs of patients. Some examples are:

- Setting up an e-referral system so that clinical nurse specialists (CNS) from all cancer sites can refer patients for one to one support.
- Establishing and organising health and wellbeing events and ‘next steps’ clinics (Next Steps) – now a rolling programme, every 8-12 weeks, with approximately 80 attendees.
- Working with CNS teams to collate patient information and establish holistic needs assessment clinics, supporting teams to identify patients and share care plans with us so that we can signpost to helpful information or services.

We work with all clinical teams within the hospital, and receive referrals from different members of the multidisciplinary teams, including consultants, cancer nurse specialists and allied health professionals. We also receive external referrals from Penny Brohn UK, Link Age and local benefits advice teams, and have seen an increase in self-referrals.

All contact with our service is recorded on hospital databases to allow referrers to access up-to-date information about how we are supporting patients.

Out in the community

As we are based in an acute setting, we play a pivotal role in helping people with cancer transition from hospital back home, and our relationships with the community continue to be very valuable.

We signpost to and liaise with local and regional charities and services to enable efficient care coordination for people affected by cancer. Some of the main services that we refer patients to for support include Age UK, British Red Cross and other Macmillan teams for benefits advice and practical or emotional support.

We have put together a working service directory, which offers a point of reference both for support workers and for other colleagues.

Recently, we have been given the opportunity to provide an outreach clinic at Penny Brohn’s National Centre in Bristol. We attend their treatment support clinic once a month to offer information and advice on non-clinical needs. This has meant we can support more people that may not have had access to us, and feedback from both staff and patients has been extremely positive.
Gemma (right) and Racheal liaise with many different members of the multidisciplinary teams.
Developing the role further
The support worker role is ever-changing to adapt to the needs of people we support. Over the past five years there have been many changes, including open access to the service, generic health and wellbeing events and an e-referral system.

An exciting opportunity has been offered to the trust to improve the quality of life and patient experience of people living with and beyond cancer in Bristol, North Somerset and South Gloucestershire. NHS England Cancer Transformation Fund money has been allocated to SWAG (Somerset, Wiltshire, Avon and Gloucestershire) Cancer Alliance to fund four new support workers over two years.

The support workers will focus on rolling out the delivery of holistic needs assessments from diagnosis and after treatment, delivering health and wellbeing events, and providing patient support and coordination across shared pathways in site specific teams including lung, gynaecological and colorectal cancers.

Macmillan has been extremely supportive of these roles, not only professionally but by aiding personal growth. Free courses and training opportunities include the Cancer Support Certificate, mandatory Macmillan events and Evidence Work Based Learning (EWBL) modules provided through our local university at degree and masters level.

In addition, Macmillan has provided funding towards Gemma's Masters in Health Psychology and she hopes to graduate next year.

Networking has also played a fundamental part in developing the support worker role.

Having attended many conferences, we have always come away truly inspired and enthused to be working for Macmillan.

We feel very privileged to be a part of a workforce that strives towards improved patient care and endeavours to give the best support to our patients. We look forward to the continued development of this role.

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Creating a community of practice

Support workers in Wessex are coming together to share knowledge.

In the Wessex region, Southampton was part of the Macmillan One-to-One Support Pilot with one of the original Macmillan cancer support workers employed at University Hospitals Southampton.

Following the national success of this role, more cancer support workers have been introduced to cancer teams. Locally we have piloted the draft Macmillan competency framework, which describes the knowledge, skills and performance required by cancer support workers to be effective in their role. This has been designed for use by all support workers working within cancer teams.

The framework aims to create a standardised approach to performance that is clear and accessible to the cancer support worker and other members of the cancer workforce. This is particularly important when a new role is introduced in many different cancer teams.

There are now more than 20 cancer support workers, predominantly Macmillan badged, employed across the seven Wessex NHS Trusts, and numbers are increasing as new support workers are recruited to support local NHS transformation plans.

Support workers in Dorset

In Dorset, Macmillan cancer support workers were first introduced in spring 2017.

Working with the partnership quality lead for Dorset and the lead cancer nurses for the three Dorset NHS Trusts, we are using the draft competency framework to support the development of our Macmillan cancer support workers.

As part of our Macmillan’s South West workforce strategy we have mapped Macmillan learning and development opportunities against the competency framework, including face-to-face courses, Learn Zone e-learning courses, booklets and website information, as well as local development opportunities such as shadowing.

Selecting the most appropriate learning and development opportunity for an individual cancer support worker forms part of the development discussion with their manager, recognising that support workers are recruited from a variety of backgrounds and have different development needs – one size does not fit all.

Creating a community of practice

The lead cancer nurses from the three Dorset Trusts have worked together with the local Macmillan team to create a ‘community of practice’, where cancer support workers can support each other to achieve the competency levels. Community of practice is a term originally developed by Lave and Wenger (1991). It describes a group of people who do similar work and meet at regular intervals, usually for at least a day, to share ideas, learn together and identify opportunities to collaborate in order to do things quicker, better or more cost-effectively.
The forum is open to all cancer support workers across Wessex. This means that newer support workers can meet with those who are more experienced. The purpose of developing a community of practice was to provide a safe space for cancer support workers to:

- share and exchange information, knowledge and experiences
- share successes, top tips and examples of best practice in their organisation
- ask questions without judgement
- support each other to overcome any challenges.

Three community of practice events have taken place since October 2017, with two more planned in July and October 2018.

The regional Macmillan learning and development team has co-ordinated and facilitated the events with the Wessex partnership quality leads, in addition to providing funding for the venue as well as administrative support.

External speakers have been invited to talk about relevant topics, best practice and top tips, and have also led collaborative problem-solving sessions. Key topics discussed during the three events include:

- defining the support worker role and managing expectations
- learning and development opportunities linked to support worker competencies
- role of the support worker in implementing the Recovery Package
- implementing holistic needs assessments
- documentation of care plans – sharing best practice
- health and wellbeing events – sharing of good practice
- role of the Macmillan Engagement Lead
- support and self-help groups.

The support workers have brought great energy and enthusiasm, and have started to develop their own relationships in between events. They value the opportunity to connect with their peers to share and learn. One support worker who attended an event said: ‘It’s really useful to meet other support workers and realise we all face similar challenges.’ Another said, ‘We are all doing things slightly differently but can still support each other.’ Members of the community share any knowledge gained from the group with their local cancer teams. Time is often saved by sharing resources and information and new learning is translated into refinement of working practices.

**Next steps**

We are hoping to agree the competency framework and associated development opportunities for cancer support workers in Wessex with the cancer nurse leads and the Cancer Alliance team before the next community of practice.

We also hope to identify any gaps in the current learning and development offer to support these competencies, with suggestions as to how they might be filled.

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Evaluating the support worker role in neuro-oncology

Patients and staff report positive impact of a new care coordinator role in Hull.

A new neuro-oncology care coordinator (NOCC) role was introduced to the neuro-oncology clinical nurse specialist (CNS) team, based across Castle Hill Hospital and Hull Royal Infirmary, in June 2016.

The role has been funded by Macmillan for the first two years, and was introduced as part of the wider Macmillan Brain Tumour and Central Nervous System Cancer Service Improvement Programme. This is part of Macmillan’s national Redesigning the System programme, which works with organisations to make large-scale changes that ensure people affected by cancer are receiving the best possible support.

The programme team worked with the neuro-oncology CNS team to develop a competency framework for the role. Patients and carers were also involved in developing the job description and were represented on the interview panel. The main tasks for the NOCC include:

- responding to patient and carer calls and e-mails and triaging as necessary
- making and changing appointments
- chasing up MRI reports
- making referrals, for example to community teams, benefits advice, welfare rights
- updating the internal system for patient information
- checking that scans for the following month have been booked
- making sure patients have a management plan following an MRI
- general admin

The NOCC has also been supporting specialist nurses in migrating patient information across to a new system, as well as supporting an audit of MRI scans.

Measuring impact

Prior to introducing the NOCC role, the Cancer Service Improvement Programme evaluation team conducted a patient survey to measure patient experience of a variety of areas that we expected the NOCC role to positively impact. We received 30 responses.

Once the NOCC had been in post for just under a year, we conducted a second survey of patients and carers, with 58 responses.

The initial survey was designed to measure the extent that patients had experienced difficulties in receiving the care and support they needed across a range of factors. These included:

- having queries answered about non-medical issues
- getting information about their condition when needed
- booking appointments
- finding out when appointments or scans will be
- having queries answered about medical issues
- talking to somebody at the hospital about emotional or non-medical concerns
- getting information about where to find help and support
- finding out scan results
- arranging for other services required after treatment
- filling in paperwork
The findings from the second survey showed that most respondents had not experienced difficulties accessing the support they needed. All respondents reported that they were either extremely satisfied (81%) or satisfied (19%) with the time it took to receive a response from telephone enquiries. And 98% of respondents reported they felt their needs were met when they contacted the neuro-oncology team.

Survey respondents were also asked about their experience of contact with the NOCC. Themes that were consistently reported were:

- high quality of help and support provided and a willingness to help
- patients and carers valued knowing that there was someone there if they needed them
- ease of accessing information and advice
- positive impact of practical help provided to relieve a burden or ease anxiety.

Since the NOCC has been in post, the CNS team has participated in focus groups and one-to-one consultations to help understand how the role has impacted on the team. Almost all the activities carried out by the NOCC would previously have been done by specialist nurses. This has resulted in significant time savings for the CNS team, who can focus on patients who require their specialist skills and spend more time on the wards.

Having the NOCC role in place makes it easier to manage and cope during times of CNS staff absence, leading to a more resilient team.

Feedback from the NOCC post-holder showed that they have found the role hugely satisfying and rewarding. They believe that they are making a positive difference to patients, carers and CNS colleagues.

The NOCC also reported that patients are now getting an enhanced service, where complex or clinical enquiries are more quickly and effectively triaged to the appropriate health professional, while lower level queries and problems are dealt with immediately by the NOCC.

The NOCC has more time to check in with patients and carers, meaning that emotional and psychological support needs are more likely to be identified and addressed. The NOCC reported that direct patient contact is the most enjoyable and rewarding aspect of the role.

Evaluating the impact of support roles is key to securing further funding. This work contributes to that effort by highlighting the impact of the NOCC role for patients, carers and professional colleagues.

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An adaptable role that must be clearly defined

Lead Cancer Nurse Karen Henry on developing cancer care coordinator roles in Leeds.

Leeds Cancer Centre is one of the largest in the UK. Over the past few years, we have been introducing more support worker roles, which we call cancer care coordinators, into our multi-disciplinary teams for specific cancers. This has resulted in many positive outcomes for both staff and patients.

The first cancer care coordinator was recruited to the gynaecological cancer team, and the success that role had in a short space of time led to applications for support worker roles within other teams, initially including lung, urology, lower gastrointestinal and upper gastrointestinal cancers.

The roles are very adaptable to different teams, fitting in with the type of work required. Support workers can take on jobs that cancer specialist nurses (CNS) were doing, which did not need to be undertaken by a trained nurse, to free up some of their time. They are also undertaking tasks that were previously not being done at all, improving the experience of care for people with cancer.

For example, within the gynaecological cancer team, we knew that women with low-risk endometrial cancer were often not supported by a CNS. The cancer care coordinator in that team took on this role, following clear guidelines, offering sensible and empathetic support and signposting to further help where needed. She now has her own case load of women with low-risk endometrial cancer, escalating cases to a clinical nurse specialist where appropriate.

COORDINATORS CAN HAVE A REAL IMPACT AS THEY DEVELOP NEW SKILLS AND SPECIALIST KNOWLEDGE. FOR EXAMPLE, IN THE UROLOGY TEAM, CANCER CARE COORDINATORS ARE NOW REMOVING PEOPLE’S CATHETERS POST-SURGERY. THIS IS SOMETHING THAT DOES NOT REQUIRE A BAND 6 NURSE, AND HAVING A COORDINATOR DO THE PROCEDURE ALSO ENSURES CONTINUITY FOR THE PATIENT, AS IT IS CARRIED OUT BY THE SAME PERSON WHO WILL SEE THEM BOTH PRE- AND POST-SURGERY.

BUILDING CONFIDENCE
The first cancer care coordinator was recruited to the gynaecological cancer team, and the success that role had in a short space of time led to applications for support worker roles within other teams, initially including lung, urology, lower gastrointestinal and upper gastrointestinal cancers.

BUILDING CONFIDENCE
These are tricky roles for people to come into, and our cancer care coordinators often need to build up confidence, for example in talking to cancer patients, or seeing people who have had major surgery.

Sometimes people come from more clinical-based backgrounds, so they find it frustrating not to be doing more clinical work.

The main challenge is that, despite detailed job descriptions and explanation prior to coming into the role, these positions are quite unique and people often don’t fully understand what they are coming into.

They often need a lot of support in the first 12-18 months, as well as a clear definition of what is expected from the role, and what the expected outcomes are for the team. Whether it’s telephone triage or help with patient information, support workers want to keep busy and understand how they fit in with the team so that everyone can benefit.
Support workers

Shadowing a more experienced cancer care coordinator can help, and this is now part of the induction for anyone new coming into the role.

**Learning and development**

Over time we had enough cancer care coordinators in post across the West Yorkshire region to warrant a training course. The regional lead cancer nurse group adapted a two-day workshop, which is normally run for qualified staff and provides an overview of cancer and cancer care.

At the end of the course, attendees take away a competency workbook, which they complete over the next six months. We then follow up with a half day course, where those competencies are signed off. We have run this course twice in the past two years.

The lead cancer nurse group has also adapted a set of generic competencies originally developed by Macmillan for head and neck support workers. These can be used in any cancer setting and cover all elements of the cancer pathway. These are given to all new cancer care coordinators coming into post and are completed over the first 12-18 months.

The generic competencies mean that everyone in these roles can develop their skills to an appropriate level. The competencies can be adapted to fit different roles, including more of a surgical or clinical focus, or concentrating more on patient support or providing patient information.

Other generic competencies are based around communication, or understanding of a cancer type, treatment and side effects.

We also run a regular forum for cancer care coordinators working within the trust around three to four times a year, with the ambition to bring everyone across the region together once a year to meet up as a larger group.

**Evaluation**

Leeds Teaching Hospitals NHS Trust is very supportive of these roles and keen to share learning across other hospital departments.

We have been working with the University of Leeds to conduct a preliminary evaluation of the impact of cancer care coordinators. This has involved interviewing clinical support workers, cancer nurse specialists and doctors, and conducting patient focus groups. We are expecting a first draft of this qualitative evaluation later this year.

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Capturing data to show the impact of cancer care coordinators

A bespoke tool is providing a deeper level of insight in South Tees.

In June 2016, eight Macmillan lower case roles were recruited as part of a new approach to developing the cancer workforce at South Tees Hospitals NHS Trust.

An initial 12-month pilot was extended to two years as part of the wider Macmillan Integration of Cancer Care (MacICC) Programme workforce workstream. The programme aims to integrate care by promoting patient choice and streamlining working practice.

The eight cancer care coordinators work in individual cancer teams: lung, colorectal, lymphoma, head and neck, prostate, acute oncology service, cancer of unknown primary and brain and central nervous system.

Collaborative working
The cancer care coordinator role is there to provide effective, high quality support and care to people with cancer within a multi-disciplinary team (MDT). They act as a point of contact for people with cancer and their carers, signposting enquiries to appropriate teams and departments within hospital or community settings.

Care coordinators work with cancer nurse specialists and allied health professionals to enable:

- coordination of high quality patient care via telephone and face-to-face contact and proactive identification of needs
- collaboration and communication with wider health care teams to ensure provision of appropriate services
- coordination of care and support for people with cancer, their carers and families
- cancer nurse specialists and allied health professionals to have more time to deliver more complex interventions
- timely and efficient progress of patient care to support cancer standards, working closely with MDT coordinators and cancer trackers.

Measuring impact
In order to measure the impact of the care coordinator roles effectively, especially when working with multiple stakeholders internally and externally, members of the MacICC programme team developed an Intervention Metrix. Working with our colleagues within the trust, we created a bespoke tool, which aimed to provide quantitative measurement and some qualitative insight of the care coordinator roles, along with cost benefits.

The cancer care coordinators populated a spreadsheet with the individual tasks that they completed on a daily or weekly basis. They also provided explanations and evidence as to how interventions had supported patient experience, the 62-day target for referral to treatment and the wider patient journey, as well as saving the time of cancer nurse specialists or allied health professionals.

As part of the rigorous measurement process, completing the Intervention Metrix is mandated for cancer care coordinators, and must be ratified by their cancer nurse specialist and submitted each month. It is then further analysed by the programme team.
The Intervention Metrix has been continually reviewed by the MacICC programme team, looking at the types of interventions included and whether they remain appropriate. As the cancer care coordinator role continues to evolve, the programme team have removed or added interventions based on their relevance to the role and the value of the data produced, as care coordinators become more confident, both in their roles and in using the tool.

**Intervention Metrix findings**
The data showed that across the different tumour sites, cancer care coordinators were undertaking similar tasks, including:

- organising appointments
- telephone calls with patients
- telephone calls with carers
- face-to-face contact
- administrator tasks such as populating patient data into hospital systems.

The data also highlighted nuances within different MDTs, which helped the programme team to understand how the new roles were being integrated into different cancer pathways, and helped to explain the variation in the numbers of patients being seen by the cancer care coordinators.

The contribution that these roles have made along the pathway, and the time savings that have been made for cancer nurse specialists, have meant that nurses have been able to take on additional services for patients, including:

- a new colorectal remote cancer follow-up clinic, which in turn has freed up consultant clinic slots
- a new telephone radiotherapy review clinic within head and neck, with cancer nurse specialists now able to support a new thyroid service
- an additional nurse-led clinic for lymphoma, which performs urgent bone marrow biopsies
- additional capacity for a new ‘on-call’ service for lung cancer, where nurses cover A&E, wards and oncology clinics.

In addition, the 2017 cancer patient experience survey showed notable improvements across tumour sites, including a 15% increase in patients who said they could access their CNS easily.

From January 2017 to February 2018, our cancer care coordinators have supported 8,038 patients. The data from the Intervention Metrix suggests that this role has contributed towards the trust achieving the 62-day standard, and highlights the positive contribution that these roles are making to the experiences of people affected by cancer, their families and carers.

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Resources

Further information
You can read more about the Macmillan One-to-One Support Programme at macmillan.org.uk/onetoonesupport

You can also download two reports on our pilot project to provide one-to-one support to people following cancer treatment:

Evaluation of Phase 1 of the One-to-One Support Implementation Project: Baseline Report
An overview of Macmillan’s One-to-One Support Pilot, which began in 2012.

Evaluation of Phase 1 of the One-to-One Support Implementation Project: Final Report
Reports on the findings and learning from phase 1 of the pilot, used to shape subsequent investment in support for people affected by cancer.

Learning and development
Learnzone: Macmillan Cancer Support Course
This course provides training to people supporting others affected by cancer and is based on national standards of best practice. The course is made up of four units:

- Effective Communication Skills to support people affected by Cancer
- Introduction to Counselling Skills
- Working with Loss and Bereavement
- Cancer Awareness

learnzone.org.uk/stack.php?s=21

Learnzone: Recovery Package Toolkit
Key information about the Recovery Package for health and social care professionals, including:

- Detailed learning modules on each component of the Recovery Package
- Guidance on how to implement each intervention
- Useful templates and resources to help you implement the different components of the Recovery Package

learnzone.org.uk/courses/course.php?id=305

You can see more Learnzone courses for support workers at learnzone.org.uk/stack.php?s=12

References
Have you got an idea for a future issue of Sharing good practice? Get in touch at macvoice@macmillan.org.uk