‘Caring for patients is the most important part of my job. People should always feel looked after.’

Mark Foulkes
Macmillan Lead Cancer Nurse

In focus
Palliative and end of life care
Sharing good practice
Allied health professionals
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If you change role or address, or you’ve missed an edition or two, please let us know at macvoice@macmillan.org.uk
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An award-winning placement
Macmillan and Lloyds Bank are working together to provide more people with financial support following a cancer diagnosis.

More than 80% of people diagnosed with cancer find themselves £570 a month worse off, on average. Money worries at this already difficult time can be confusing and overwhelming.

Macmillan Support Line is 25 times more likely to receive calls about financial issues than those related to death or dying. And our research shows that only 11% of people are turning to their bank for help. One of the reasons behind this is that people often do not know what to expect from their bank, which leads to many not getting much-needed financial help.

Macmillan is working with Lloyds Bank to support their customers to make informed financial decisions following a cancer diagnosis. Together we have created the Cancer Support Team at Lloyds Bank, with dedicated advisors trained by Macmillan so they understand the financial impact of a cancer diagnosis.

The Lloyds Bank Cancer Support Team can help customers manage their money through bespoke support for personal banking, savings, loans, mortgages and credit cards.

Following a successful pilot and an independent evaluation of the service, Lloyds Bank, Halifax and Bank of Scotland customers affected by cancer are now receiving vital support to help them manage their finances.

Lloyds Banking Group has 30 million customers and establishing the Cancer Support Team is a significant milestone in reaching more people affected by cancer. We have seen an increase in calls of more than 250% since Lloyds Bank launched its advertising campaign about the Cancer Support Team in August.

Richard Manson, Macmillan Financial Guidance Technical Lead, says, ‘Personal finance is a huge concern for people contacting Macmillan. Our referral partnership is very important because it allows us to ensure that customers are speaking to the most appropriate team at the bank. Being able to refer customers to the Lloyds Bank Cancer Support Team gives us confidence that they will receive the best possible support from a team trained by Macmillan.’

You can refer anyone affected by cancer who is concerned about their finances to the Macmillan Support Line on 0808 808 00 00, or directly to their bank if they are a Lloyds Bank, Halifax or Bank of Scotland customer.

Tracy’s story
You may have spotted Tracy as the face of the latest Lloyds Bank TV ad.

After being diagnosed with ovarian cancer, Tracy contacted Macmillan for help with her money worries. We provided financial support and guidance and carried out a benefits check. We also secured a Macmillan grant to pay for clothing and heating.

As Tracy is also a Lloyds Bank customer, we referred her to the Cancer Support Team at Lloyds Bank for support with her bank account and mortgage.

Tracy says, ‘The joint service between Lloyds Bank and Macmillan made me feel confident that Lloyds Bank actually understood my situation and actively wanted to make it easier for me. You tend to be focused on your own treatment and in fact, you need someone watching the financial side in a supportive, kind way. And that’s exactly what they did.’
MISS expands into Wales and the North West

New buses Bronwen and Basil will help reach more people with information about cancer.

Our Mobile Information and Support Services (MISS) tour the UK throughout the year, staffed by Macmillan cancer information and support specialists. They offer free, confidential information and support to people affected by cancer in their communities.

The main advantage of the buses is that they are an easily accessible community resource, often reaching people who wouldn’t usually seek information and support via conventional channels. The confidential, drop-in style of the service attracts people who tend not to access traditional sources of information.

We have recently expanded our fleet from four buses to six, with two new vehicles that will help us reach people in places we simply couldn’t get to before – particularly across rural, deprived and marginalised communities.

The smaller, nimbler design of the two new buses, Bronwen and Basil, provides practical benefits such as flexibility around the display of branding and messaging and a welcoming space for people to visit. Like our existing fleet, these new units will be staffed by teams of frontline health and social care professionals with years of experience of caring and supporting people living with cancer.

Bronwen (pictured above with the team) is visiting areas across Wales, while Basil will be a fixture around the North West.

Working closely with local partners, we’ll be testing new ways of working. These include the introduction of new technology that supports integration with wider Macmillan services, flexible opening hours and follow-up visits to enhance the service.

More information
Contact Amanda Fry, MISS Expansion Project Manager, at afry@macmillan.org.uk

In brief

New research on adult cancer workforce

Since October we have been conducting research to assess the current size and make-up of the adult cancer workforce in England and Wales. This insight is vital if we and partner organisations are to assess any changes in the cancer workforce that might help to inform future planning. We would like to take this opportunity to thank all those who have taken part in the research and look forward to sharing the results early next year.

Our new office in Edinburgh

The Macmillan office in Edinburgh relocated in September to a new location at the 3rd floor, Caledonian Exchange, Canning Street, EH3 8EG.

World’s Biggest Coffee Morning

A huge thank you to all of you who took part in this year’s World’s Biggest Coffee Morning. So far, we have raised an incredible £18.6 million. Whether you held a coffee morning at work or joined fundraisers in your local community, the money you’ve raised will help to provide medical, emotional, practical and financial support, as well as campaigning for better cancer care.
Update from the Quality and Evaluation team

Macmillan’s Quality and Evaluation team, part of the Cancer Information Development team, evaluates and improves the quality of our cancer information. We ensure all our information is as accessible as possible and we produce it in a range of formats, available at macmillan.org.uk/otherformats. We also coordinate book reviews and our e-newsletter Inside Information.

Here is an update on some of our recent projects:

**Meeting the information needs of people in Wales**

With the launch of our new Welsh mobile bus, we have reviewed our range of Welsh information. We now offer more content, in shorter formats, which we hope will be even more popular. The new range includes the signs and symptoms z-card and our leaflet What to do after cancer treatment ends: 10 top tips.

You and your colleagues can order these resources for free from be.macmillan.

**Signs and symptoms z-card in 11 languages**

We have translated the popular signs and symptoms z-card into 11 languages, and these are ready to order from be.Macmillan. Please do help us spread the word about these cards.

**Gathering data on our easy read information**

We’ve sent out surveys to people with learning difficulties, their carers and health professionals, to find out more about our easy read information and how people like to access this. The findings will support us to develop and market the range in 2018.

**Cancer and dementia**

If you treat someone with cancer and dementia, or identify a carer for someone with cancer and dementia, we have produced two new booklets that can help. Visit macmillan.org.uk/dementia for further information and to download or order free copies.

**Get in touch**

If you have any questions about our work or feedback about our range of information we’d love to hear from you. Contact us at cancerinformationteam@macmillan.org.uk

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Meet the team: Lynn Fox, Quality and Evaluation Officer, Abi Delderfield, Quality and Evaluation Lead, Genevieve Osei-Kuffuor, Information Production and Promotion Officer and Sue Hawkins, Information Materials Researcher
Tameside Macmillan Unit now open

New facility means cancer care is now provided in one location.

The new £1.8 million state of the art Macmillan Unit is now open at Tameside Hospital in Greater Manchester.

The unit provides a single point of access for all appropriate assessment, treatment and support services, where people with cancer are supported in a calm and relaxing environment.

As well as a chemotherapy suite and private room for acute chemotherapy, a dedicated information and support centre with Macmillan staff is on site to provide much needed support for patients and their families.

Julie Atkin-Ward, Macmillan Strategic Partnership Manager for Greater Manchester, said, 'The Tameside Macmillan Unit offers vital support for anyone affected by cancer across Tameside and Glossop, whether it’s people living with cancer, their families or carers. I am really excited that this much-needed facility is now open and providing the very best treatment and support to the local community, and ensuring more peoples’ needs are being met, right on their doorstep.'

Karen James, Chief Executive of Tameside and Glossop Integrated Care NHS Foundation Trust, which runs Tameside Hospital, says that before the new unit was built, cancer care and provision was given in several different locations and many patients and their carers often had to travel to more than one hospital site for their treatment.

She explains, 'Now, all that has changed, and with more and more people hearing every year the devastating news that they have cancer, we know our unit – with services, information and support all under one roof – will help ease anxiety and fear.'

Patient survey reveals confusion about cancer

Many cancer patients in England feel unprepared to deal with a cancer diagnosis.

Analysis of the Cancer Patient Experience Survey for England has revealed that around 1 in 4 (75,000) people in England diagnosed with cancer did not completely understand the explanation of what was wrong with them.

More than a quarter said they did not receive easy-to-understand written information about the type of cancer they have. Worryingly, almost half were not given all the information about the potential future side effects of treatment.

Feeling fully informed at diagnosis can help relieve anxiety and distress experienced by people with cancer and help them to cope better. Macmillan has 200 GPs working to provide leadership in cancer care in their local area and is calling for all health care professionals to ensure cancer patients have access to better information at diagnosis. Dany Bell, Specialist Advisor on Treatment and Recovery at Macmillan, says, 'It’s vital that patients come away from their appointment fully understanding their diagnosis, with digestible written information and an understanding of what support they might need throughout treatment and beyond.'

Healthcare professionals and the general public can download free leaflets and booklets about cancer at be.macmillan.org.uk. There is also more information including how to find your nearest Macmillan information centre (often based in hospitals) at macmillan.org.uk/in-your-area

Read more about the results of the Cancer Patient Experience Survey for Wales on page 18.
The Macmillan Professionals Excellence Awards 2017

The annual Macmillan Professionals Excellence Awards recognise and thank teams and individuals delivering the highest standards of care for people affected by cancer. Having been nominated by their managers or colleagues, the winners have demonstrated true excellence and innovation in their field and were chosen after presenting their work to our specialist awards panel.

The winners were announced on 16 November at an awards ceremony hosted by Kyran Bracken MBE.

To find out more about their work, visit macmillan.org.uk/professionalsawards

Innovation Excellence Award winners

Innovators who are driving new initiatives, products and services to shape the future of cancer care.

Macmillan Head and Neck Oncology Speech and Language Therapy Team
Leeds Teaching Hospitals NHS Trust

The Macmillan Head and Neck Oncology Speech and Language Therapy Team have designed a reliable and exemplary service that manages one of the heaviest caseloads in the country. By using a predictive model to identify patients at risk of swallowing difficulties before radiotherapy treatment begins, the team are significantly reducing hospital admissions. Their proactive approach involves offering education, therapy and exercises to patients in order to improve their outcomes. What’s more, the new model is a shining example of using resources effectively and responsively.
Integrated Assessment Map (IAM) Portal Project Team
University Hospital Bristol NHS Foundation Trust

The IAM Portal Project Team is improving the cancer journey for teenagers and young people by making their voices central to their care. Patients complete an innovative digital holistic needs assessment on the portal, and the results form the backbone of multidisciplinary team discussions about their needs. Users can also utilise the portal to find a comprehensive range of age-appropriate information, and to contact their medical team with any concerns. The third component of the Portal is SWIMMS – a bespoke MDT management system which allows professionals across the region to register young people with the TYA service; provides a way to manage and record MDT meeting activity, including the generation of a care plan; and the production of activity data reports for service management purposes. The Portal, which was jointly funded by Macmillan and Teenage Cancer Trust is now being take forward nationally.

Celebrate your colleagues’ achievements
Being nominated for an award is the biggest compliment you can give a Macmillan professional – and it’s never too early to start thinking about next year.

You can nominate anyone who’s been a Macmillan professional for at least a year, whatever their role or level. You can also nominate any team that includes at least one Macmillan professional.

Nominating is easy
The deadline for next year’s awards submission is 31 March 2018, so there’s plenty of time to gather your thoughts. The nomination period opens on 2 February 2018.

Find out more about celebrating the best of Macmillan professionals’ work at macmillan.org.uk/professionalsawards

Sharon Manning
Macmillan Gynaecology Clinical Nurse Specialist
Betsi Cadwaladr University Health Board

When Macmillan Gynaecology Clinical Nurse Specialist Sharon read about cutting-edge permanent catheters that would allow her ovarian cancer patients to have ascetic fluid drainage at home rather than in hospital, she pushed hard for funding. Thanks to her dedication, passion and persuasive prowess, Sharon’s efforts were successful and she now runs a life-changing service that’s being rolled out in Wales. As well as dramatically improving quality of life, the innovative service has saved at least £68,000 on hospital admissions.

Celebration is in order
Sharon is one of the many Macmillan professionals who have gone above and beyond in their work. To go to the heart of what’s been achieved in the past year, visit macmillan.org.uk/professionalsawards
Integration Excellence Award winners

Developers of integrated services that have greatly improved patient experience and outcomes.

Tracey Wright
Macmillan Commissioning Manager for Cancer and End of Life, NHS Eastern Cheshire, South Cheshire and Vale Royal CCGs

Tracey’s innovative approach to commissioning has made a huge difference to people affected by cancer in central Cheshire. As a skilled negotiator, she is an expert at building consensus and bringing stakeholders together to improve care and outcomes for patients. She has developed a number of initiatives including a lung cancer project that resulted in patients presenting earlier and with fewer emergency presentations, the first community acute oncology nursing service in the country, and the award-winning Cheshire End of Life Partnership, which supports people to die in the place of their choice.

Fiona Gilmour
Macmillan Service Improvement Lead for Palliative Care, Northern Health and Social Care Trust, Northern Ireland

Fiona’s ethos of compassion and collaborative working has led to her success in delivering an impressive array of palliative care service improvements at the Northern Trust and shared across Northern Ireland. Among other initiatives, she has introduced a palliative care key worker role within district nursing, led on the co-design of a bespoke palliative care education programme for district nursing sisters, and developed a palliative care aide-memoire for holistic needs assessments. She also goes to great lengths to raise awareness of palliative care among the general public, using a range of mediums such as videos, social media and drama.

Move More Aberdeen
Sport Aberdeen

As passionate advocates of the benefits of physical activity for people living with cancer, the trailblazing team members of Move More Aberdeen have improved many lives. Move More Aberdeen is the first ever cancer-specific physical activity programme in the city and offers an extensive, person-centred package of activities that includes walks, gentle movement classes, circuit training and gardening. Through skilfully forging new ways of working with NHS Grampian and enthusiastically embracing cross-sector collaboration, the team has successfully integrated physical activity into routine cancer care.

Macmillan @ Glasgow Libraries
Glasgow Life

The Macmillan @ Glasgow Libraries programme was set up to fulfil the need for high quality information and support for individuals affected by cancer, including patients, family members, friends and carers. After a successful pilot, the service launched in 2012 and has since developed a comprehensive network of cancer information and support services across Glasgow.
Service Improvement Excellence Award winners

Visionaries whose commitment and foresight have made a lasting difference to the quality of services.

Macmillan Nottingham Cancer Support Service
Nottingham CityCare Partnership

The Macmillan Nottingham Cancer Support Service was developed to offer vital cancer support in the community. Working alongside a specialist needs service, the team of two clinical nurse specialists and two assistant practitioners offers an array of practical, emotional and financial support, all underpinned by their motto, ‘What can we influence and what can we add?’.

Breast CNS teams across City of Manchester
Pennine Acute Hospitals NHS Trust and South Manchester University Hospitals Trust

By working in partnership, the breast CNS teams of the Pennine Acute Hospitals NHS Trust and the South Manchester University Hospitals Trust have transformed aftercare for women with breast cancer across Manchester. They have designed a patient-centred pathway with cancer patients that is consistent, embeds all the elements of the Recovery Package, and eliminates any disruptive and unnecessary routine hospital appointments.

NHS Lothian and Macmillan Cancer of the Unknown Primary Team
Edinburgh Cancer Centre, NHS Lothian

The NHS Lothian and Macmillan Cancer of the Unknown Primary Team offers a vital service that’s the first of its kind in Scotland. Passionate about delivering equity of care to the highly disadvantaged group of patients with metastatic cancer from an unknown primary, the team have gone above and beyond to improve patient care. By reducing the length of time people have to spend in hospital and reducing the number of invasive investigations they have to undergo, the service has resulted in cost savings too.

Lifetime Achievement Award winner

Dr Wendy Makin, Medical Director, Christie NHS Foundation Trust

During a distinguished career including more than 20 years as a Macmillan palliative care doctor, Wendy’s work has made a huge impact on many people. Her extensive knowledge and extraordinary dedication to people living with cancer have consistently led to excellent outcomes, and deserve the highest recognition.
Can you tell us about your professional background?
Before becoming a nurse, I completed a degree in biological sciences, but I knew I didn’t want to work in a lab. My mother was a nurse and was always saying it would suit me. I resisted for years but gradually came around to the idea. I applied to the London hospitals to train. St Mary’s was the only one to respond, probably because of my complete lack of experience at the time, but fortunately they took me on as a student nurse. Since starting my training in 1988, I have worked constantly as a cancer nurse.

What does your role involve?
I work partly in the clinical role of nurse consultant, and partly in the more strategic job of lead cancer nurse. As a nurse consultant, a significant part of my work is in clinical practice. I spend half of my week looking after the acute oncology service, doing ward rounds with colleagues. We see people who might be known to us already or who have come in with side effects from treatment, have developed metastases from their cancer, or are diagnosed with a new cancer through an emergency admission.

Our acute oncology service offers advice and support to doctors and nurses caring for people with cancer, as well as to the patients themselves. If needed, we can
admit them to our own ward. In many hospitals across the country Macmillan has provided funding and support to set up these services.

I’ve been working with Macmillan for most of the time I’ve been in nursing. They funded my very first clinical nurse specialist job in head and neck cancer in London and many of our posts here at the Berkshire Cancer Centre. It’s good to see the organisation campaigning more, giving a voice to patients, as well as providing fantastic information. You can’t imagine cancer care now without Macmillan.

What is the most rewarding part of your job?
Working with people is very rewarding. Some people ask me if being a cancer nurse is depressing, and I always say no. I can help people, and even if their prognosis is not very good, they always appreciate it. I can’t take away their problems but I can listen to them and offer support.

I love my job and look forward to coming to work – it’s totally integrated into my life. I regard looking after people as a privilege. I think people can be at their very best when they are ill – at their most fantastically stoic and resourceful.

Last year I won the Pride of Reading Health Worker of the Year Award, which was a complete surprise. The person who nominated me was anonymous, but I think it must have been related to my charity work and the fact that I have a very public-facing role. I see a broad range of patients, from people who come to A&E with a cancer-related emergency through to people receiving treatment on the chemotherapy ward, so I’m very visible. The award nomination statement said ‘he’s always there, he works very hard and he’s a total legend!’. So that was very nice to hear.

What are the challenges?
Not having enough time or resources. I like a bit of chaos and having worked in the health service for 29 years I know you need to be able to think on your feet and fight your corner, often with very limited resources. It always makes me smile that TV programmes like Casualty are so popular and yet the real thing is just outside and not adequately funded. There’s a lot of good work that goes on in the health service but we’ve been running on a shoestring for the past five or six years and that’s tough.

What have been the biggest improvements in cancer care that you have seen?
Survival rates have improved, people live longer, they are fitter, there are a lot more treatment options available and the facilities for patients have got better.

There has been a sea change in the way professionals communicate with people. Now you can’t believe that when I first started out in nursing there were debates as to whether people should be told about their diagnosis. It was very common for doctors to be cautious with what they said. Another big change is the knowledgeable patient. Many people research their condition through the internet, which can be very helpful. Occasionally there are issues because of course there’s no filter on the net, but people want to be empowered. The more informed patients are the better, so that they can choose the treatment that’s best for them.

We’ve talked about what has changed over the years you’ve been in cancer nursing, but what would you like to see change in the future?
For me, caring for patients is the most important part of my job. People should always feel looked after. We’ve got very experienced nurses and doctors but there are other professionals who are missing. For example, we need more dietitians and speech therapists so that everyone has the chance to see one if they need to.

We are also moving towards having more cancer care services in the community, which I would like to see more of. There’s no reason why people should come into hospital to have chemotherapy for example. We’ve started to work towards this with mobile chemotherapy units. We’ve got one bespoke service in Bracknell and we are building another one in Thatcham where people can park more easily.

Finally, what are you most proud of?
I’m very proud of the team here, the work they do and the cancer centre. We recently received our Cancer Patient Experience Survey results and they were really good. I’m very proud of the fact that people feel well looked after here.
When I started as Macmillan Skin Cancer Care Coordinator in 2014, this was a new role for the department, developed in partnership by Macmillan Cancer Support, Blackpool CCG, Fylde and Wyre CCG and Blackpool Teaching Hospitals.

I work alongside the lead skin cancer specialist nurse in a clinical setting, providing support to patients throughout their cancer journey from when they first come to an urgent clinic to diagnosis and beyond.

As well as supporting the team through triaging calls and administrative support, a large part of my role is raising awareness of skin cancer and the need for sun protection. Blackpool and Fylde Coast has a high incidence of skin cancer, so addressing prevention through awareness is a priority.

I organise and attend a programme of events, reaching out to communities through GP surgeries, supermarkets and even Blackpool Zoo. This has proved invaluable and word of mouth has kept me very busy. I have also put together a training package with the help of the nurse specialist, which I deliver to teachers, college students, outdoor workers, nurses, hairdressers, beauticians and many others. Anyone who attends gets a basic knowledge of skin cancer and preventative measures.

For the past couple of years, I have been working with local nurseries and primary schools. And in March, I was honoured to be asked to be an ambassador for the Melanoma Charity SKCIN. They provide me with free resources to help raise awareness of skin cancer through education, promoting prevention and early detection.

SKCIN offers a free national accreditation for workplaces, schools and nurseries, which works well alongside our free Macmillan training sessions.

So far in the Fylde, there are seven accredited organisations that work with children, with
more currently working through their accreditation. I feel that the Macmillan skin cancer training sessions that I have delivered are really making a difference.

The seven childcare settings were awarded with a special UV board and sun cream dispenser to encourage children to apply sun cream on a regular basis. The boards were funded by an awareness event I organised back in May this year, and I’m hoping to get these boards into every childcare setting on the Fylde coast.

Fairy Godmothers Home from Home Childcare was the first childcare setting on the Fylde coast to become sun safe. Owner and manager Linda Irvin said, ‘All of our parents and carers have embraced the Macmillan training session. Even our smallest children are promoting sun safety by wearing hats and sun cream and making shelters for shade.’

Local support has been overwhelming. I have been invited to talk at some local primary school assemblies, meaning I could reach more than 300 pupils, as well as staff, in one session. I’ve also attended sports days to promote the use of sun cream to children, parents and staff.

This very rewarding role allows me to keep up my clinical skills and never be too far away from patient care, which I love. I also feel I am making a difference to future generations and hopefully reducing the number of skin cancer patients.

I have experienced lots of positivity from the public in this role, as people recognise Macmillan and have confidence in the messages I am giving.

Jackie Brunton, Lead Cancer Nurse, says, ‘Michelle’s role is an excellent example of how support workers can work with medical and nursing teams to develop and enhance services and play a vital role in building programmes for awareness and prevention. Michelle’s knowledge and skills have gone from strength to strength and this model should continue to be considered for other areas.’

Heather Baines, Skin Cancer Specialist Nurse, adds, ‘Education and raising awareness is vital to reducing the numbers of patients coming to us year on year. The dangers of sun exposure and using sunbeds are still a huge problem, especially with younger people. We need everyone to be aware that they need to protect their skin.

‘It’s so preventable and often treatable, but early detection remains paramount. Michelle’s role enables us to do this in a structured way and with resources that enable the consultants and our specialist nurse team to provide timely diagnostics and treatment.’

You can find out about Macmillan’s updated information on skin cancer on page 28.

Want to know more about melanoma?

Lianne Jackson, Macmillan Skin Cancer Specialist Nurse at Wirral University Teaching Hospital and Rhiannon Walters-Davies, Advanced Pharmacist at the Clatterbridge Cancer Centre, have co-written an article recently published by the Pharmaceutical Journal outlining the risk factors for melanoma and advice on sunscreen use.

You can read the full article at bit.ly/2yP750V
The emotional impact of being there

Research Associate Patty Doran talks about her project to better understand the impact of social support for older people living with cancer.

Before starting my PhD at the University of Manchester in 2013, I was a Macmillan information and support service manager for several years. Inspired by Macmillan’s Age Old Excuse campaign to ensure older people are offered cancer treatment and care based on their needs, not on their age, I started a research project to try and produce evidence about the positive impact of social support on the experiences of older people living with cancer.

The focus of the research was how social support could firstly influence treatment inequality experienced by older people with cancer, and secondly impact the quality of life of cancer survivors. We hoped to work out what it was about social support that created a positive effect on the lives of older people living with cancer.

The complex interplay between cancer, older people, and social support, led to integrating qualitative and quantitative methods. Statistics alone do not tell the full story, so the first stage of the research involved listening to older people who had used advocacy services through the Older People’s Advocacy Alliance (OPAAL) Cancer, Older People and Advocacy project.

The second stage was directed by the findings from the qualitative research. Analysis was carried out on data from the English Longitudinal Study of Ageing to understand the relationship between social support and quality of life of older people living with and beyond cancer.

What we found

The qualitative findings highlighted emotional support needs relating to coping and loneliness, as well as practical support needs associated with problems such as housing issues or caring responsibilities. Although advocates could help in practical ways, it was the emotional support provided through the act of ‘being there’ that had the greatest impact on the experiences of people living with cancer.

Most people reported high social support and had good quality of life (although cancer survivors on average had slightly lower quality of life compared to people without cancer). However, those who reported having low support from partners, children or other family, or having no friends, reported much poorer quality of life. The findings potentially reflect complex situations (such as being a carer or not in stable accommodation) that are adversely affected by also living with cancer. Therefore, it is those with the highest need who are also the most affected by living with cancer.

Increasing inequalities

As the population ages alongside a decline in welfare state, it is likely we will see increasing inequalities in old age. Life can become complicated when living with cancer, and for those older people who were already dealing with complex lives before a cancer diagnosis it can be hard to cope. Consequences for quality of life will be worse for older people living with cancer who also have low social support.

Interventions that increase social support, particularly through the act of ‘being there’, will improve quality of life for older people living with cancer. The support provided by the advocates through the Cancer, Older People and Advocacy project is one example of a successful intervention.

Further information

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A different way of delivering health information

Penny Meadows and Marcelle Robbins describe how they are delivering health information to people with learning disabilities.

As the Information Resource Service at St Luke’s Hospice in Basildon, it is important that the information we provide is of the highest quality and meets the Accessible Information Standard.

Working in partnership with St Luke’s, we have started holding interactive workshops to help deliver health information to specific groups of people with learning difficulties or enhanced needs.

Our experience shows that much of the health information available to this group of people is frequently outdated or based on misconceptions. They may be less likely to access accurate information, and are often unaware of where to get good quality information from.

Carers and educational staff are often very protective of the students, and some people didn’t attend the first workshops as their carers felt it could be upsetting for them. Staff were also protective of us, warning us about potential challenging behaviour and negative reactions.

A learning curve
From our first workshops to our current format, we have incorporated lots of changes and thought a lot about how best to engage the students.

Initially we asked for minimal interaction, as we were afraid that we would lose control of the group and find it difficult to keep people focused on the subject matter. However as our confidence has grown, and we have experienced different client groups, we now offer a fully interactive session that enables everyone to make a contribution.

Providing students with information and materials to take away from the session enables them to share their experience and information with carers, family and friends. This continues the conversation and encourages them to share their knowledge. We have since been asked to provide further sessions and follow-up workshops.

Holistic health
Talking about emotional and mental health as well as physical wellbeing encourages students to think more holistically about themselves and each other.

We also promote mindfulness and try to deliver the workshops in a way that prompts further thinking, as well as ensuring that students and staff know how to contact us if there are any issues they want to discuss following the sessions.

We take a large bowl of fruit to promote the ‘5 a day’ principle, and give out water with a simple message about staying hydrated. This also helps to identify members of the group that, although quiet during the sessions, excel at the kind of interaction required to distribute fruit or water, enabling them to contribute and feel involved.

We have had to think about how we deliver information in a way that involves more than just amending our language. Delivering a variety of materials in a way that young people with different abilities and disabilities can engage with helps to ensure that the information meets their needs.

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Results of second Wales Cancer Patient Experience Survey

Every year more than 19,000 people in Wales are told that they have cancer. In 2015, Macmillan Wales worked in partnership with the Welsh Government to run the Wales Cancer Patient Experience Survey for the second time. This was designed to measure and understand patients’ experiences of cancer care and treatment in Wales to help drive improvement at the national and local level.

The survey was sent to 11,000 people who were treated for cancer in Wales. It asked them about every stage of their care, from how many times they visited their GP before being diagnosed to the support they received when their treatment ended.

The survey had a good response, with 6,714 people (65%) giving their time to tell us about their care.

Positive results
Vaughan Gething, Cabinet Secretary for Health, Well-being and Sport for Wales, launched the results of the survey with Macmillan Wales back in July, with many positive outcomes.

Overall, patients reported high levels of patient satisfaction for cancer care, with 93% rating their care as at least seven out of 10 (on a scale of 0–10 where 10 = very good).

Almost every person who responded (97%) said they had all their treatment options explained to them. The survey also showed that having a clinical nurse specialist has an overwhelmingly positive impact on a person’s experience of cancer care.

More than 70% of people who had a clinical nurse specialist said they had been given the right amount of information about support and self-help groups, compared to just 36% of people who did not have one. Macmillan Wales wants every person diagnosed with cancer to have a clinical nurse specialist to coordinate their care and to guide them through often-complex discussions and decisions about cancer treatment.

Room for improvement
The results also highlighted some areas for improvement. The Welsh Government’s Cancer Delivery Plan says everyone diagnosed with cancer should have their holistic needs – such as finances, information needs and psychological needs – assessed, and be offered a written care plan. However, only 18% of people surveyed said they were given this.

The Cancer Delivery Plan also says that every person with cancer should be told how to access financial advice, but only 48% said they were given this information. Being told how to access timely financial advice, including benefits, is important so people with cancer and their loved ones can get financial advice and support before any money problems escalate.

What do people in Wales who’ve had cancer treatment think about their care?

- 93% of people rated their care as highly positive, with 93% of patients selecting a rating between seven and ten (on a scale of 0–10 where 10 = very good).
- 89% of people said that they were treated with dignity and respect.
**Next steps**

The positive results from this survey are testament to the high quality and compassionate cancer care provided by staff within the NHS in Wales. There are also areas where work is still needed to ensure every person receives high quality care based on their needs, as set out in the Cancer Delivery Plan for Wales.

Macmillan Wales will use the results to share what’s working well, campaign for improvements where needed and to develop services to support people with cancer. The findings of the survey will also help support ongoing efforts to deliver more person-centred cancer care.

Vaughan Gething said, ‘It is a tremendous testament to the dedication, skill and compassion of those delivering cancer care that 93% of respondents rated their care seven or more out of 10. This is exceptional and is only possible due to the quality and dedication of healthcare professionals across Wales.

‘Whilst it would be very easy to focus on only the positive outcomes of this survey, it is vital that we do not lose sight of areas where we can do better. We will not rest until all these issues are addressed. We have a new cancer plan, a new cancer network and new commitment to person-centred cancer care. We will continue to work with key partners such the cancer alliance and cancer network to support progress in these areas.’

**Other nations**

Cancer Patient Experience Surveys have also been carried out in England, Scotland and Northern Ireland. Find out more at [bit.ly/2y8vMB1](https://bit.ly/2y8vMB1)
Strengthening holistic support for self-management

A local cancer charity and hospital trust have developed a new health and wellbeing service.

The Royal Devon and Exeter NHS Foundation Trust has collaborated with local cancer charity, FORCE (Friends of the Oncology and Radiotherapy Centre), for many years. A recent jointly-run, psycho-educational support programme for patients at the end of treatment revealed that many people would have liked information about holistic care and support services much earlier in the pathway.

This feedback and funding for project support from Macmillan resulted in the Trust and FORCE implementing a new ‘After a cancer diagnosis, what next?’ health and wellbeing clinic, which is offered to people with cancer soon after being diagnosed. The aim is to provide people with information and signposting to appropriate facilities to support them to make informed choices throughout and after treatment, enhancing patient experience and strengthening supported, self-managed follow-up.

Last year the team was awarded the local ‘clinical school award’ for new ways of working and future development opportunities within the clinic.

The pilot phase
During an eight-month pilot phase, clinics were delivered twice a month. A broad range of experts shaped the initiative, including members of patient groups. The pilot adopted a phased approach involving patient referrals from four cancer sites (breast, colorectal, urology and skin). The FORCE Cancer Support Centre provided a non-clinical, relaxed setting to deliver information around practical and emotional concerns.

Initially 10 patients, along with a family member or friend, were invited to each clinic, which included a presentation and facilitated informal discussion. Feedback after each session helped shape future design and delivery.

Results so far
The team have seen a move from ‘self-selecting’ delivery of patient support to structured, adaptable and dedicated health and wellbeing clinics, designed for the person with cancer at the right time and place. Attendance is increasing, with information provided to more than 40 patients each month.

Here are some of the results from feedback collected from 249 people with cancer, friends, family members and carers at the end of a clinic:

<table>
<thead>
<tr>
<th>Question</th>
<th>Percentage answering ‘yes’</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did the clinic provide useful information?</td>
<td>100%</td>
</tr>
<tr>
<td>Do you think the information will help you to manage your illness in the future?</td>
<td>92%</td>
</tr>
<tr>
<td>As someone supporting a person with cancer, has the information helped you to understand and support the person affected by cancer?</td>
<td>93%</td>
</tr>
<tr>
<td>Did the clinic meet your expectations?</td>
<td>75%</td>
</tr>
</tbody>
</table>

Cancer nurse specialists and other healthcare professionals are being trained to co-facilitate a growing number of clinics and ensure continuity. Other potential outlets are being explored, including site-specific clinics, website portals and a community outreach programme.
IN FOCUS: PALLIATIVE & END OF LIFE CARE

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27 Increasing engagement with advance care planning
Transforming training for end of life care

Macmillan End of Life Care Facilitator Joe Potts is supporting colleagues to provide first class care for people who are terminally ill.

I took up the role of Macmillan End of Life Care Facilitator at University Hospitals of North Midlands (UHNM) two years ago, in a new position for the Trust. The Royal College of Physicians quality indicators for end of life care recommend that each NHS Trust employs one or more end of life care facilitators, but the role has been interpreted in different ways to meet different needs.

My role is non-clinical and involves training and supporting clinical staff in their caring role.

In 2015, the Trust was inspected by the Care Quality Commission (CQC) and given a ‘requires improvement’ rating for end of life care. One of the key recommendations was to launch a care plan for last days of life that had recently been developed at the Trust, and this was the top priority during my first year in post.

Rolling out a new plan across two hospital sites and more than 50 wards brought many challenges. With a large workforce and many bank and agency nurses, I found the best way to reach staff was to go onto the wards and deliver training at a time and place that suited busy clinical staff.

Easy to access education
This provided an opportunity to develop and adapt the end of life training provided. It was really useful to complete a training needs analysis, which enabled me to meet frontline staff and talk to them about what training they needed and how we should deliver it. I asked staff 12 questions about how confident they felt providing several aspects of end of life care. More than 280 registered nurses and 100 medical staff completed the surveys, which helped me to deliver training that staff need, in a way they can access. I plan to repeat the survey this year and include non-registered staff.

I am fortunate to work with highly experienced specialist nurses and consultants who are willing to help to develop and deliver training. This has allowed us to reach a wider group of staff of all professions and grades.

‘Working with patient and carer representatives... has given valuable insight into the needs of our local population.’

We currently use the ‘Homeward Bound’ teaching resources created by the National Council for Palliative Care. They tell the story of Seth and Lesley Goodburn and their experiences of being cared for in a hospital towards the end of Seth’s life. I have found this resource allows staff to relate what they have learned to the care they provide each day and the people and families they care for. We also use the Sage & Thyme communication skills training, which is available to all staff.

The training opportunities are presented in an attractive brochure and staff can book on using their
online account, saving them time. We also provide regular newsletters through a network of clinical champions who encourage colleagues to attend our training.

Enabling and empowering professionals
Nursing & Midwifery Council (NMC) revalidation encourages registered nurses to seek out opportunities to learn and develop, and so we have added the NMC Reflection template to the back of our certificates. Now, staff ask for more sessions to help them meet their revalidation requirements. Every person who attends a teaching session or workshop completes an evaluation and these are used to shape future training sessions. In May 2017, we held our first national End of Life conference. More than 250 delegates from across the country came to hear speakers including Claire Henry MBE, the Chief Executive of the National Council for Palliative Care. This meant our staff could attend a professional event close to where they work, and many said the event had motivated them in their caring role and provided new ideas to take back to their colleagues.

Sharing best practice
Working with local organisations has always been important to the palliative care team at UHNM and developing these relationships has been key to my role. We decided as a team to hold an annual education day for palliative care professionals in the local area. Last year we focused on advance care planning, which was a great opportunity to share expertise. This year we plan to launch a specialist palliative care prescribing forum to bring professionals together to discuss new research, treatments and learn from expert speakers. We have also worked with patient and carer representatives, particularly during Dying Matters awareness week. This has given valuable insight into the needs of our local population.

My first two years in this role have passed very quickly and we have achieved a lot, but there is still much to do. We are due to be inspected by CQC by the end of the year and hope to see improved results when the report comes out in 2018.

We are currently doing some quality improvement ‘spot checks’ where I visit the wards and evaluate care plans for patients in the last days of life. I then give support and feedback to the team to ensure that best practice is followed. Helping staff to feel confident and able to care well for people at the end of their life remains my top priority.
Financial support at the end of life

Benefits are available for people who are terminally ill, but many are not claiming the help they are entitled to.

With more than £90 million of disability benefits going unclaimed by terminally ill patients each year, it is crucial that more people know what support is available to them.

Having cancer is expensive, as people face rising bills and loss of income, yet confusion and stigma mean they do not always claim the benefits they are entitled to.

For terminally ill patients, signposting to information and guidance is important, but professionals can also support people at the end of life by applying for financial support on their behalf under ‘special rules’.

Fast track to financial help
‘Special rules’ refers to certain benefits that are fast tracked for terminally ill patients, avoiding extra assessments and paying higher rates so people get vital help faster.

To qualify, a person’s life expectancy must reasonably be expected to be less than six months. It does not have to be certain and this is not an upper limit, meaning someone with a possible prognosis of five to 36 months could qualify.

Special rules apply to Employment and Support Allowance, which pays a weekly income. This can be means-tested or based on national insurance contributions, meaning it won’t matter if patients have savings or a partner who works, assumptions that can sometimes stop people from claiming. Other benefits include Personal Independence Payments (PIP), Disability Living Allowance (DLA) and Attendance Allowance (AA).

DS1500s have changed
To apply under special rules, a DS1500 form needs to be completed by a cancer nurse specialist or doctor and sent to the Department for Work and Pensions (DWP). This must be the new version of the form issued on 1 September 2017, otherwise the claim may not be processed.

It’s important to remember that a patient must still make a claim for the benefit even when a DS1500 form is sent to the DWP.

Digital DS1500 pilot
The DWP recently launched the digital DS1500 form in England to speed up the claims process for professionals who support people at the end of life. Macmillan Cancer Support contributed by identifying key cancer pathways and stakeholders as well as arranging for developers to shadow cancer nurse specialists and speak to benefits advisers and information centres.

The digital DS1500 was then tested with Macmillan nurses at Airedale Hospital before going live. Early results show that many users find it simpler and quicker to use than the paper version, resulting in terminally ill patients getting their money sooner.

The new digital DS1500 should speed up the claims process by an average of 10 days. Professionals need to have an NHS Smart Card to access the form so it is currently only available in England, but options for other nations are being explored.

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1. www.macmillan.org.uk/Documents/AboutUs/Health_professionals/PCCL/primarycareupdates
Supporting end of life patients financially in an acute trust

Professional and patient education is helping to raise awareness about financial support for terminally ill patients and their carers.

The process for making a claim for PIP and AA under special rules can be complex, and at the Wirral University Teaching Hospital NHS Foundation Trust, a lack of understanding was resulting in patients missing out or experiencing a delay in receiving benefits, which cannot be backdated.

The acute hospital does not have any specific benefits advice and patients are often too unwell to travel.

A ‘task and finish group’ of health and social care workers from a variety of sectors was assembled to explore ways of ensuring that patients are signposted appropriately and don’t miss out on financial support.

The group consisted of representatives from the Clatterbridge Cancer Centre, Macmillan Cancer Support, local charities offering benefits support (Age UK, Wirral Welfare Rights, Citizens Advice Bureau), Wirral Community NHS Trust, social services and the Wirral University Teaching Hospital. The breadth of knowledge, skills and experience within the group was pivotal to the success of this initiative.

Within the Trust, support was provided by the medical illustration, learning and development and communications teams, as well as governance and patient representative groups.

We have provided patients with leaflets about benefits and where to seek advice, and alerts have been added to patients’ records to encourage clinicians to consider whether someone is eligible for special rules.

A training podcast for health professionals has been created and all clinical areas have been allocated a special rules pack, including the DS1500 forms, letter templates and patient information leaflets. These materials are also available online.

This work has been included within the organisation’s end of life care strategy and we anticipate that more of our patients in the last weeks or months of life will now be recognised as eligible to claim under special rules, with a significant impact on their quality of life.

We have got lots of information about financial help and benefits for people living with cancer and their carers. You can find out more at macmillan.org.uk/benefits or download free information at be.macmillan.org.uk

You can also refer people to the Macmillan Support Line on 0808 808 00 00 where they can speak to an experienced welfare rights adviser or financial guide.
Preparing students for palliative care

Debra Morris and Angela Kelly from the hospital specialist palliative care team at Salford Royal NHS Foundation Trust talk about their award-winning student placement.

NHS England’s Strategy for End of Life Care supports the need for an increased focus on education of generalist and pre-registration nurses in end of life care. However, very few pre-registration students are exposed to specialist palliative care during their training.

Salford University had asked if we were able to provide ‘hub’ placements for pre-registration nurses. Whilst we recognised that students would benefit from exposure to practice, we did have some reservations as to whether we could spend enough time with the student and whether it was appropriate to shadow a palliative care cancer nurse involved in giving bad news and challenging conversations.

However, we were also mindful of the rich learning that could take place within palliative care and the need for confident staff trained in using recognised end of life care tools, able to engage in early conversations and aware of the importance of good care after death.

We decided that we would accept a student on a full hub placement with the team and review the experience.

Experiential learning
Research has suggested that pre-registration students have feelings of hesitancy and anxiousness when caring for a dying person. So we designed a welcome booklet and planned an individualised student program with a timetable of available learning opportunities.

We used reflection to highlight any concerns and offered students opportunities to discuss any experience that they may have found distressing.

Our aim was to prepare students for the realities of working with people at the end of life, encouraging them to be assertive and to seek out support whilst developing confidence to advocate for patients.

An invaluable experience
Students have said that they felt welcomed and valued when on placement with the team, which increased their confidence when working with patients nearing the end of life.

Our evaluations show that students have left this placement feeling a lot more prepared for caring for a person with palliative care needs, gaining valuable exposure in areas such as breaking bad news, end of life care and challenging pain and symptom management.

Students also understood the importance of early conversations with regards to a patient’s preferred place of care and death.

We were happy to receive a Student Nursing Times award this year, for best student placement of the year, and we now take pre-registered students on a regular placement.

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Increasing engagement with advance care planning

The new ACP Triple E Model helps to make sure that people are given the opportunity to plan for their future care.

The benefits of advance care planning (ACP), particularly in relation to improving a person’s end of life experience, are widely recognised at a strategic level, but there is still a reluctance to engage in this type of conversation.

Macmillan ACP facilitators within the Aneurin Bevan University Health Board, including Christine Fretwell and Pat Worlock, have developed a new model to increase awareness of the benefits of ACP among professionals and the public. It also aims to increase professionals’ knowledge, skills and confidence to open up the ACP conversation.

The model is in line with the Welsh Government’s End of Life Delivery Plan and the Gwent Palliative Care Strategy in South East Wales, and aims to empower people, through education, to engage with ACP. Known as the ACP Triple E model, it has been developed for the public, all health and social care professionals and stakeholders within Gwent. The vision is that this could be adopted throughout Wales.

Raising awareness
Using the principles of Byw Nawr / Live Now (Dying Matters in Wales), we have engaged with more than 1,400 members of the public in our first year. These interactions have taken place in public places, hospitals and more formally in health and local authority forums.

The evaluation and feedback from these events have informed the development of patient leaflets, posters and other promotional materials, including interactive games and merchandise, to encourage interactive conversation and start people thinking about their future wishes.

Empowering professionals
Our model uses education to empower health and social care professionals by supporting them to improve the knowledge, skills and confidence they need to engage in conversations about ACP with the people they support and care for, within the limits of their role.

We use a bespoke, blended e-learning tool, which features person-centred scenarios and interactive learning. This is supported by facilitated workshops with role play to reinforce learning. ACP champions are also being identified and trained within each sector to take ownership and responsibility for implementing the model and encourage sustainability.

Measuring impact
We are currently testing the impact of the ACP Triple E model in a pilot study focusing on the patients of six respiratory consultants. The aim is to determine whether increased public awareness and professional education make a positive difference to:
- health and social care professionals’ knowledge and perceptions of ACP
- documented ACP discussions with individuals.

This will be measured by comparing data that we collect before and after implementation of the model. The pilot will help us refine the model before it is cascaded throughout Gwent.

Dying Matters now works in Wales under the name of Byw Nawr (Live Now) as part of a three-year programme funded by the Welsh Government. Find out more at www.dyingmatters.org/wales

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Updated

**Self employment and cancer**
MAC12818
4th edition
This booklet is for people who have a cancer diagnosis and are self-employed. It includes practical information about cancer and treatments, balancing your health needs and your work, deciding who to tell and what to say to them, keeping the business operating, and managing finances.

**Understanding skin cancer**
MAC11653
10th edition
A booklet explaining skin cancer, covering the causes and symptoms, diagnosis, staging and grading, treatments and clinical trials. It also talks about emotional, practical and financial issues.

New

**Cancer and dementia**
MAC16126
1st edition
This booklet is about cancer and dementia. It is for anyone who has both cancer and dementia. It explains what may happen after you are diagnosed with cancer. It also has practical advice about ways to look after yourself when you have cancer and dementia.

**Understanding thyroid cancer**
MAC11655
10th edition
A booklet explaining thyroid cancer, covering the causes and symptoms, diagnosis, staging and grading, treatments and clinical trials. It also talks about emotional, practical and financial issues.

**Coping with hair loss**
MAC11627
9th edition
A guide for people whose hair has been affected by cancer treatment – for instance by becoming thinner or falling out. Offers advice on how to cope emotionally, as well as practical tips on wigs, headscarves, hats and turbans.

**Cancer and dementia – a guide for carers**
MAC16831
1st edition
This booklet is about cancer and dementia. It is for carers of people with both cancer and dementia. It has also information for family and friends. It includes tips on how to get support and look after yourself.

Crossword

**Clues across**
1 To go separate ways (4,7)
7 Crocus or daffodil
8 Stew vegetables, neeps
9 Cricket club?
10 A throng of bees
11 Replace with another
13 A fry-up, bubble-and-
16 Gate fastening
18 Fresh and modern
19 Without any definite flavour
20 Ferrous metal
21 The good luck arachnid? (5,6)

**Clues down**
1 A pot-belly
2 Inked typewriter strip
3 Bulls and cows
4 Scores or grades
5 Stir up public feeling
6 Muslim women’s veil
11 Essential for bones and teeth
12 Skilled workman
13 Make fun of (4,2)
14 Become less tense
15 Chain mail
17 Pleased and content