Dr Anne Johnson
Macmillan Consultant
Occupational Therapist

In focus
Technology

Sharing good practice
Mental health and cancer
Welcome

Welcome to the Autumn 2019 edition of Mac Voice.

In our Q&A we meet Dr Anne Johnson, Macmillan Consultant Occupational Therapist and Joint Clinical Lead at the Bath Centre for Fatigue Services. Find out why she set up the service and how it supports people with cancer on page 10.

On page 14, we introduce the Macmillan team supporting the North East Ambulance Service to improve palliative and end of life care for people with cancer. And on page 18, we hear about the impact of partnership working on cancer care in Leeds. You can also find out more about the inspirational winners at the Macmillan Volunteer Awards on page 22.

The In Focus section explores how professionals are using technology to support people with cancer. This includes online consultations in the Scottish Highlands, a new app for physiotherapy exercises and a virtual reality project to create calm, soothing environments for people going through treatment.

Sharing Good Practice looks at mental health and cancer – from new research into the experiences of people with cancer who have a mental health condition, to best practice examples of current psychological cancer care.

And on page 32, find out more about new and updated Macmillan resources for people with cancer.
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How we did in 2018

Macmillan published its annual report in July, showing the life-changing impact that professionals are making for people with cancer.

In 2018, 1.9 million people received personal, in-depth support from one or more Macmillan professionals or services. This is up from 1.6 million in the previous year, an increase of 14%. And if we include people who used our information resources and range of online support too, this figure rises to a total of 6.7 million people.

Macmillan professionals are key to enabling us to reach these people. Thank you for the life-changing work you do every day to make this possible.

Our supporters raised an incredible £230.8 million in 2018. While this was lower than the year before, the money we spent on services for people with cancer increased. We spent a record £195 million – £3 million more than in 2017.

This allowed us to fund more Macmillan professional roles to meet the individual needs of people living with cancer and make cancer services more effective. We now have 1,200 more Macmillan professional posts than in 2017, an increase of 14%. Macmillan nurses made up more than half of this growth.

We are making good progress, but there is still so much to be done to meet the needs of the growing numbers of people with cancer.

It is a challenging time for the sector. Brexit negotiations have caused much uncertainty, both in terms of fundraising and the implications for health and social care. And last year we saw a general trend of fewer people making donations and new rules around who we can contact, which had an impact on our fundraising.

This meant we had to review our plans, but our focus is on protecting frontline services that support the people who need us most, and making sure we are innovating to meet the challenges of a changing fundraising landscape.

Last year we set out a five-year strategy and already we are seeing results. This year we have taken great strides in developing services and other professional roles to help people with cancer navigate their way through the healthcare system, from diagnosis onwards. These include:

• Establishing 12 ‘Right by You’ test sites around the UK, trialling different ways to support people with cancer as they move through the health and social care system.

• Setting up new End of Life collaborative sites to help us spread best practice principles of end of life care.

• Testing a new, integrated approach to our money and work support service. This comprises face-to-face advice on benefits and Macmillan grants in hospitals in Nottinghamshire. The service can directly refer people for further advice on the Macmillan Support Line.

This is just the beginning. With your support, we look forward to being even more ambitious in demanding more for people living with cancer.

You can read the full annual report at macmillan.org.uk/annualreport

You can find out more about our strategy, including Right by You, at https://learnzone.org.uk/strategy
Surge in work-related concerns

Macmillan expands its Work Support Service following a rise in calls about work and cancer.

Last year, Macmillan saw a staggering 74% rise in calls to its Support Line about work-related issues. We have now expanded our Work Support Service – a team of advisers on the Macmillan Support Line, who are trained to provide information and support to people struggling with the impact of cancer on their working lives.

A 2018 online survey conducted by YouGov1 shows that 87% of people in work when diagnosed with cancer felt that it was important to continue working after their diagnosis. Yet:

• 10% felt pressured into returning to work before they were ready
• 23% of people who did return, said they went into work despite not feeling well enough to be there
• 10% felt the need to disguise cancer symptoms, like fatigue and sickness, in the workplace.

Worryingly, more than a quarter (27%) of people said they received no support to help them return to work. Lisa, a former administrator, went back to work after being diagnosed with womb cancer. She recalls: ‘I was made to take holiday for necessary medical appointments. There were days when I was exhausted and couldn’t face work, but I pushed myself to go in and pretend everything was okay as I had bills to pay and was terrified I would lose my job.’

Employers could be breaking the law if they do not make reasonable adjustments to support people with cancer at work. These can include giving employees an adjusted work pattern to help them cope with fatigue during and after their cancer treatment.

The Macmillan At Work programme offers employers a free toolkit, advice and training sessions to help them support employees returning to work after a cancer diagnosis. Over 10,000 line managers and HR professionals are already participating in this programme.

Employees with cancer can call our work support advisors for free on 0808 808 00 00 (Monday to Friday, 8am to 6pm). See page 32 for our resources on work and cancer, or for more information about Macmillan’s Work Support Service, visit macmillan.org.uk/work  

1. Reported statistics from YouGov online survey between 29 June and 22 July 2018.

News in brief

Men and cancer campaign
Around 500 men are diagnosed with cancer every day in the UK. Yet, men often find it difficult to talk about cancer and its emotional impact or ask for support. In June this year, Macmillan launched a new campaign, supported by our corporate partners, to encourage more men with cancer to talk about what they find it hard to say. One of the men featured is 38-year-old Kiwi, who was diagnosed with chronic myeloid leukaemia in 2012 and subsequently had a breakdown. He explains, ‘I spoke to someone on your Support Line at a time that I was very, very low and sad. I will be eternally grateful. When you have cancer, dying is not an abstract concept, it’s real. People don’t want to hear that you’re scared of death, but it’s important to talk and it’s important that people listen.’ To find out more, visit macmillan.org.uk/letstalk

Macmillan celebrates Volunteer’s Week
Volunteer’s Week took place on 1-7 June 2019 and this year the theme was ‘Time to celebrate’. We celebrated the massive difference that Macmillan’s tens of thousands of volunteers make to people living with cancer. From taking calls on our Support Line to visiting people at home or running marathons, volunteers are key to helping us deliver our strategy. In 2018 our volunteer committees and fundraising groups raised £7.5m, while 517 volunteers gave 19,149 hours of practical and emotional support to 1,166 people with cancer. Last September 1,412 volunteers took part in Marks & Spencer collections, making this our single largest volunteering activity ever. You can read about the fantastic winners at this year’s Macmillan Volunteer Awards on page 18. For more information about volunteering for Macmillan, visit macmillan.org.uk/volunteer

Mac Voice online
Did you know you can read Mac Voice online? Both Mac Voice and Sharing Good Practice are available as downloadable PDFs at macmillan.org.uk/macvoice We upload the latest issue at the start of every quarter. You can also see previous editions from the past two years.
Transforming Cancer Services Together

New programme aims to deliver better cancer care in North Wales.

Betsi Cadwaladr University Health Board and Macmillan have set up a new programme to redesign the way services are delivered to provide better care and support for patients.

The recent Wales Cancer Patient Experience Survey found that while most people diagnosed with cancer in North Wales have a positive experience of care, there are also areas for improvement.

The Transforming Cancer Services Together programme aims to identify and deliver these improvements. It is looking specifically at breast, lung, colorectal and urological cancers in its first phase.

The ideas of health professionals and people affected by cancer will help shape the redesign of services. Vivienne, 56, was treated for breast cancer in 2012, and again last year after it returned. She says, ‘For me it was about the co-ordination of care. I felt I wasn’t receiving enough information and it meant I had to telephone around to find out what was going on. Had I not asked questions or clarified, things may not have run so smoothly.’

This is the first programme in Wales to examine a patient’s entire journey, from referral by a GP, to treatment in hospital, to living with and beyond cancer. Macmillan is funding the £900,000 programme as part of a £6 million investment in local cancer services since 2010.

The programme will run for the next two to three years and is being led by Macmillan Programme Manager Yvonne Lush, who is also a former breast cancer nurse specialist.

Yvonne says: ‘There are lots of ways for patients to get involved, by attending meetings, to taking part in surveys, joining a group discussion or talking to us one-to-one about your experience. By sharing your story, you can help us to make a big difference.’

For more information on Transforming Cancer Services Together visit bit.ly/2W0vHKB.
Award-winning service for parents with cancer

Macmillan Lead Cancer Nurse, Sheree Hall, explains how a hospital information and support centre has become a vital community resource.

The Macmillan Information and Support Centre at Chesterfield Royal Hospital has supported over 7,000 people since it opened in 2017.

The centre offers a range of information and support services, such as welfare rights advice, emotional support, a walking group, hair loss services and much more. Personalised care is at the heart of our service design. We also have a user reference panel, who are instrumental in developing the services that we provide.

The service is run by a Macmillan Information and Support Lead, and supported by a Macmillan Information and Support Associate and an Information and Support Assistant. We also have a fantastic small team of volunteers, who assist our staff and give valuable support to people affected by cancer.

Our Macmillan Information and Support Lead, Maria Leadbeater, won the Fiona Littledale Award at the 2019 Patient Experience Network Awards. This prestigious award recognised her service supporting parents diagnosed with advanced cancer, who have dependent-aged children. She encourages parents to:

- plan difficult conversations with their children
- consider whether they want to write letters for the future
- start thinking about memory boxes, if appropriate.

At a one-to-one support session, Maria can help to identify age-appropriate resources to facilitate conversations between parents and children. These resources can then be given out during the session.

The centre is a vital resource for both clinical staff and people affected by cancer. It helps to free up clinical staff time, so that they can concentrate on dealing with specialist clinical issues. They signpost people to our centre, where we can spend time talking to them and then personalise the information and support needed.

Not all clinical staff and people affected by cancer have their clinic appointments close to the centre. For this reason, we needed to consider how we could ensure equal access for all. Macmillan Information and Support Associate, Sian Woodcock, has been in post since September 2018. She takes mobile resources out to all suitable clinical areas, providing information and support to certain clinics. Sian has also recently started a walking group, which meets at the centre every week. The group is well attended and is a great way to encourage people to return to exercise after a cancer diagnosis.

Soon we hope to start a Holistic Needs Assessment (HNA) service run by our Information and Support Associate and Assistant. This service will be offered to people whose clinical teams have completed their first HNA. If you have experience of this that you would like to share or wish to ask anything about our service, please get in touch.

Further information

Sheree Hall
Macmillan Lead Cancer Nurse
Chesterfield Royal Hospital
shereehall@nhs.net

macmillan.org.uk/macvoice
Cancer waiting times continue to spiral upwards


According to a new Public Accounts Committee report, only 38% of NHS trusts in England are meeting the 62-day waiting times standard for referral to treatment for people with cancer.

NHS operational standards state that:

• 93% of patients should be seen by a cancer specialist within two weeks of being urgently referred by a GP for suspected cancer

• 85% of patients diagnosed with cancer should be treated within 62 days following their GP referral.

The NHS has not achieved the 62-day waiting time standard since 2013. Poor performance against waiting times standards is widespread, although there are significant variations across local areas and hospitals. This regional variation is closely linked to shortages in staff who are involved in diagnostic tests, such as pathologists, radiologists and radiographers.

Dr Fran Woodward, Macmillan Executive Director of Policy and Impact, said, ‘We need the government to ensure that the final plan for the NHS workforce is urgently prioritised and fully-funded. We desperately need enough staff with the right skills to provide people living with cancer with the right care at the right time.’

She added, ‘Waiting for a diagnosis or treatment can cause increased levels of anxiety during what is an already stressful time. These unnecessary delays only serve to prolong the anguish and increase the strain on people living with cancer and their families.’

Between 2010/11 and 2017/18, the number of urgent referrals for suspected cancer increased by 94%. This growing patient demand risks exacerbating the continued failure to meet cancer waiting times standards.

The report calls for the NHS to take urgent action for treating patients within the set waiting times. The long-term funding settlement for the NHS, the NHS Long Term Plan and the current review of waiting times standards all create ‘an opportunity to get the NHS back on track’ in meeting national targets.

The Chair of the Public Accounts Committee, Meg Hillier, said, ‘NHS England’s review of waiting times is now more crucial than ever. However, this cannot be an opportunity for standards to slip, any changes must protect and improve patient outcomes. Ultimately, NHS England must steer waiting times standards back on course to prevent further decline. We call on the NHS to outline and commit to a firm timescale and plan for delivering this.’

For more information and to read the full report, visit bit.ly/2KQK3eK
Physical activity campaign

Leading health charities launch a new campaign to help people with long-term health conditions become or stay physically active.

The We Are Undefeatable campaign is running in partnership with 15 leading health and social care charities in England, including Macmillan.

The campaign aims to challenge misconceptions that people with long-term health conditions can’t be physically active. Insight from the campaign indicates that living with a long-term health condition can feel unpredictable and make it difficult to be physically active. The campaign seeks to empower people to build activity into their lives in small and achievable chunks, in a way that suits them.

The campaign will be promoted in England on TV and radio, in GP surgeries and pharmacies and through charity communication channels. People can visit weareundefeatable.org.uk for information and advice about being active, as well as signposts to charity partners’ websites for information about physical activity services.

Although Macmillan is not currently funding new physical activity services, we are using evaluation and insight to improve our existing physical activity services. This includes signposting people to services outside of Macmillan that can help meet their needs.

As part of our strategy, we want to make sure more people with cancer have regular conversations with healthcare professionals about their needs, including physical needs, to enable them to find the right support.

We’re also using evidence to inform and influence the wider system to work together to help people living with cancer become more active. Being a part of the We Are Undefeatable campaign is an example of this.

Trusted health professionals are well placed to recommend physical activity to people living with and beyond cancer. We know that brief advice from a health professional would help one in four people to be more active, and we value their help in encouraging people who are inactive or face challenges to become and remain active.

We find that most people using physical activity behaviour change services are referred by health and social care professionals.

Macmillan has free online training for professionals on physical activity and cancer, and how to give effective advice. We have also developed evidence and insight to support and influence those commissioning or reviewing services in cancer care, and other long-term health conditions, to recognise the value of physical activity. You can find out more at macmillan.org.uk/physical-activity.

We also have a range of resources to support people with cancer to become or stay active. This includes our Move More guide to becoming more active with ongoing digital support. More information is available at be.macmillan.org.uk.
## Q&A: Dr Anne Johnson

**Job title**  
Macmillan Consultant Occupational Therapist

**Location**  
Bath Centre for Fatigue Services

**In post**  
Since 2012

**Contact**  
anne.johnson19@nhs.net

**Why did you set up the Bath Centre for Fatigue Services?**

I qualified as an occupational therapist in 1991 and have cared for people with a variety of conditions. In 2003 I was leading the rheumatology therapies service at the Royal National Hospital for Rheumatic Diseases, and all the patients we saw had significant fatigue, but there weren’t any dedicated fatigue services. My co-lead Nikie Catchpool and I saw an invitation from the Department of Health for expressions of interest to start fatigue services from scratch. After speaking to our medical director, local GPs and service users, we put together a bid. Although we got less than half the money we asked for, we managed to set up the service with just one full-time occupational therapist and a part-time secretary. The service has grown, and we now provide outpatient services for more than 400 adults with complex fatigue linked to a variety of long-term conditions.
How does the service support people with cancer?
We originally set up the service to support people with chronic fatigue syndrome, also known as ME (myalgic encephalomyelitis). Then three people I knew locally had cancer treatment themselves, and all experienced cancer-related fatigue. We were starting to understand more about this, and in 2012, we worked with oncologists and service users to bid for Macmillan funding to extend our fatigue services for people living with and beyond cancer.

All of our services here have been designed with strong patient and public involvement. Patients are our greatest ally. Our aim is to empower people to take back control over their lives.

What does treatment involve?
We ask people to complete a set of questionnaires telling us about their diagnosis and symptoms, their work and leisure activities, and their fatigue and mood scores. Importantly, we ask them to tell us what they expect from our service, which helps us to understand the level of support they will need. We provide a six-week fatigue management programme, and support over Skype or phone for people who live further away.

We provide a range of interventions, including strategies for re-engaging with values-based living, working out energy baselines and understanding what impacts energy. One of the main interventions we provide is vocational rehabilitation. This can be anything from information and social prescribing about work and cancer, to providing letters of support for reasonable adjustments to their workplace, role and routines, or advocacy between the patient and their employer.

We don’t discharge people from the service after six weeks – they can contact us any time if they need further support. After six months we invite them back for a follow-up appointment. We know that after six months, a significant number of service users will see a reduction in the impact of fatigue on their day-to-day lives.

What does your day-to-day role involve?
As well as seeing more complex patients, I am responsible for making sure that we embrace and reflect new evidence. I also support a variety of health and social care professionals on academic placements. We are very inter-professional here – we don’t work in silos. The team provides a good skill mix, including backgrounds in mental health and recent experience in social and community care. It’s about pushing boundaries and promoting the development of cancer rehabilitation.

I am also involved in national work, including sitting on the Macmillan allied health professional (AHP) expert advisory group. Recently I have been part of the James Lind Alliance steering group for the Royal College of Occupational Therapists, who are currently setting their research priorities in partnership with patients and health professionals. I have also really enjoyed facilitating a series of roadshows with Leukaemia Care UK to provide information and education about fatigue for people with blood cancers. I also do lot of teaching at the University of West England, and we often take students on placement here, so that links up nicely.

How does being a Macmillan professional support your work?
I can’t thank Macmillan enough for providing us with funding for training and personal development, which helps us keep up to date with the latest interventions and evidence for patient benefit. Macmillan also supports our awards at the University of West England for the best AHP-related undergraduate research project, as well as our AHP conference.

What improvements would you like to see in the care of people with cancer-related fatigue?
I would like to see NHS England prioritising fatigue. Fatigue is one of the National Cancer Research Institute’s top 10 research priorities, so we need to support services in line with that. It seems remiss not to support services like ours, as part of primary care, to reduce the burden on GPs, on patients, and on our economy by helping people to stay in work. It would make a great difference to people living with and beyond cancer and their families.
The Recovery Package in action

Macmillan Recovery Package Programme Manager, Avril van der Loo, and Macmillan Lead CNS for Uro-oncology, Hilary Baker, on providing personalised holistic support for men after prostate surgery.

Recovering from cancer treatment can be a difficult time for many. There are various ways that life can change because of treatment. People can often manage better with tailored or personalised support and the Recovery Package interventions are designed to help provide this. University College London Hospitals is working to implement these interventions and we are making great progress.

The pathway for men having a prostatectomy (the surgical removal of all or part of the prostate gland) within our service has significantly improved due to the Recovery Package. In the third quarter of 2018/19, over 80% of men received a holistic needs assessment (HNA) before treatment and 69% attended a tumour-specific health and wellbeing event.

When treatment options are explained to patients with prostate cancer, there is a significant amount of information for them and their families to absorb. To make an informed choice about treatment, the support of a clinical nurse specialist (CNS) is crucial. In view of this, we wanted to embed all elements of the Recovery Package and hopefully succeed in delivering personalised holistic support.

Holistic needs assessment (HNA)
HNAs have always been used, but this was not systematic. We began by looking at ways to make that happen.

An HNA should first be provided around the time of diagnosis. This was challenging because the appointment structure did not provide appropriate time and space. We therefore decided...
to introduce the first HNA at a newly-established ‘surgical school’, which all patients attend before treatment. This is a two-hour session led by a CNS, covering topics such as:

- what to expect on the day of surgery
- specific details of the operation
- what to expect in both the short and long term.

The new way of carrying out the HNA gives us a much better opportunity to explore holistic support and common concerns. We tested various methods of completing the assessments and care plans. Due to the group nature of the sessions, we implemented a paper-based HNA.

We introduce and give out the assessments at the beginning of the session. Patients are invited to select concerns and think about them. At the end of the session, they are given time to consider whether they have outstanding concerns that have not been addressed. They can highlight these for individual discussion with the CNS.

Subsequently, the CNS contacts the person with cancer to prepare their care plan. All paper plans are retrospectively entered onto an electronic HNA system to complete the record. We aim to use the data collected (displayed in the pie chart) to respond actively to concerns on the day and help inform future sessions and delivery of information.

Treatment summaries
Unlike the HNA, treatment summaries were introduced as a brand-new concept. The initial challenge was the lack of an obvious person to complete them. We started by asking surgeons to prepare these summaries, but that did not work well because they tend to see patients shortly after surgery. This was felt to be the wrong time for delivering an effective treatment summary.

After the first post-operative appointment with a surgeon, patients have more follow-up support with a CNS. We therefore arranged for a CNS to complete the treatment summary. That felt much more appropriate and is working well. However, this is still a work in progress. We hope to ensure that all patients are given a treatment summary over the coming months by establishing a dedicated clinic.

Health and wellbeing events
All patients at University College London Hospitals have access to our generic group event, which is run by the Macmillan Support and Information Service. In addition, for prostate surgical patients, we have introduced a dedicated two-hour post-treatment seminar. This provides access to important information for a good recovery.

The seminar is typically held around 10 weeks after surgery. It covers a range of topics, including psychological health, continence, vacuum pump demonstrations and exercise. A CNS oversees the session to provide any additional support or advice, including onward referrals. The CNS also ensures that patients are offered a HNA and have a follow-up care plan.

Our patient representative, Chris Cottrell, helps to host the post-treatment seminar. He explains, ‘In the seminars, I talk about my prostate cancer journey since 2011 and how structured exercise has made an enormous difference to my outlook and my quality of life. Talking about my experience provides encouragement, inspiration and support to patients and partners during what can be a challenging period adjusting to post-surgery life.’

Avril van der Loo
Macmillan Recovery Package Programme Manager
University College London Hospitals
avrilvanderloo@nhs.net

Hilary Baker
Macmillan Lead CNS for Uro-Oncology
University College London Hospitals
hilary.baker2@nhs.net

Further information

1. macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package

References

Further information
Providing palliative care within the North East Ambulance Service

Macmillan Nurse and End of Life Care Facilitator, Sarah Turnbull, on supporting more people with cancer to achieve a good death.

The North East Ambulance Service NHS Foundation Trust (NEAS) covers 3,200 square miles across the North East region. It employs more than 2,600 staff and serves a population of 2.7 million people. The trust handles all NHS 111 and 999 calls for the region, patient transport and ambulance response services, training for communities and commercial audiences and provides medical support cover at events.

The Macmillan Supportive Palliative and End of Life Service team was set up at NEAS in 2018. I’m part of the team that also includes engagement officer Paul Galloway and administrative assistant Chloe Ince. Together we provide:

- a dedicated point of contact for acute and community services
- timely transfer of information sharing from primary and acute care to the North East Ambulance Service
- engagement with developing services to enhance care for specialist palliative and end of life patients
- influence in national, regional and local palliative and end of life care agendas.

The World Health Organisation defines palliative care as an approach that improves the quality of life of patients and their families facing life-limiting illness, through the prevention and relief of suffering by means of early identification, assessment and treatment of pain and other problems such as psychological, social and spiritual. Many palliative and end of life patients will be cared for in hospitals or hospices, but others will be cared for in their own homes, care homes and other facilities. They may require care and support from various other professionals.

Ambulance services play a crucial part in delivering high-quality care at the end of life and in enabling people to achieve what they would consider a good death, especially in times of crisis and uncertainty. This was recognised in the Department of Health's End of Life Care Strategy (2008), which highlighted three important roles for ambulance services:

- the rapid transfer of the dying patient
- developing appropriate transport for the patient or carer
- developing robust information sharing systems.

However, to enable ambulance services to provide high-quality care, a unique set of challenges and barriers need to be addressed and overcome. Ambulance clinicians often find themselves responding to people at the end of life with very limited information about the person’s history, condition, preferences and wishes. They may have to make difficult and time-critical decisions, often in isolation. Education and training for frontline staff in palliative and end of life care is often limited and varies across organisations.

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The Route to Success – A guide for ambulance services was published in 2012 and aimed to improve the quality of end of life care provided by ambulance services. It was recognised that ambulance services could support more people to achieve a good death and reduce unnecessary
or unwanted hospital admissions. This would involve providing clinical expertise through training, education and coaching for staff, and developing and implementing policies and guidelines to improve services.

We are implementing a service development plan focusing on six key themes:

- strategy
- education
- end of life care transport
- information sharing
- governance and reporting
- networking and engagement.

We work closely and collaboratively with internal and external stakeholders nationally, regionally and locally and with our acute, primary and third sector partners. We provide education and training for frontline staff, student paramedic staff and our health advisors. We also offer a dedicated point of contact within NEAS for acute and primary care services, offering timely responses to information requests.

We work with healthcare providers throughout the North East to promote and encourage information-sharing about their patients. This can include end of life care plans, such as DNACPR (do not attempt cardiopulmonary resuscitation), EHCP (emergency health care plan) and ADRT (advance decision to refuse treatment). We audit some of this information-sharing, which is communicated at a strategic level.

We will continue to embed, promote and audit the use of our unique and dedicated end of life care transport service throughout the region. This specialist service ensures that patients are discharged to their chosen setting for end of life care. The overall aim is to reduce unwarranted and unnecessary hospital admissions for people with palliative care needs and people nearing end of life.

So far, we have reduced emergency department attendances to 24% in the first quarter of 2019, down from 27.5% in 2018. This figure relates to patients that NEAS are aware of, and who have end of life care planning in place. The team are currently engaging with patient and carer focus groups within the region to help further shape and co-design the service.

Further information

Sarah Turnbull
Macmillan Nurse and End of Life Care Facilitator
North East Ambulance Service NHS Foundation Trust
sarah.turnbull@neas.nhs.uk

macmillan.org.uk/macvoice
Examining the problem of funeral poverty

Macmillan Social Welfare Officer, Kevin Moore, highlights the increasing struggle to afford funeral costs faced by families after a loved one has died.

Five years ago, I wrote an article for Mac Voice called ‘Too poor to die’. This highlighted the difficulties that some people have in affording funeral costs for loved ones and family members. Since then, awareness of the issue has increased. Yet, the problem of being unable to afford funeral expenses persists and research shows that it has escalated.

When the welfare state was introduced in 1948, funerals and disposal of the body became fully funded through a Universal Death Grant available to everyone. Over the years, however, the grant decreased in value and was eventually replaced in 1989 by a means-tested Funeral Expenses Payment. This meant that only those getting certain benefits would qualify.

Rising costs
As eligibility criteria have tightened and austerity measures have affected other benefits, funeral prices have increased by 122% since 2004. The average cost of a basic funeral is now £4,271. By contrast, the Funeral Expenses Payment has not risen in real terms since 2003 and now averages only about £1,500 (including disbursements of around £700). Geographical variations can affect these average sums.

Processing delays are another problem and about 50% of applications for a Funeral Expenses Payment are refused. This often happens after the funeral has taken place and can leave those taking responsibility with considerable debts. There is also a societal expectation of a ‘good send-off’ and decisions may be influenced by emotion rather than financial prudence.

Possible solutions
The causes of funeral poverty are multi-faceted, and the possible solutions can be just as varied.

The Funeral Expenses Payment system may be regarded as a cause of funeral poverty. However, it is also the only way that some people can afford to pay a lump sum towards funeral costs. People sometimes have to use Bereavement Support Payments, which are meant to help with the financial changes after a spouse or civil partner has passed away, to pay off funeral debts instead. In both cases, eligibility criteria limit who can claim.

Grants from charitable organisations can help towards funeral costs and social media crowdfunding has been used in individual cases. Advance planning and purchasing pre-paid funeral plans can help avoid a crisis, but many people cannot afford the instalments.

Basic funerals are available, which offer people a limited choice of service. There is also the more recent option of direct cremations, which allow the funeral director to carry out the cremation in their own time. There is no service with a direct cremation and family and friends cannot attend. In this case, the price is reduced to an average of £1,712.

Local authorities and hospitals have a statutory duty under the Public Health (Control of Diseases) Act 1984 to make funeral arrangements in certain circumstances. These are where an individual dies intestate (without a will) and no-one is willing to take responsibility. Termed as public health funerals or national assistance funerals, many see these as a last resort.
A work in progress
As a Macmillan Social Welfare Officer, I have long been aware that the social stigma associated with public health funerals can deter people from making legitimate applications. Instead, they may take out loans to fund any shortfall. Being unable to fulfil the expected celebratory obligations to the person who has died can create emotional and psychological issues. It can also affect the grieving process.

Culturally, there has been a reluctance to talk about death and dying. According to the SunLife Cost of Dying Report 2018, only 1% of family members knew the wishes of the person who has died. That needs to change, and Macmillan professionals, health and social workers and hospice staff are in an ideal position to initiate those talks. Recently, we have seen the emergence of ‘death cafes’ that encourage people to talk about death and their wishes. This openness should be promoted.

In terms of policy, Funeral Expenses Payments should be increased, and the criteria widened to allow more people to apply. Hopefully the impetus for change should continue and, in time, ‘no-one should be prevented from having a dignified funeral and no-one should be forced into debt by the cost of organising a funeral’.

For more information about the Funeral Expenses Payment visit gov.uk/funeral-payments

Macmillan offers a range of financial support for people affected by cancer. By calling the Macmillan Support Line free on 0808 808 0000, people can access support from our money and work team 7 days a week. This includes information about benefits, Macmillan grants and dealing with energy bills. Find out more at macmillan.org.uk/supportline

Financial support from Macmillan

Further information

Macmillan financial support and welfare rights advisers can help with money worries.

Kevin Moore
Macmillan Social Welfare Officer
Care Plus Group
kevin.moore1@nhs.net
The power of partnerships

Professor Sean Duffy, Clinical Director for the Leeds Cancer Programme, reflects on working closely with Macmillan to improve cancer services and outcomes for people in Leeds.

I moved back to Leeds in 2016 after working in London as National Clinical Director for Cancer with NHS England. Following the launch of the National Cancer Strategy in 2015, key leaders in the field of cancer wanted to bring together a range of partners to improve the delivery of cancer services in Leeds.

There is a shared will and unity across clinical commissioning, acute providers, public health and Leeds City Council to improve outcomes significantly for people affected by cancer in Leeds. From these early conversations, Leeds Integrated Cancer Services (LICS) was established, with myself acting as Co-Chair with Dr Sarah Forbes, following on from Professor Peter Selby.

Through bi-monthly networks, we developed a city-wide mechanism to steer and oversee cancer ambitions and system-wide change. Involving Macmillan in the set-up of LICS was key to the partnership. We could all see the benefit that partnership working and funding could bring to transform the infrastructure of Leeds’ cancer services.

Macmillan Programme Manager Steve Edwards says, ‘Despite best efforts, cancer outcomes in Leeds, whilst improving year on year, are not the best in England and there is a city-wide ambition to do better. Macmillan’s partnership with LICS is a unique opportunity to be involved in a city-wide programme for cancer transformation that will function across health and social care to improve outcomes for people with cancer in Leeds. This programme allows Macmillan to help deliver change at scale and at pace for people being diagnosed and living with cancer.’

Bringing together the NHS in Leeds, Leeds Teaching Hospitals, Leeds City Council, Public Health, Cancer Research UK, Macmillan and the University of Leeds, LICS developed several key priorities and identified opportunities to apply for national funding. This was the start of a highly structured approach to managing projects across the range of cancer pathways. We implemented areas of work that supported the breadth of a cancer experience – and a city-
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wide approach allowed us to create a programme of work that was patient-centred and encouraged cross-boundary working.

This network was the inception of the Leeds Cancer Programme, which was launched in 2017. We recruited a small workforce to develop and implement four work streams:

- Preventions, Screening and Awareness
- Early Diagnosis
- Living With and Beyond Cancer
- High Quality, Modern Service

Two years on, I can see the tangible results of that combined vision and drive. For example, in a relatively short space of time, our bowel screening champions (usually non-clinical practice staff) encouraged 1,089 people to complete a screening test who may not have done so (April 2018 – March 2019).

We have also implemented ‘teledermatology’ equipment in primary care, where we equip GPs with an iPod with an attached dermatoscope to take high quality images of suspected moles or legions. These are then sent electronically to clinicians to assess and triage within secondary care. To date, 5,810 people have been triaged electronically, reducing wait, anxiety, and the burden on hospitals.

Our cancer care reviews have yielded some fantastic results. Unique and tailored support has been provided to 213 people in two areas of Leeds following their cancer diagnosis and treatment. This is a great example of how patients can be supported in their own community and a potential model for the future.

Now, in the third year of the Leeds Cancer Programme, I know that across the city we can all feel very proud of what has been implemented and achieved. Some of the work of the programme will naturally move towards ‘business as usual’ for a wide range of organisations that prevent, diagnose, treat or care for people with cancer.

We leave a legacy from our activity, as the model of the programme has developed into a template for use by further large-scale, multi-million-pound investments in cancer care, as well other serious diseases in the city. We will progress towards making Leeds a ‘Cancer Aware’ city, where everyone can access knowledge and information to spot vital signs of cancer and the support available.

We have also contributed to cancer developments nationally, by rolling out several national pilots. One example is the ACE pathway (Accelerate, Coordinate, Evaluate), a new initiative for patients with non-specific but concerning symptoms. The pathway brings together clinicians to assess a person’s symptoms and history. Also, our Teledermatology success will be used as a model for other clinical commissioning groups in the West Yorkshire and Harrogate regions to roll out.

I am acutely aware that these rapid successes in Leeds have been shaped by close partnership work and funding from Macmillan. This has enabled us to recruit the right Macmillan professionals into the right roles to lead change management. We have been able to work as a team across organisational boundaries throughout the city, and for that opportunity we are truly grateful to Macmillan.

For more information, visit [leedscancerprogramme.org.uk](http://leedscancerprogramme.org.uk)
Striving for fairer cancer care

Macmillan Head of Policy and Influence (Health and Care), Andrew Kaye, on a new report to tackle health inequalities for people living with cancer.

When the NHS was created in 1948, the Minister of Health Aneurin Bevan set out an ambitious vision. He stated, ‘The essence of a satisfactory health service is that the rich and poor are treated alike, that poverty is not a disability and wealth is not advantaged.’

To what extent has this vision of good healthcare for all, regardless of wealth, been realised?

In April 2019, the Macmillan Policy and Influence Team published a new report called Health Inequalities: Time to Talk. This report aims to highlight the injustices that socio-economically deprived people face when living with cancer. It also reopens the debate on what we should do in England to achieve fairer cancer care.

**Key findings**
The report highlights health inequalities throughout the cancer pathway. People living in the most deprived areas of England:

- are 20% more likely to have their cancer diagnosed at a late stage
- have less surgical treatment (40%, compared to 48% in the least deprived areas)
- receive only half the number of referrals to early-stage clinical trials
- face almost 25% more emergency admissions in the last year of their life and are more likely to die in hospital against their wishes.

We believe that the key to addressing these inequalities is to understand their root causes. Diagnosis delays in deprived areas may be linked to lower uptake of cancer screening, health literacy and awareness of symptoms.

There are also barriers to getting the right support after being diagnosed with cancer. Rahma from Buckinghamshire described how she was given her diagnosis in terms that she did not understand: ‘I was told that it was Burkitt’s lymphoma on the evening of April 17, when I had nobody there with me. I actually had to ask them if lymphoma was cancer, because they weren’t saying it. I was upset and emotional and just in a daze.’

Inequalities persist right up to the end of life. People from deprived areas are less likely to engage in early or open conversations with health professionals about their end-of-life care.
Unmet needs
According to our new research, people living with cancer in the lowest income households are:

• almost twice as likely to express a need for more emotional support
• twice as likely to want more practical support inside the home
• three times more likely to need practical support outside the home.

Unmet emotional, practical and social care needs are associated with poor mental health, being left housebound and unnecessary hospital admissions.

Time to Talk
Our report launches a national conversation on addressing health inequalities throughout the cancer pathway. To achieve progress over the next decade, we require:

• a clear vision for tackling inequalities, both locally and nationally
• a clear account of the exact resources, evidence and support local providers need from national governments to deliver on inequalities
• a commitment to targeted action, where inequalities are most in need of attention.

One of the best ways to overcome health inequalities is through personalised cancer care. It is vital that everyone diagnosed with cancer has high quality, inclusive conversations with professionals, who are fully trained in discussing their clinical and non-clinical needs. A holistic needs assessment can capture someone’s specific needs associated with living on a low income, such as around housing and finances.

Another priority is to provide accessible, bespoke information for all people living with cancer. This can empower those from less affluent backgrounds to become actively involved in decisions about their care and treatment. The health sector should widen access to psychological therapies and better direct people to practical and community support.

The original vision of the NHS was based on social equality. At Macmillan, our goal is to see unfair differences in cancer care dramatically reduced over the next 10 years. It is time to talk about how we can protect some of the most excluded and vulnerable members of society.

You can read the full report at macmillan.org.uk/health-inequalities
Macmillan Volunteer Awards 2019

Each year we celebrate our amazing volunteers around the UK.

The Young Macmillan Champion Award
For inspiring and exceptional young volunteers

Beau McKee
Beau and his brother Alfie took part in Run January, running a minimum of three miles each day, and tackling wind, rain, snow and ice. Beau then decided he was going to run every day in 2018 – running an incredible 1,456 miles and raising almost £28,000.

The Vicky Clement-Jones Award
For using a personal cancer experience to help others

Brighton Head and Neck Buddies
The Macmillan Head and Neck Buddy service supports people with head and neck cancer visiting the Sussex Cancer Centre for outpatient clinics and cancer treatments. Drawing on their own experiences as a head and neck patient or carer, volunteers provide a listening ear, information and reassurance.

The Sir Hugh Dundas Volunteer Award
Macmillan’s most prestigious award for exceptionally passionate and committed individuals

Mark Wilson
Mark has been a member of the UK Volunteer Forum for four years. As Chair of the North West Forum, he has a real enthusiasm for spreading the word about Macmillan and ensures that volunteers in his region can be heard, network with each other and access volunteering opportunities.

The Richard Hambro Award
For inspiring leaders

Maureen Mullin
As Lead Cancer Information Support Volunteer for Helping Matters (providing emotional and practical support for people at home), Maureen has been part of the Macmillan family in Glasgow for six years. Find out more about Maureen on page 24.

Service Team of the Year Award
For passionate and determined teams supporting people affected by cancer.

Macmillan Bristol Buddies
Covering the whole county of Bristol, including North Somerset and South Gloucestershire, the Buddies offer practical and emotional support to people with cancer. This could be anything from mowing lawns and going shopping, to having a chat over a cup of tea or helping to create a memory box.

How to nominate an inspiring volunteer

Nominations for the 2020 Macmillan Volunteer Awards will be open from 1 – 31st October 2019. You can nominate a volunteer at https://volunteerawards.learnzone.org.uk If you have any questions, please get in touch at volunteerawards@macmillan.org.uk

For more information about this year’s winners, go to macmillan.org.uk/volunteerawards

macmillan.org.uk/macvoice
The Douglas Macmillan Award
For promoting Macmillan and having a significant impact.

Team McKeown
This inspirational group of volunteer fundraisers gets hundreds of people across the West of Scotland to raise money to support people with cancer and promote health and wellbeing in local communities. They exceeded their fundraising target of £1 million and now have the next million in their sights. The group, led by husband and wife Des and Carolyn McKeown, involve their contacts to raise awareness of Macmillan’s services.

The Deborah Hutton Award
For supporting people affected by cancer.

Shona Mackenzie
Shona is a Helping Matters volunteer, providing exceptional one-to-one practical and emotional support to people with cancer and their families in their homes. Despite working full time as a child-minder, Shona is passionate about volunteering and is now doing a distance learning end of life course.

Corporate Volunteer Award
For employees of our corporate partners who make an outstanding contribution through volunteering.

Rebecca Gallacher
In the three years since Macmillan’s partnership with Rebecca’s employer AG Barr began, she has helped to more than double their initial fundraising target of £28,000, raising just under £80,000. As an Event Champion, she has run event tents and cheer points at swims and runs, as well as organising coffee mornings and Family Fun Days.

Fundraising Group/Committee Award
For exceptional achievement through teamwork.

Isle of Bute Fundraising Committee
This dedicated group of five volunteers has inspired other locals to help raise just under £250,000 for Macmillan. In 2016 they funded two projects: the first transforming two rooms in the local hospital to provide palliative care on the island, and the second providing grants in the local area to ensure people can continue to live life as fully as they can.

Find out more about Maureen, this year’s winner of the Richard Hambro Award, over the page.
A true inspiration


Maureen (pictured right) has been part of the Macmillan family in Glasgow for six years. Her energy, knowledge and commitment are crucial to the success of our local community services.

Maureen is Lead Cancer Information Support Volunteer at Macmillan @ Glasgow Libraries, a free and confidential drop-in service in libraries across Glasgow. The service provides people affected by cancer with emotional, practical and financial support and reliable information in a relaxed environment.

She is also Lead Support Volunteer for Helping Matters, a local Macmillan volunteering service that provides once-a-week support and practical help at home. Maureen goes above and beyond to provide emotional and practical support for people in their own homes.

Lorna, a service user, says, ‘Maureen came to me through Macmillan services. She took me out walking. Maureen would suggest that we set goals and we would try every week to get to these goals. It helped me to try to make myself mobile.' Maureen is also an Active Outreach Volunteer, which means she helps deliver Macmillan services to people in hard to reach areas. She has also been a member of the Scottish Regional Volunteer Forum since 2016, highlighting where and how volunteering can make positive changes, now and in the future.

Maureen is the face of Macmillan’s ‘Local Knowledge is Power’ project, which trains volunteers to signpost people to local services and support.

She says, ‘Within my volunteering role I’ve developed lots of friendships. My favourite part of volunteering with Macmillan is being there to welcome people into the service, whether it be volunteers or service users. Even if it’s just one person, it makes a difference and I’m happy with that.’

During periods of volunteer uncertainty in 2018, which affected morale and capacity, Maureen recognised that fellow volunteers needed extra support. She encouraged them to deliver and maintain services by finding solutions and supporting their decisions.

She has also introduced new approaches for service delivery, telephone support and telephone signposting, which have halved waiting times for support in people’s own homes.

Life would be dull without Maureen volunteering for Macmillan. She is a true inspiration.

In focus: Technology

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Using virtual reality to support people with cancer

Strategic Lead for Health Service Research at the Royal Marsden NHS Foundation Trust, Professor Theresa Wiseman, outlines a new virtual reality project to improve psychological wellbeing.

Many people living with and beyond cancer experience poor psychological wellbeing. This may include increased levels of stress, anxiety, depression, guilt, anger, shame and other unwanted emotional states.

Apart from being unpleasant, these states can contribute to poor engagement with treatment, poor lifestyle choices and a worsening of important relationships.

The evolving use of technology in healthcare has led to new and innovative approaches. One of these is virtual reality, where an artificial environment is created with software. The environment is then presented to the user in such a way that they suspend belief and accept it as a real environment. This is often through a virtual reality headset (this method was used for the SafeSpace study).

There is a growing body of evidence to support the role of virtual reality as a distraction technique or as a treatment for psychological conditions.

SafeSpace study
The SafeSpace study, funded by Macmillan, is an example of such innovation. It aims to pilot a low-cost virtual reality intervention providing access to safe, calm, soothing environments. The user can select from three virtual reality environments: mountain, forest or beach. Once in the virtual environment, people with cancer can listen to an audio recording which guides them through a series of exercises. The exercises help them cultivate and experience self-compassion. This is associated with several therapeutic effects, helping them to relax rapidly and de-stress, while experiencing improved psychological wellbeing and self-compassion.

The study uses an adapted form of ‘experience-based co-design’ to work with people living with and beyond cancer to develop this psychological health intervention. Experience-based co-design is a way of engaging all key stakeholders to identify and design services or care pathways. An important aspect is working in partnership with service users to identify their priorities, which may be different to those of the service and the staff working within it.

Testing and development
During the first phase of the study, an initial event was organised to determine when and how the wellbeing intervention might be used along the cancer pathway. This was followed by four user-testing workshops, where participants were asked to test the virtual reality experience and give feedback at each iteration of the design process.

The SafeSpace experience has now been developed and consists of three separate virtual reality sessions, which each last about 10-12 minutes.

Based on the feedback received during the co-design, the user will hear a different, professionally-recorded audio each time that they use the experience. The concept and focus on compassion will then be developed step-by-step. The aim is to introduce the concept of ‘compassion to self’ gradually and help people adapt to this new way of thinking about themselves.
In the second phase, the study team evaluated whether it is feasible and acceptable to use the SafeSpace intervention in a clinical setting. They collected preliminary data to assess the psychological and physiological effects of the experience.

To achieve this, 20 people who are undergoing cancer treatment were recruited into the study. Each participant had an opportunity to experience all of the virtual reality environments, with each session delivered separately.

**Next steps**

Full results from the SafeSpace study are expected later in the autumn. If the intervention proves successful, the potential impact of this project could play a significant role in:

- helping to reduce suffering and increase compliance during cancer treatment
- contributing to improved wellbeing, resilience and quality of life at specific points throughout the cancer experience
- improving general engagement with life, the ability to cope with uncertainty and self-management skills.

The SafeSpace study team includes Nurse Researchers Lisa Murray and Geraldine O’Gara at the Royal Marsden NHS Foundation Trust. The team are working with Dr Tim Anstiss, Professor Anthony Steed and Dr Andrew Macquarrie, from University College London (virtual reality environments) and Professor Paul Gilbert from Derby University (compassion focused therapy).

For more information about Macmillan-funded research, visit macmillan.org.uk/funded-research

Professor Theresa Wiseman
Strategic Lead for Health Service Research
Royal Marsden NHS Foundation Trust
theresa.wiseman@rmh.nhs.uk
BAPS app promotes physiotherapy after breast surgery

Macmillan Deputy Head of Therapies and Clinical Lead Physiotherapist, Kate Baker, introduces the Breast Axilla Postoperative Support (BAPS) app.

A new app that helps women complete physiotherapy exercises after a breast operation is making a huge difference to their successful recovery.

The Breast Axilla Postoperative Support (BAPS) app was developed last year following the Welsh Health Hack – an annual event arranged by Life Sciences Hub Wales and the Bevan Commission. At this event, healthcare professionals meet with digital, technology and data companies to brainstorm how technology can solve a range of challenges faced in the health service.

The low-cost app is also generating major cost savings and efficiencies at the Velindre Cancer Centre in Cardiff. We now hope to encourage wider take-up across Wales, which could lead to significant savings for the NHS.

Physiotherapy exercise is very important following breast and/or axillary (armpit) surgery to minimise the loss of shoulder movement and function on the operated side. The exercises are believed to prevent stiffness and to keep any scars mobile after surgery. The exercises also help strengthen arm muscles, relieve and control pain, and aid tissue healing.

A person having radiotherapy must remain in one position for a period of time, sometimes more than 25 minutes. The aim of the app is to prevent delays in radiotherapy treatment due to restricted shoulder movement following surgery, and to help access earlier intervention when required.

The BAPS app has been designed by physiotherapists, a breast cancer surgeon and breast cancer survivors to encourage self-management, a sense of achievement and to improve overall wellbeing. The app was designed following constructive feedback from patients about the information on post-operative exercise that is currently available in paper format.

The app enables patients to see how to do the exercises, read instructions or hear an audio description. It gives them an idea of how they are doing, with self-checks and rewards, and includes a daily reminder that can be set up to remind people to do the exercises. At certain points throughout the app, there are triggers to contact key workers if things are not progressing.

The idea for the BAPS app came about when a breast surgeon from Cardiff & Vale University Health Board and specialist physiotherapists at Velindre Cancer Centre in Cardiff found that almost a quarter of their patients were failing to do vital physiotherapy exercises immediately after their operations.

Without the required flexibility in their arm movements, they could not achieve the arm position for radiotherapy, which delayed their treatment. They would then have to be referred urgently for intensive physiotherapy, causing distress and delays in their follow-up care. The additional radiotherapy scanning and treatment costs more than doubled per patient as a result.
Cardiff company Orchard Group Ltd came forward at the Health Hack to suggest the development of a user-friendly app, which patients could download on their phone.

Since the app came into use in January 2019, the cancer centre has not needed to schedule any urgent physiotherapy for patients.

The success of the app means that the unit does not have to bear the cost of additional physiotherapy and repeat radiotherapy planning scans, and the health outcome for the patient is much better because the process is less stressful.

We are currently in touch with the All Wales Cancer Network, who are very keen to see the app taken up more widely among physiotherapists working in cancer care across Wales. With the potential for physiotherapists in other parts of the NHS to use a version of it as well, the opportunities for improved healthcare and cost savings are enormous.

This year’s Welsh Heath Hack took place in Cardiff on 23 and 24 May. Challenges included how to help people prepare themselves for a laryngectomy (surgical removal of all or part of the voice box), how to highlight early indicators of stress among NHS staff, and how virtual reality can be used as an innovative teaching method.

The challenges were pitched on the first day, and small, cross-functional teams worked together to create solutions, a product idea, or prototype. The following day, the teams presented their responses to a panel of experts from Life Sciences Hub Wales, Welsh Government, NHS Wales and industry representatives.
My Cancer Portal – a digital health system

Macmillan Senior Clinical Research Nurse, Margaret Lewis, on a co-designed digital tool to support people with colorectal cancer in NHS Highland.

My Cancer Portal is a digital health system comprising a website for people with cancer and a patient management system, which we call the dashboard. Together the website and dashboard create the portal, which allows patients to fill out holistic needs assessments (HNA) and symptom diaries, and exchange messages with the healthcare team.

The patient website also includes a section called ‘My information’, which provides signposting to information resources. Working with the University of Aberdeen, we have also incorporated the colorectal cancer ‘symptom tracker’. This allows patients to answer some straightforward questions on the app about their wellbeing and physical symptoms. The data is then displayed graphically on the dashboard for the healthcare team to see.

The patient-facing website is easy to use on mobile and tablet. Having access to information and contact with the healthcare team from home is particularly helpful for people in this region, as a large proportion of the population live in remote, rural areas.

My Cancer Portal was co-designed with a wide range of stakeholders and delivered over two years (April 2015–2017) as part of the Transforming Care After Treatment programme in Scotland. It was originally introduced for people with colorectal cancer in NHS Highland, on the basis that all patients should have a multidisciplinary team (MDT) discussion, a treatment summary and an HNA. We have incorporated treatment summaries into My Cancer Portal and have pre-populated many of the treatment summary fields with information from the MDT form (used in NHS Highland for people with colorectal, upper gastrointestinal and hepatobiliary cancers and compiled in real time by clinicians during the MDT meeting).

**Meeting a new need**

Staff and patients are becoming increasingly familiar with digital health applications and there is an expectation that care will be delivered in the future using digital platforms.

We wanted to provide a virtual safety net for patients to be able to contact the cancer team for help or advice, and to identify potential traps within cancer pathways, where people were being transferred from one service to another. We also wanted to explore how digital health could be used to deliver treatment summaries andHNAs efficiently.

**Impact**

Patient engagement has been excellent. Currently, we have around 150 registered users. Users are remaining on the site for more than five minutes, which is a very high rate of engagement. Of the people who are using the portal, 97% are looking at the information available. We also know that just under half of users are accessing the system each month, suggesting ongoing demand for the service. The information pages are the most popular pages, followed by the messaging function and the HNA page. The messaging function has been used to ask about symptoms, appointments and results.
Since we started the project, use of My Cancer Portal has grown, and the numbers of people using the site has been maintained as people continue to use the information available.

There had been concern that the message function might impact on the workload of cancer nurse specialists. However, as yet, there is no significant increase in workload for the team. Patient feedback is positive as people feel reassured that they can contact the team if they need to.

After discussion with cancer nursing and Macmillan colleagues, we plan to introduce the Macmillan Care Plan into My Cancer Portal to address specific needs. We are well positioned to take advantage of the training currently being given to nurse specialists across the North of Scotland Cancer Network, and allowing patients to fill out the electronic holistic needs assessment (eHNA) at home, in their own time, is advantageous.

Concerns can be discussed in virtual consultations and then summarised in a care plan, which can then be shared with the patient and stored in electronic patient records. Self-help support is being developed within the portal to help patients find community or online resources to meet their needs.

**Next steps**

Work is ongoing to make the patient-facing website sound less clinical and feel more interactive. This will allow people using the site to say if the content is helpful or not, and ultimately direct the type of information they want us to provide.

More work has been done to increase signposting for content on self-help for pain, fatigue, sex and relationships, and nutrition. We are also introducing information about tests. We have recently created a new general library of information about prostate cancer, to support the future rollout of My Cancer Portal to this specific group of patients.

Finally, we are also working to embed the Macmillan eHNA into My Cancer Portal, which currently has a stand-alone HNA.
Work and cancer
MAC11675
Edition 7
This booklet explains how cancer and its treatments can affect someone's ability to work. It covers employment rights, coping with side effects at work and talking about cancer. The booklet is also available in audio format.

Questions for carers to ask about work and cancer
MAC13509
Edition 4
This leaflet aims to help carers get the information they need about work and cancer. Includes examples of key questions and who to ask.

Managing cancer in the workplace
MAC12891
Edition 5
This booklet helps employers to support staff affected by cancer. Includes examples of best practice and your responsibilities as an employer.

10 top tips for line managers
MAC13294
Edition 3
10 top tips for managers to support staff affected by cancer.

Working while caring for someone with cancer
MAC11688
Edition 6
This guide is for anyone who is working while caring for someone with cancer. It includes advice about employment rights, flexible working, getting support and talking about cancer.

Questions to ask about work and cancer
MAC14580
Edition 4
This leaflet aims to help people get the information they need about work and cancer. Includes examples of key questions and who to ask.

Your rights at work when you are affected by cancer
MAC12981
Edition 3
This booklet includes information about rights at work for people affected by cancer, including carers.

Self-employment and cancer
MAC12818
Edition 5
This booklet is for people with cancer who are self-employed. It includes practical information about treatment, talking about cancer and managing a business and finances if you are unwell.

Work Support Route Guides (England, Scotland, Wales and Northern Ireland)
MAC13538_ENG, MAC13538_SCOT, MAC13538_WALES and MAC13538_NI (Edition 3)
Signposting resources for professionals in each of the four nations. These guides support professionals to guide people with cancer who are working or on long-term sick leave, self-employed or out of work, and want to discuss work options.

Easy read booklets
We have a range of easy read booklets. These use simple language and pictures. They can be useful for anyone who finds it hard to read. You can read or order the booklets at macmillan.org.uk/easyread

Our easy read booklets cover lots of topics including tests for cancer, side effects of treatment, living a healthy life, end of life and coping after someone dies. We have just added a new title, Treatments for prostate cancer.

You can order these booklets and leaflets, plus many more, at be.macmillan.org.uk. To find out more about our full range of information, including translations, audiobooks and easy read, visit macmillan.org.uk