Mac Voice
For Macmillan Professionals | Issue 86 | Autumn 2018

Influencing the future workforce

Julie Armoogum
Macmillan Senior Lecturer

In focus
Supporting hard-to-reach communities

Sharing good practice
Enhanced recovery after surgery
Welcome


Last year our incredible fundraisers raised £247.7 million – £2.8 million more than the year before. Thanks to the hard work of our supporters, volunteers and Macmillan professionals across the country, we provided personal, high-impact support to an estimated 1.6 million people, a 16% increase on the previous year. You can read more about the report on page 4. And on page 10, find out how Macmillan’s recent investigation into the cancer nursing and support workforce highlights the urgent need for investment to ensure a sustainable and well-equipped workforce for the future.

We also know that cancer education for young professionals and healthcare students is of vital importance. I hope our Q&A on page 12 with Macmillan Senior Lecturer Julie Armoogum will leave you feeling inspired.

This issue, our In focus section demonstrates how Macmillan teams in some of the most remote areas of the UK are working together to support local people affected by cancer.

Sharing good practice looks at new innovations and projects in Enhanced Recovery After Surgery – a growing area of practice that is making a real difference for people undergoing cancer treatment.

And finally, we are looking forward to the 2018 Macmillan Professionals Conference, which will take place on 7-9 November in Birmingham. For more information, visit macmillan.org.uk/professionalsconference
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Annual report reveals rise in Macmillan professional posts

Macmillan Chief Executive Lynda Thomas talks about some of the highlights of 2017.

This year’s Annual Report shows that we gave high-impact support to an estimated 1.6 million people in 2017 – 16% more people than the previous year.

At Macmillan, we work to support people affected by cancer at the times they need and want it most: at diagnosis, during treatment and recovery, if they have treatable but not curable cancer, and at end of life.

Macmillan professionals are central to this. We are proud that at the end of 2017 we had over 5,700 Macmillan nurse posts, almost 600 more than in 2016. These committed individuals supported 658,000 people throughout the year.

We also had another 2,000 healthcare professional posts across the UK, including cancer support workers, who work closely with clinical nurse specialists to help people living with cancer access the different types of support they need.

I want to thank each of our Macmillan Professionals for the incredible job you do, caring every day for people who are affected by cancer.

And of course, everyone who supports Macmillan – volunteers, campaigners and fundraisers – plays a crucial part in making all of this possible. Our magnificent fundraisers, for example, raised £247.7 million in 2017 – £2.8 million more than the year before.

Thanks to the money they helped us raise, we spent £192 million in 2017 to improve the lives of people living with cancer – an investment which enabled us to increase our number of Macmillan professional posts across the UK by 13%.

We also delivered a wide range of services to meet people’s emotional, practical and information needs. We extended the reach of our mobile information and support services in deprived and rural communities, and the Macmillan Support Line answered around 152,000 calls, emails and letters. Having access to the depth and quality of information provided by our professionals and volunteers through these services really does help people when they need us the most.

We remain committed to managing our work responsibly and spending the money that our supporters donate and raise for us wisely. We continue to do our utmost to provide everyone who supports us with the best possible experience and to ensure our fundraising work meets all relevant rules and regulations.

The number of people living with cancer is set to grow from 2.5 million to 5.3 million by 2040, which means more pressure will be placed on the UK’s already struggling health and social care system. For this reason, we will continue to work with our partners to highlight the challenges facing those working in cancer care, and to improve cancer care and support on a local, regional and national level.

We also need to be clearer than ever before about how we will focus our efforts to deliver our ambition for the ever-increasing number of people living with cancer. Look out for updates in Mac Voice on our new strategy, which is due to be finalised this year and will shape our approach in the coming years.
Macmillan Chief Executive leads breast screening inquiry

In brief

GDPR – What we are doing
For the past 18 months Macmillan has been making improvements to prepare for the General Data Protection Regulation (GDPR) and the Data Protection Act 2018. We have made major changes to better manage and protect our data. These include improving our technical security policies, governance and accountability, processes and procedures, improving our reporting measures and investing in training our staff. If you have any questions relating to the use of your data, please email macvoice@macmillan.org.uk

In May, Public Health England (PHE) announced that, since 2009, 450,000 women have not been invited for their final breast screen due to an IT error.

The NHS Breast Screening Programme offers screening to all women aged 50 to 70, and the final screen for these women should have taken place between their 68th and 71st birthdays.

PHE has since carried out urgent work to identify the problem and fix it. Yet the fact that so many women have been missed from breast cancer screening over a number of years will undoubtedly create a great deal of concern and anxiety for those affected.

The Secretary of State for Health and Social Care commissioned an independent review of the NHS Breast Screening Programme to look at its processes and IT systems, as well as further changes and improvements that can be made to the system to minimise the risk of any repetition of this incident.

Macmillan Chief Executive Lynda Thomas is chairing the inquiry with Professor Martin Gore, Consultant Medical Oncologist at The Royal Marsden.

Lynda said, ‘The priority now must be for women who have been missed from screening programmes to immediately get support and, if appropriate, treatment. Macmillan will help in any way we can to ensure people get support through this worrying time through our support line and online support services.

‘However, it is absolutely critical we understand what happened and make sure this situation never happens to another person again. As a joint chair of this inquiry, I am committed to ensuring the voices of people affected are heard and the lessons are learnt.’ The inquiry is due to report before the end of the year, so look out for further updates in Mac Voice.
‘Fighting talk’ prevents advance care planning

Reluctance to talk honestly about death is preventing people with cancer from dying ‘well’.

New research from Macmillan shows that more than 1 in 4 people with cancer (28%) have difficulty talking honestly about their feelings around cancer. The *Missed Opportunities* report also shows that three quarters (76%) of people with cancer have thought about the fact that they may die from the disease.

Yet in-depth conversations with professionals and people with cancer reveal a number of barriers preventing honest conversations about dying.

Professionals can feel pressured to support people to ‘fight’ cancer, even when they have a terminal diagnosis. For many, vital conversations, including about end of life preferences, do not occur until it is too late, with thousands of people with cancer unnecessarily dying in hospital against their wishes.

Adrienne Betteley, Macmillan’s Specialist Advisor for End of Life Care, said, ‘For professionals, there is often a fear that the person is not ready to talk about dying. But when staff have a record of where someone would like to die, that person is almost twice as likely to die in the place of their choosing as well as have other care preferences met.

Macmillan wants to support professionals to have more open and honest conversations about end of life using a process known as advance care planning.

Our free e-learning module on advanced care planning is available at [learnzone.org.uk/courses/course.php?id=238](http://learnzone.org.uk/courses/course.php?id=238)

You can read the full report, *Missed Opportunities*, at [macmillan.org.uk/planning-end-of-life-care](http://macmillan.org.uk/planning-end-of-life-care)

References
Surge in men seeking emotional help

Requests for emotional support and counselling from male callers to Macmillan’s Support Line increased last year.

On average, eight men per day called Macmillan’s Support Line last year to talk about their feelings, compared to an average of six per day in 2016— an increase of around a third.¹

Macmillan GP Dr Anthony Cunliffe said, ‘A cancer diagnosis can impact so many aspects of your life such as your health, finances and relationships. These changes can cause emotional strain so it’s encouraging to see more and more men talking about how they feel.

‘From Princes Harry and William, to comedian Johnny Vegas, brave men have spoken publicly about their emotions, helping us all realise it’s okay to talk about our feelings. Despite this shift, there is still a long way to go and it’s crucial that men ask Macmillan for help before reaching crisis point.’

Despite the increase in men asking for emotional support, more women continue to call the Macmillan helpline than men. However, men are 22% more likely to get cancer and 45% more likely to die from cancer than women.²

Craig (pictured below) was diagnosed with thyroid cancer when he was 29. He spoke to the BBC during Macmillan’s Say the Word campaign in April: ‘I didn’t talk about personal stuff – I didn’t believe I should talk about how I felt – and I found out that was the wrong thing to do. Now I cry all the time – everyone who knows me has seen me cry at some point, but I feel good.’

Macmillan is encouraging even more men to access the emotional support it offers. Professionals on the helpline are there to provide a listening ear and to signpost people to appropriate local services such as counselling. The free helpline is open Monday - Friday, 9am – 8pm on 0808 808 00 00. Alternatively, people can log on to Macmillan’s Online Community.

Working with our corporate partners from the construction, home improvement, electrical and technology sectors, we want to reach and empower men across the UK to take control of their health and seek the support they need.

For more information about the campaign, our corporate partners and the support services Macmillan offers, visit macmillan.org.uk/saytheword

References
2. Cancer Research UK. Available at cancerresearchuk.org/health-professional/cancer-statistics/incidence/all-cancers-combined, Accessed April 2018
Problems with swallowing after cancer treatment

Macmillan Speech and Language Therapist Annette Zuydam on evaluating the use of clinical assessments for people with head and neck cancer.

Treatment for head and neck cancer can have a major impact on swallowing function, which is frequently identified by patients as a priority concern after treatment.\(^1,2\)

This can mean people require a modified diet, and to supplement oral intake via a feeding tube to meet additional nutritional needs. Taste changes and dry mouth can also make eating more uncomfortable and influence diet choices.

The Macmillan Integrated Therapy Service in Shropshire provides speech and language therapy, dietetics, physiotherapy and occupational therapy for people with cancer across two hospital trusts and in the local community.

There are many patient-reported and clinician-rated outcome measures available for use with people who have head and neck cancer. These are often time-consuming to complete and can be a burden on the patient. In 2016/2017 we conducted an 18-month study to evaluate which assessments should be used routinely in a busy clinical setting.\(^3\)

Our method
We collected data on 49 patients, at 3 months and at 12 months after chemo-radiotherapy or radiotherapy, including induction. We used the following measures:

- University of Washington Head and Neck Cancer (UWQoL)
- Performance Status Scale for Head and Neck Cancer Normalcy of Diet scale (PSSHN)
- Functional Oral Intake Scale (FOIS)
- Clinical assessment carried out using the Water Swallow Test (WST)

What we found
There were a number of correlations between the PSSHN and FOIS tests at both time points, suggesting these different instruments have a relationship to each other, and using both is unnecessary. Either tool can provide valuable information, so it is important to determine what information you need when choosing which to use.

Patients with low PSSHN and FOIS scores at three months were likely to have low scores at 12 months. This may help to identify people who may need signposting to other services for support in their recovery.

The results of the UWQoL taste questionnaire correlated significantly with both the PSSHN and FOIS. This suggests that taste impairment has a significant impact on patients’ ability to progress to full oral intake and normal diet.

We would recommend use of both the UWQoL swallow test and WST to identify patients with swallowing problems who may require further intervention.

With thanks to Macmillan Speech and Language Therapist Clare Probert, Statistician Kate Grayson and Macmillan Dietician Katie Mclaughlin. Funding for statistics was provided by Macmillan Cancer Support.

Further Information

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References
3. Evaluation of patient and clinician reported outcomes in the routine clinical setting. BAHNO 2017 poster presentation.
Empowering patients and encouraging self-management

Macmillan professionals Karen Livingstone and Debbie McMullan talk about a new one-stop-shop for practical advice before and after breast surgery.

Receiving a breast cancer diagnosis is difficult – especially when people don’t know what to expect before and after surgery, what to look out for and how best to care for themselves.

The Macmillan Breast Cancer Rehabilitation Project, based at the Nightingale Centre at the Wythenshawe Hospital, part of Manchester University NHS Foundation Trust, set out to answer some of the key questions that people have after surgery: how will I be, what can and can’t I do, and where can I go for help?

In 2016, the team identified gaps in patient knowledge after carrying out a survey of almost 100 people. The responses identified opportunities to increase understanding of physical activity, lymphoedema, pain management and post-operative complications.

Our specialist physiotherapist was under pressure from increasing referral numbers, which lengthened the time people had to wait to access help. A new innovative solution was required.

A Macmillan-funded project was designed with service users and key stakeholders to ensure all patients with breast cancer have access to clear, practical advice before and after surgery. The concept was to empower patients and encourage self-management through improved knowledge.

A model of pre and post-operative rehabilitation was developed to provide clear and easy to understand educational material through a website, yoursurgeryandrehab.co.uk and a group class taught by a specialist physiotherapist.

The website was launched in October 2017 as a key resource to offer pre- and post-op advice and access to rehabilitation exercise videos and self-massage techniques. It provides a one-stop-shop for patients and carers to access relevant, timely information.

Patients are also invited to attend a group class post-operatively, which provides an informal learning atmosphere and encourages shared experience. Patients can be signposted to other support services, so those with complex rehabilitative and lymphoedema needs are more quickly identified and treated.

All written and online resources have been made available in four languages: English, Urdu, Mandarin and Polish. This aims to improve accessibility of information within the local community.

The project has had great feedback so far, with 99% of people saying they would recommend the service to other people with breast cancer.

The project has also had a positive impact on service provision. We have seen an increase in productivity, with more than 800 patients seen to date and the previous waiting list of up to 26 weeks reduced to two weeks.

There has been a reduction in the number of physiotherapy referrals due to early identification, intervention and self-management. The project has successfully embedded itself within the patient pathway.

Further information

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Results of workforce census revealed

Census highlights urgent need for properly equipped cancer workforce.

In 2017, Macmillan conducted a census of cancer, palliative and chemotherapy speciality nurses and support workers in England, the first in-depth investigation into the cancer nursing and support workforce in England since 2014.

The results reveal a broad variation in the number of new patients diagnosed each year per specialist cancer nurse, with some specialisms in certain areas seeing three times as many patients compared to others. For example, the number of new lung and respiratory cancer patients per nurse varies between 62 patients in some areas and 203 patients in other areas.

While the workforce as a whole has grown, a greater proportion of specialist nurses are now employed in lower pay bands than in 2014. Macmillan warns that a trend of specialists taking on increasingly complex caseloads for lower pay may be exacerbating recruitment and retention problems in the cancer nursing workforce.

The census looked at four roles: specialist cancer nurses, chemotherapy specialist nurses, specialist palliative care nurses who focus on cancer and cancer support workers. It found vacancy rates higher than the UK rate for health and social work across all four roles, with as many as one in seven chemotherapy nurse positions being unfilled in some parts of England.

Dr Fran Woodard, Macmillan’s Executive Director of Policy, said, ‘We welcome the progress Health Education England is making on the cancer workforce strategy. However, this census highlights the urgent need for this essential part of the NHS workforce to be properly equipped to cope with the increasingly complex challenge that cancer poses in the years to come. It is therefore vital that the Department of Health and Social Care ensures that the cancer workforce strategy is appropriately funded.’

Macmillan is also looking at other parts of the workforce such as allied health professionals, and has recently published the results of a census looking at specific cancer care roles in Wales. Look out for more information in future editions of Mac Voice.

To read full results of the census, visit: macmillan.org.uk/cancerworkforceengland

The report provides information about four different types of posts employed within the NHS in England (numbers are calculated based on whole time equivalents (WTE) working in cancer):

- Specialist cancer nurses: 4,020
- Adult chemotherapy nurse posts: 2,686
- Cancer support workers: 635
- Specialist palliative care nurses: 978

There is variation in the ratio of newly diagnosed patients to specialist cancer nurses (calculated based on WTE).
Communicating with people diagnosed with cancer

Former cancer nurse Bruce Gilligan is sharing his tips on effective communication with people who are newly-diagnosed.

A former cancer nurse, who also had cancer himself, has put together a booklet for health professionals. The short publication shares his tips for effective communication to meet the informational needs of people diagnosed with cancer.

More than 30 years ago, Bruce Gilligan was diagnosed with non-Hodgkin’s lymphoma at the age of 25. He was married with two children, with the youngest just eight weeks old.

He felt that his sense of fear and isolation at the time was made worse by a lack of communication from health professionals. A year after diagnosis, he was inspired to give up an engineering career and train to be a nurse himself. This was when he quickly realised the challenges faced by professionals. He worked on acute general wards as a staff nurse, and eventually specialised in oncology at the Royal Marsden.

Although he left the nursing profession 22 years ago, Bruce has spent the last 30 years working in the oncology pharmaceutical sector. During that time, he has supported friends and family also living with cancer. He has also had a recent diagnosis of a cancer-related illness himself, and was saddened to experience the same level of isolation and lack of information he experienced when diagnosed with cancer for the first time.

His personal experiences have shown him that some professionals still struggle to consistently and effectively communicate with people newly diagnosed with cancer, or those dealing with the long-term effects of cancer and its treatment.

As someone with experience as a patient and a professional, he wanted to share his experience and thoughts with health professionals. His booklet summarises the things that he thinks are important when communicating and caring for people with cancer, and features his own illustrations.

It is available to download on iTunes at apple.co/2zsJVhi. Bruce is donating 30% of the profits from the sale of the booklet to Macmillan.
How did your professional background lead to this role?
I studied for my undergraduate nursing degree at King’s College London. After graduating I worked at University College London Hospital (UCLH). I worked there for more than 10 years and was privileged to undertake a variety of roles including clinical research sister and bone marrow transplant clinical nurse specialist.

During that time I completed an MSc in Advanced Cancer Nursing. It was hard work juggling a clinical job with studying, but I really enjoyed it, and studying improved my clinical practice and knowledge of cancer and research.
My final role at ULCH was in education. This was a great role and it confirmed to me that my passion lay in cancer education and research. It felt natural to move to the university setting and I joined the University of the West of England (UWE) in 2012.

The university had a good relationship with Macmillan and together developed some really innovative modules. My post, Macmillan Senior Lecturer, was adopted by Macmillan in 2016.

Tell us about the teaching part of your role. When planning and developing modules I work with lecturers and clinical practice partners to provide clinically relevant, academically stimulating and evidence based modules. We ensure that modules reflect the changing nature of cancer care and service delivery and aim to include learning on each possible stage of the cancer journey – from initial symptoms and diagnosis, through treatment and then living with and beyond cancer. We adopt many different teaching strategies and host an annual conference. When teaching, I love the buzz of being in a room with students and hope my knowledge and enthusiasm shine through.

And what about research? Research is the other half of my role. I’m working on a PhD, which focuses on the healthcare needs and experiences of cancer survivors with chronic pain and is investigating if current service provision meets their needs. As part of this I am systematically reviewing the literature, conducting qualitative interviews with cancer survivors with chronic pain, and mapping service provision in England. I am so grateful to Macmillan and UWE for enabling this piece of work to take place. I thoroughly enjoy the research process, but the best thing about this for me is that our findings are going to directly impact and inform clinical care and services.

What is the biggest challenge in your role? It can be tough juggling all the different elements of my job, particularly studying and teaching. However, this gives me empathy and understanding for students who are studying whilst balancing busy clinical jobs. I’ve developed some good coping strategies over the years and share these with students to help them maintain a good balance of work, study and life.

What does being a Macmillan professional mean to you?
As well as the undergraduate modules, Macmillan has enabled us to develop innovative postgraduate modules including the ‘Macmillan Evidencing Work Based Learning’ module. I’ve also benefited from several Macmillan learning and development grants, which have helped me attend some invaluable conferences.

On a more personal level I was honoured to have Macmillan acknowledge my PhD as a valuable and important piece of research. The organisation’s presence at UWE adds an additional ‘stamp of excellence’ to our programmes, which is appealing to current and prospective students, especially those hoping to specialise in oncology.

‘My passion lay in cancer education and research.’
Julie Armoogum, Macmillan Senior Lecturer
New resources promote equal healthcare

David Campbell from ENABLE Scotland on supporting professionals to provide appropriate care for people with learning disabilities.

Macmillan and learning disability charity ENABLE Scotland have produced a new resource for healthcare professionals to support them in caring for someone with a learning disability.

The guide, titled 7 Steps to Equal Healthcare, is the result of a study commissioned by Macmillan and conducted by ENABLE Scotland, to learn more about the experiences of people who have a learning disability and are affected by cancer in some way, either through having cancer themselves or being close to someone who had cancer.

The Your Story Our Guide study began in 2015, with information gathered from 24 healthcare professionals and volunteers, and 20 people with learning disabilities over a 12-month period. All information was gathered through interviews or a focus group setting.

What we found
The study revealed a varied picture of the quality of support that people with a learning disability received when they were affected by cancer. There were some examples of excellent practice and some examples where the quality of care could have been much better.

For example, one young man spoke about the distress he experienced when he had to give a blood sample, making the procedure almost impossible to complete for the healthcare team, and resulting in a very upsetting experience for the young man and his family.

The team worked with the man and his family to come up with a solution to this problem. They found that allowing him to choose his own needle for the blood test was enough to reassure him, making him feel much calmer and more accepting of the procedure.

This is one example of good practice. However, other stories showed that healthcare staff were often unable to offer support or disinclined to work together with patients and their families or carers to find solutions to the specific challenges often faced by people with learning disabilities.

The study highlighted a number of themes:

Attitudes/values
A positive determined attitude and willingness to provide a person-centred approach led to a more positive overall experience for the patient.

Information
Both information shared with the patient about the cancer, and helpful information about the patient shared with the professionals, are key.

Communication
In the case of a person with a learning disability, there could be multiple agencies and organisations involved, so it’s important to have really good communication lines on a number of different levels.

Environment
For some people with a learning disability, a sensory overload (lighting, sound, smell etc.) will be very difficult to process and cope with, and this should be considered carefully when any medical procedure or consultation is going to take place.

Treatment
A learning disability may affect someone’s ability to receive certain medical treatment options, so searching out different treatment methods can make a big difference.

Systems
Currently, there does not appear to be a system in place that recognises an individual with a learning disability and cancer diagnosis early in their cancer pathway, to ensure appropriate support.

Partnership working
When all those involved in a person’s cancer pathway work in a co-productive way, then the overall experience for the person and everyone else involved is more positive.
The new 7 Steps to Equal Healthcare resource encourages healthcare professionals to consider each of these themes. We hope it will support them to deliver equal healthcare to everyone. It also provides prompts for them to think about when working with someone with a learning disability. For example, this might be considering that person’s likes and dislikes, and the best way to communicate with them. The 7 Steps to Equal Healthcare are:

1. Imagine being me
2. Find out who and what matters to me
3. Listen to me
4. Give me the information I need, in the way that I need it
5. Think about where we are
6. Work with others who are in my life

New resources for people with learning disabilities

We have also produced two new easy read booklets for people with learning disabilities, which aim to empower people by supporting them to understand their right to expect equal healthcare:

• 7 steps to equal healthcare runs through the 7 steps, explaining what someone with a learning disability should expect from healthcare professionals, as well as signposting to further support.

• Things that are important to me provides a place for people to write down things about themselves, including how they best like to communicate.

The booklets show that, regardless of their disability, reasonable adjustments can be made to suit them.

Equal healthcare for people who have a learning disability is not always straightforward, however it is achievable.

Both resources are now available at macmillan.org.uk/easyread
Redesigning patient pathways

Macmillan Cancer Pathways Programme Manager Lisa Janiec describes how rolling out electronic holistic needs assessments (eHNAs) is encouraging self-management and freeing up valuable clinic time.

A project to roll out eHNAs across Nottingham University Hospitals NHS Trust and the Macmillan Nottingham Cancer Support Service has exceeded its targets.

The project is part of the wider Macmillan Cancer Pathways Redesign Programme, which was launched four years ago to improve patient outcomes and experience by redesigning cancer care follow-up pathways in breast, colorectal, gynaecological, lung, upper GI and urological cancers.

The new pathways offer tailor-made patient care and are comprised of eHNAs, care plans and treatment summaries to ensure support for patients continues when treatment ends. They also aim to empower patients to self-manage following treatment and signpost them to other support services and extended members of the cancer team.

Prior to the eHNA project starting, only 22% of patients were offered a holistic needs assessment, which ensures that people’s physical, practical, emotional, spiritual and social needs are met in a timely and appropriate way.

In 2016 and 2017, surveys were completed by patients who had undertaken a holistic needs assessment at Nottingham University Hospitals Trust. Over 90% reported that they would recommend the assessment and care plan process to someone who has been told they have cancer.

During the lifetime of the project, from April 2016 to August 2017, 3,305 individual patients were offered an eHNA. Subsequently 2,066 patients completed an assessment, resulting in 1,339 having a care plan.

The team also engaged with staff to understand their experiences of using the eHNA with their patients. Feedback suggests that staff are now having different conversations with people affected by cancer, while people are thinking about other issues that affect them alongside the cancer diagnosis – eHNAs are an excellent tool to help support a patient as a whole person.

A video showcasing staff views on implementing the eHNA at the Trust can be viewed at vimeo.com/187782917

Measuring results

The project’s success has earned it a number of award nominations, including winning a Health Service Journal Award for ‘Enhancing care by sharing data and information’ in 2017.

As a result of the programme, more patients are being encouraged to self-manage and access support from their GPs and community organisations. This is freeing up clinic capacity for new patients. In Nottingham, the implementation of stratified follow-up pathways has increased outpatient clinic capacity to enable an estimated 414 extra breast cancer patients and 70 gynaecological cancer patients to be seen each year.

We started offering eHNAs because we believed it was the right thing to do for patients. Creating a meaningful care plan that is patient centred and
shared among teams ensures that different healthcare professionals understand what support and information patients need at any given time. The eHNAs are highlighting areas of patient need where we can make a difference and ultimately this is better for patients.

One patient said, 'It helped me to take time out and think about each different emotion and need. To come out of the fog for a moment. My nurse who spoke with me was lovely and explained it all.'

Macmillan has already invested £850,000 in the Macmillan Cancer Pathways Redesign Programme and funding is due to run until 2020. It is part of the Macmillan Cancer Partnership in Nottinghamshire, which brings together local health organisations to improve services and support the growing number of people being diagnosed and living with cancer.

Launched in 2015, the programme has already invested more than £6 million over the past three years to improve local cancer services. It currently funds 23 different services, projects and pilots – including the cancer pathways work - to support people living with cancer.

Sue Sanderson, Macmillan Partnership Manager, says, 'The team are improving the patient experience while also freeing up vital clinic capacity for new patients, which is a really important step forward. The number of people living with cancer in Nottinghamshire is expected to double by 2030 so it’s more important than ever that we are able to support their ongoing needs.'

For more information on the eHNA visit macmillan.org.uk/HNA

Further information

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At this year’s Macmillan Volunteer Awards, Sheila Barrow (pictured above) was presented with the Deborah Hutton Award, in recognition of the huge impact she has had while volunteering with Macmillan for more than 10 years.

Deborah Hutton wrote a book published by Macmillan called *What can I do to help?*, which offers 75 practical ways that family and friends can help a loved one through cancer. Sadly, Deborah passed away from lung cancer in 2005. The award was created in her memory and celebrates individuals who provide practical and emotional support to people affected by cancer, beyond the expectations of their role.

Support to people living with cancer was severely disrupted several years ago, due to a Macmillan post becoming vacant while there was a recruitment freeze across the Trust. Already an experienced volunteer, Sheila, together with a small team of volunteers, stepped in and kept the centre open and enabled it to remain operational. Sheila liaised between Macmillan and the trust to ensure service continuity. She kept services going and maintained key relationships with professionals at the hospital, as well as developing, updating and improving processes to help provide a better service for people going through their cancer journey.

We now have a centre manager in place, but the service is very much in debt to Sheila and her team of volunteers for keeping things going for several years and making such a significant contribution.
Since then, Sheila has also made a big impact on our direct volunteering service in Carlisle as a lead volunteer. She was particularly keen on getting involved with an emotional support project we were working on, and was fundamental to the development and success of that project. She knows many of the cancer nurse specialists and lead nurses at the hospital and is well-respected there. So, as well as being a fantastic befriender and information specialist, she was also key to promoting the service among professionals and people living with cancer.

Cumbria Libraries
The third role that Sheila has had during her time volunteering with Macmillan is as a lead volunteer within the Macmillan Project in Cumbria Libraries, a joint venture between Macmillan, North Cumbria NHS Trust and Cumbria County Council. This has played a vital and consistent part in supporting people affected by cancer in a huge geographical area, and volunteers enable the project to make a real impact on people in their local communities.

Sheila has put together systems for reporting, manages stock, coordinates volunteers and liaises with the Cumbria County Council Libraries Service. This type of work really is the bread and butter of Macmillan’s presence in this area.

Sheila wanted to support people affected by cancer following her own experiences. Her mother died from breast cancer when Sheila was just 13 years old, with little information and support available. In 2005, Sheila was diagnosed with acute myeloid leukaemia, and in 2009 she was diagnosed with breast cancer, going through 17 months of treatment.

She says, ‘I’ve carried on volunteering for this long simply because there is a need for providing information and support for people affected by cancer.

‘I’m in awe of Sheila’s commitment and impact.’

Jane Mielniczek

in this area. I feel that we have been able to assist people over the years and that’s something I’m passionate about. It’s a very special feeling when somebody says that you have helped them, even if it’s something small. That’s why I always recommend volunteering to other people.’

She adds, ‘When we started the libraries project in 2005 with nine libraries, we did drop in sessions for people to come and talk to us about things they were worried about or needed help with. We’ve now got 19 libraries, and I would like to see a way for people to get this type of support in a nice, relaxing environment, particularly for those who have finished treatment. It can be such an overwhelming feeling of being on your own, so just having someone to listen to can really help.’

In a rural area such as this, a long-term presence is key to supporting local communities, and Sheila has really been Macmillan’s constant presence out in the community for over 10 years, building a valuable reputation and making a real difference for people living with cancer in Cumbria. I haven’t come across anyone else who has demonstrated such a high level of commitment over such a substantial length of time – I’m in awe of Sheila’s commitment and impact.

You can nominate a Macmillan volunteer for the 2019 Macmillan Volunteer Awards at volunteerawards.learnzone.org.uk

Further information

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Reach your goals with Macmillan Professionals coaching

The Macmillan Professionals Coaching programme supported the professional and personal development of more than 150 professionals in 2017.

The programme’s primary purpose is to support the development of professionals during times of workforce, organisational or service change. As a key part of our wider learning and development offer for Mac Professionals, it also aims to help develop your knowledge and skills for both current and future roles and to support your personal development.

Coaching is an invaluable opportunity to take the time and space to reflect on your professional practice and explore and address specific work-based issues in a safe and confidential setting with an external expert coach.

Each coaching programme consists of up to six, two hour sessions, is based on agreed objectives and outcomes and takes place at the pace of the coachee. Most professionals take between six and nine months to complete their programme. We aim to deliver the coaching as locally as possible and most sessions take place in a quiet room at or near your workplace.

The programme is open to Macmillan professionals at all levels and across all roles, as long as you have been in post for six months and have the support of your line manager in applying for coaching. We aim to deliver the coaching as locally as possible and most sessions take place in a quiet room at or near your workplace.

The programme is open to Macmillan professionals at all levels and across all roles, as long as you have been in post for six months and have the support of your line manager in applying for coaching. Importantly, coaching is not intended as a substitute for clinical supervision and neither is it counselling. Professionals joining the programme continue to represent the increasingly diverse range of Macmillan professional roles.

Our coaches are all professionally qualified and highly experienced and come from a wide range of backgrounds across the UK. All have their own experiences and tools to draw upon to help you to reach your goals. Some coaches come from health and social care and others from very different sectors. When you join the coaching programme we arrange for you to meet up to two different coaches, chosen by you, to ensure there is a best fit between you.

‘I had a fantastic coach, whose personal experience has been invaluable’

Jenn Blake, Macmillan Professional

Around 350 professionals have taken part in the programme since it began in late 2014 and the overwhelming majority have found coaching to be a supportive and often transformational experience.

Macmillan Acute Oncology & Cancer of Unknown Primary CNS Jenn Blake successfully completed her coaching programme earlier this year. Jenn says, ‘Through coaching, I have been able to identify the professional I would like to be and identify what I need to do to become that person.

‘I had a fantastic coach, whose personal experience has been invaluable in identifying how my own challenges can be addressed. I really feel that she understood the challenges, helping me to become a more confident practitioner and leader.’

Further information

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In focus: Supporting people in hard-to-reach communities

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Providing non-clinical support on the Isle of Man

Macmillan Cancer Information and Support Service Manager Tim Moughtin outlines the challenges for this remote location.

The Isle of Man is a Crown Dependency of the United Kingdom, located in the Irish Sea between Great Britain and Ireland. It has a population of around 83,000, and is not a member of the European Union, or part of the European Economic Area (EEA).

The Macmillan Cancer Information Centre and Support Service at Noble’s Hospital provides information and assistance to people living on the Isle of Man who have been affected by cancer. This includes patients, carers, friends and family and members of the public.

We offer a walk in, no appointment needed service. Many people who access our service are referred by a member of their clinical team. In June 2018 we were awarded Macmillan’s Quality Standard for Cancer Information and Support Services (MQuiSS).

**Accessing services in the UK**

One of the key differences for Isle of Man residents is the reciprocal health agreement with the UK. This provides people living on the island with free emergency healthcare when visiting the UK.

For people with cancer who are attending appointments in the UK, their elective treatment is arranged as part of their referral from the Isle of Man.

Many people coming to our centre access services in hospitals in the North West of England, such as Aintree University Hospital and the Royal Liverpool Hospital.

To assist them, we provide a comprehensive patient transfers booklet, and a sheet of frequently asked questions about off-island travel.

A key link to our service is the Patient Transfers Team based at Noble’s Hospital, who arrange and co-ordinate travel and transport for patients travelling off-island for appointments. Once the patient’s travel has been arranged, we can support them by identifying and arranging accommodation close to the hospital they will be attending.

Some people might need to spend several days in the UK, and the Isle of Man Department of Health and Social Care offers a contribution towards the cost of accommodation, which can be expensive. We also regularly support people to access Macmillan Grants to help with the cost of travel and accommodation.

As well as this, we have a comprehensive leaflet about accommodation which lists nearby places to stay, rates and local bus or rail routes to the hospital.

**Supporting self-management**

Once someone has returned from their treatment, or is nearing the end of treatment, we also support them to self-manage their care where possible. Macmillan Health and Wellbeing Events were established in 2016, and offer patients, their families and carers, the opportunity to learn more about self-management, taking charge, and setting SMART goals towards engaging with hobbies and interests.

These events are hosted in a non-clinical setting, and attendees are able to speak to their clinical teams and other people with cancer about their experiences. Many are post-treatment and are seeking advice on topics such as travel insurance and nutrition.
We advertise these events on the radio and through poster campaigns in hospital and community care settings, as well as inviting people who are reaching the end of their treatment, at the discretion of their clinical nurse specialist.

**Working with our cancer care coordinator**

The Macmillan cancer care coordinator provides an important link between people who have received a cancer diagnosis and our service. A key part of this role is to conduct an electronic holistic needs assessment (eHNA) with the patient prior to treatment in the Noble’s Hospital oncology day unit, and record any identified needs in the form of a care plan. The cancer care coordinator will then signpost the person with cancer to support services that address their non-clinical needs, while escalating any clinical issues to their specialist nurse.

They also liaise with the Macmillan Cancer Information Centre and Support Service on a daily basis, ensuring that patients receive the most up-to-date information resources for their care plans, while also improving their own knowledge of local services.

This relationship is key, as the Macmillan Cancer Information Centre and Support Service will typically see people at a later stage of their cancer journey, for example when someone needs information regarding self-management. The two roles combined ensure that people are being offered an eHNA and subsequent care plan as part of their cancer pathway. They can also re-engage with the service at a later stage by dropping into the Macmillan Centre and speaking to a member of the team. 🔄

*‘In 2018 we were awarded Macmillan’s quality standard for cancer information and support services’*

Tim Moughtin

The Macmillan Cancer Information Centre at Noble’s Hospital.

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Providing care wherever it is needed

Macmillan Lead Cancer Nurse Gill Chadwick on battling challenging travel conditions to reach local people affected by cancer.

In the Western Isles of Scotland, also known as the Outer Hebrides, there is no hospital Macmillan team and no community Macmillan team. We have just one team of Macmillan nurses who provide care wherever it is needed. As much as possible, a person with cancer and their family will be supported by the same Macmillan nurse from the point of diagnosis through to the end of their need for care. The work of our team is planned and implemented as a needs-led service.

Our team
The Macmillan team is led by a Macmillan lead cancer nurse, who also has the role of lead cancer clinician for the health board. Two members of the team are disease-specific cancer nurse specialists, one for colorectal and stoma patients and one for breast and lymphoedema patients. They are based in Stornoway, Isle of Lewis, but support patients throughout the Western Isles.

Two part-time Macmillan nurses are based in the Isle of Benbecula, serving a population of approximately 6,000 people spread over several islands connected by causeways, bridges and ferries. Three Macmillan nurses are based in Stornoway, Isle of Lewis, serving a population of approximately 20,500 people spread over one large land mass and smaller islands linked by bridges.

Each of these Macmillan nurses provides a generic cancer support service for anyone with a cancer diagnosis. They are also recognised as the local palliative care experts, as they provide advice to colleagues.

Our service in numbers:

- **65** mins flight time
  From Stornoway to Glasgow

- **8** Macmillan nurses

- **26,500** Population covered

- **120** miles
  Distance covered by the service

macmillan.org.uk/macvoice
supporting people who are dying from other conditions. They plan their work around patient need, but must also take into account travel time and the cost of seeing some patients. However, if a person with cancer requires frequent visits, we ensure that those visits will happen despite their remote location and the cost of travel to the Health Board.

A challenging location
The Western Isles is a group of islands off the northwest coast of Scotland. From the northern-most point of the Isle of Lewis to the southern-most point of the Isle of Vatersay is approximately 120 miles. The islands are linked by ferries and causeways, providing numerous challenges to the provision of local care to people affected by cancer.

Most people live in remote, rural communities with few neighbours and little public transport. As Macmillan nurses, we do whatever we can to overcome the challenges set by the geography of the islands, the road conditions, the ferry crossings, the weather conditions and the animals on the roads to care for our patients.

The distance from where we are based to a patient’s home can be as far as 60 miles, with a journey time of approximately 90 minutes – each way! We can also face immense geographical and climactic challenges to providing care, with nurses travelling in poor weather conditions on single-track roads, dodging sheep and deer as they go. And poor weather doesn’t just happen in winter.

Working together
The Macmillan team has built good working relationships with our colleagues in the cancer centres on the mainland of Scotland. Most specialist cancer treatments, such as surgery, radiotherapy and chemotherapy, are provided for patients in these cancer centres, mostly in Inverness and Glasgow. Some chemotherapy is delivered in Stornoway to minimise patient travel.

The Macmillan nurses provide a key link between people with cancer and their mainland cancer specialists. Prompt recognition of problems by local Macmillan nurses, followed by a phone call to the cancer specialist, can often facilitate an earlier appointment with a consultant. This can sometimes happen by video conference. This link is appreciated by both the patients and the mainland consultants. Having to travel to the mainland for a hospital appointment can eat into precious time for people with cancer and their families; sometimes an appointment will require an overnight stay because of transport challenges. If the local Macmillan nurses can help minimise that travel, we can help people to feel much happier and more in control.

Local reputation
Our Macmillan nurses are welcome guests at local cancer support groups throughout the islands. They are seen as an important source of advice, support and expertise as well as being approachable, affable people. Most of the population of the Western Isles have had an experience with a Macmillan nurse or have heard about our work. Rather than associating us with bad news or a terminal diagnosis, most patients seem to recognise the benefits of being supported by one of our nurses, and are often resistant to being discharged!

‘The Macmillan nurses provide a key link between people with cancer and their mainland cancer specialists.’
Gill Chadwick

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Mobile buses take a creative approach

Macmillan Senior Cancer Information Support Service Lead Lucy Rogers describes how Macmillan is reaching more people living in deprived and rural areas.

The Mobile Information and Support Service (MISS) provides support to people affected by cancer in England, Wales and Scotland. Macmillan professionals travel on branded buses, parking in public places and providing free, confidential information and support.

In 2017, the Expansion Project was launched in Wales and the North West to try to engage more people with MISS services, including those living in more deprived and rural locations.

A report on the project published earlier this year shows that more than 68,000 people have accessed the new MISS services. Importantly, the expanded service is reaching more people from deprived communities and more rural communities, compared with business as usual. The new design for the buses means it is easier for them to visit harder-to-reach communities. This is particularly evident in Wales, where almost half of all communities visited are rural.

MISS has been an essential provider of information and support for customers. A customer survey found that 85% of respondents reported that they would not have got information elsewhere if MISS had not visited.

These figures, and the following case studies, demonstrate the public’s need for support from MISS in the future, and the real impact this service is having in supporting people affected by cancer.

Focusing on fishermen in Cornwall
MISS services need to adopt a creative approach in order to reach rural communities and deprived communities within the counties of Devon and Cornwall. Many of the small rural towns, particularly the coastal ones, cannot accommodate the bus on small streets.

The team has built up a good relationship with the Fishermen’s Mission, a charity that specifically services the community of fishermen who work from the small harbours of Cornwall.

Providing information and support within work settings often best serves the needs of those communities and has been received well. The service includes dental checks and men’s health checks, either from social centre locations or from a van commissioned by the Fishermen’s Mission. Tide times dictate the windows of opportunity to provide support, so flexible working patterns have been adopted.

Outreach for Eastern European communities
Last year, MISS was approached by a manager from a fresh food factory in Lincolnshire. The company wanted the local MISS bus to visit the factory to provide information and advice, visiting on three separate occasions to cover the factory’s shift patterns. One of the visits was at night, to reach people working the nightshift.

Event posters were printed and placed in the canteen and other nearby locations, and we also created a rolling presentation about cancer to play on the staff TV in the canteen, both before and during the MISS outreach visits.

Signs and symptoms leaflets in English, Polish, Russian, Portuguese and Arabic were on display, while the Macmillan Recipes booklet was used for conversations about nutrition.
The workforce comprised around 500 people, and our information and support specialists saw 232 people, who were predominantly Eastern European and Portuguese. As well as various types of cancer, the main topics discussed were sun awareness and skin cancer, healthy eating and bereavement.

**Beryl attends biking event**

In June, the Beryl bus attended an annual event in Yorkshire organised by Motorcycle Action Group (MAG), which protects and promotes the interests and rights of motorcycle riders.

The event provided an opportunity to target a group of men that is often hard to reach through the biking community. Around 1,500 bikers attended, and MISS staff and volunteers handed out literature to 374 people, promoting information about prostate cancer, the signs and symptoms of cancer and cancer prevention. There were also good interactions with people who were concerned about symptoms they were experiencing including signposting to health professionals.

Beryl is scheduled to attend further MAG events in 2019.

**Reaching out on residential estates**

The Matson Estate is a large residential estate on the outskirts of Gloucester. It is recognised as an area of high deprivation and unemployment.

MISS visited the estate in 2017, but there was a low level of interest in accessing our service. However, during the visit, the local information and support specialist visited the Redwell Community Centre on the estate, which seemed like a good place to introduce the work of Macmillan and the MISS service.

The centre offers a wide variety of activities and clubs for young people, families, older people and people with learning disabilities. In February, we returned to the centre and set up an information stand. The information and support specialist also gave a talk to an elderly people’s exercise group about the signs and symptoms of cancer and cancer awareness.

Several people were interested in the information provided and many said they knew other residents affected by cancer, who were likely to benefit from the service. People gave very positive feedback about the visit and asked when we are going to visit again.

We will therefore be going back to provide the information and support that is needed and valued by this community.

For more information about MISS, including upcoming dates when the Macmillan mobile team will be at a place near you, visit [macmillan.org.uk/information-and-support/coping/getting-support/local-information-centres](https://macmillan.org.uk/macvoice)
Understanding early (localised) prostate cancer
MAC11639 (Edition 5)
This booklet explains early (localised) prostate cancer, covering causes and symptoms, diagnosis, staging and grading, treatments and clinical trials. It also talks about emotional, practical and financial issues.

Understanding the PSA test
MAC11665 (Edition 7)
This guide is designed to help men decide whether to take the prostate specific antigen (PSA) test for prostate cancer. It covers key issues, such as what the test involves and the pros and cons.

Understanding advanced (metastatic) prostate cancer
MAC11686 (Edition 5)
This booklet explains advanced (metastatic) prostate cancer, covering causes and symptoms, diagnosis, staging and grading, treatments and clinical trials. It also talks about emotional, practical and financial issues.

Understanding locally advanced prostate cancer
MAC11686 (Edition 5)
This booklet explains locally advanced prostate cancer, covering causes and symptoms, diagnosis, staging and grading, treatments and clinical trials. It also talks about emotional, practical and financial issues.

Having tests for prostate cancer
MAC13704 (Edition 3)
This booklet is for men who may be having tests for prostate cancer. It aims to answer some of their questions and help people to deal with some of the feelings they may have.

Updated

Clues across
1 University grounds and buildings
2 Implore
3 Having widely different opinions (5,5)
4 Bog moss
5 Grey-brown striped cat
6 Experienced actor
7 Multicoloured arch
8 Broken piece of pottery
9 Full range of words employed
10 Automated machine-man
11 Mountain top

Clues down
1 Soft flooring
2 Plan of a play
3 Railtrack support
4 Sow with seeds
5 Epoch
6 Little poem to be sung
7 Indian temple
8 Fizzy like champagne
9 Countryside strolls
10 Australian marsupial
11 Break off a relationship
12 Sum to be deducted
13 Stiffly formal
14 Taxi

Crossword