

Mac Voice

For Macmillan Professionals | Issue 92 | Spring 2020



Maggie Wilkieson

Macmillan Cancer and Palliative
Care Nurse Specialist

In focus

Seldom heard groups

Sharing good practice

Social prescribing

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Welcome

Welcome to the Spring 2020 edition of *Mac Voice*.

Macmillan Cancer and Palliative Care Nurse Specialist, Maggie Wilkieson, has been awarded the title of Queen's Nurse in recognition of her fantastic work supporting people with cancer in rural Scotland. Find out more about her role on page 10.

On page 6, we outline Macmillan's latest research on the numbers of people living with treatable but not curable cancer. And on page 7, find out about our new campaign to reach more people at diagnosis so that we can start supporting them as early as possible. On page 16 we hear about a project to help people having cancer treatment to stay active, and on page 22 we explore the Macmillan Cancer Navigator role.

Our **In Focus** section demonstrates some of the important work going on across the country to raise cancer awareness and improve engagement with people in seldom heard communities.

Sharing Good Practice examines how Macmillan is supporting services to provide social prescribing. This takes a holistic approach to meeting the needs of people with cancer and connecting them with support available in their local communities.

If you would like to write an article for *Mac Voice*, or want to tell others about your service, please get in touch at macvoice@macmillan.org.uk



Rachel Hunter
Managing Editor





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Macmillan Explore

This course is now available for professionals wanting to develop their knowledge of cancer care.

Macmillan Explore is a role development programme that can enhance professionals' knowledge of the cancer experience and provide a strong foundation in cancer care.

It is aimed at band 5 and 6 nurses seeking professional development or a move into cancer care, as well as newly-recruited band 7 nurses and allied health professionals across disciplines.

This free programme was developed as part of Macmillan's response to shortages within cancer care teams. It provides an opportunity to prepare generalist nurses to move into cancer care, but also bolster the confidence and skills of those already in the speciality to step up into more senior roles.

Macmillan Explore consists of e-learning and telephone mentoring, which people can access in their own time. The course takes six months to complete, although this is flexible. Participants complete a workbook, as well as a series of practical tasks such as visiting your clinical audit team or your Patient Advice and Liaison Service team.

The four core modules are:

- Increase your knowledge about the cancer pathway
- Macmillan services to help you, your patients and their carers
- Managing yourself
- Increase your knowledge about key elements of the specialist role.

The programme aims to take a pragmatic and engaging approach to developing knowledge about cancer to support future job applications. A one-day celebration event for delegates completing the course includes a session on interview skills and career coaching. Macmillan will pay for travel costs for those that can attend.

Macmillan piloted Macmillan Explore in 2016, with the aim of recruiting 30 sign-ups. In fact, 180 people registered, demonstrating the potential of the programme. Since then, Health Education England and the Morrisons Foundation have provided funding for further cohorts. The next sessions will open in March and May, with a separate programme for band 4 staff who are new to cancer care roles.

Lindsay, a Macmillan Colorectal Cancer Nurse Specialist (CNS), was one of the first professionals to complete the programme. She says, 'As both a delegate and mentor, I found the Macmillan Explore programme informative and beneficial to my role.'

'It's a great programme for those looking to improve their knowledge around caring for cancer patients, developing into a CNS role or just improving knowledge around services and signposting within your local area.'

To find out more about Macmillan Explore, or if you are interested in mentoring on the programme, contact Angela Cleary, Macmillan Delivery Lead – Morrisons Project, on acleary@macmillan.org.uk To register, visit learnzone.org.uk/explore (accessible to any professional). 



Lindsay found Macmillan Explore helpful in her role.

Macmillan Grants applications go 100% online

An online application process will help us deliver Macmillan Grants more quickly and efficiently.

We know how devastating a cancer diagnosis can be and the impact it can have on someone's finances. Macmillan Grants are small, discretionary payments to help people with the extra costs that cancer can cause. They are usually a one-off payment to help the people who need it most, when they need it most.

Since January 2020, our Macmillan Grants application process has moved to be 100% online. We hope this will help us deliver Macmillan Grants to people living with cancer more quickly and efficiently and ensure we are making the most of every donation.

What does this mean for health and social care professionals?

Professionals now have two options when deciding how to apply for a Macmillan Grant on behalf of a person with cancer:

1. By completing an online application form

To apply online, you must complete a one-off registration process. You can find the link at macmillan.org.uk/grants-application This allows you to access our online application platform, where you can submit applications. and track their progress and outcomes.

You must register with your professional details as personal email addresses cannot be accepted.

2. By calling 01274 537 874

If you cannot access the online form directly, you can call the number above. This takes you to our dedicated grants team on the Macmillan Support Line, who will complete the application over the phone with you.

To access frequently asked questions and a 'how to' guide for applying online, visit macmillan.org.uk/grants-application For any other questions contact the Macmillan grants team directly at macmillangrants@macmillan.org.uk 

In brief

Call to transform pancreatic cancer survival

Every year, around 10,000 people are diagnosed with pancreatic cancer. It has one of the worst survival outcomes and 93% of people die within five years of diagnosis. Pancreatic Cancer UK is calling for national action to make pancreatic cancer a survivable disease, including research investment of £25 million a year and a public awareness campaign to highlight vague, non-specific symptoms. Read the campaign report at pancreaticcancer.org.uk

Macmillan's first national podcast

Macmillan has launched a new podcast called Talking Cancer. Hosted by Magic Radio DJ and Macmillan supporter Emma B, the podcast is another way for us to support people living with and affected by cancer. The first series covers six overarching topics: diagnosis, treatment, treatable but not curable cancer, life after cancer, end of life and living with cancer. In each episode Emma has honest conversations with people affected by cancer, and chats with a Macmillan professional who shares advice and information. To listen, search for 'Talking Cancer' on your preferred podcast platform.

People with cancer at higher risk of dying from heart disease

More than 1 in 10 people with cancer die from heart and blood vessel problems, rather than the cancer, according to new research published in the *European Heart Journal* in November. For some cancers, including breast, prostate, endometrial and thyroid, around half of patients will die from cardiovascular disease. Researchers compared the general population in the United States with more than 3.2 million American people who were diagnosed with cancer between 1973 and 2012. They called for greater awareness of the risks and closer monitoring of patients.



What's coming up?

April

Bowel Cancer Awareness Month

bowelcanceruk.org.uk

May

Sun Awareness Week

4–10 May

bad.org.uk/sun-awareness-campaign

Dying Matters Week

11–17 May

dyingmatters.org

Nurses' Day

12 May

rcn.org.uk/nurses-day

Mental Health Awareness Week

18–24 May

mentalhealth.org.uk

June

Carers Week

8–14 June

carersweek.org

Cervical Screening Awareness Week

15–21 June

jostrust.org.uk

Men's Health Week

15–21 June

menshealthforum.org.uk

Volunteers' week

1–7 June

volunteersweek.org

New research on treatable but not curable cancer

Macmillan publishes first estimate of how many people are living with a more chronic form of cancer.

Until now, little has been known about the numbers, needs and experiences of people living with treatable but not curable cancer. Macmillan defines this as cancer that can very rarely be cured, but can be treated to help manage symptoms or slow progression of the disease and extend people's lives.

Working with the National Cancer Registration and Analysis Service (NCRAS), we have shown that there are around 136,000 people in England currently living with these more 'chronic' forms of cancer. Further research from Macmillan estimates that 100,000 of those people are not getting all the support they need to live life as fully as they can.

Carol is one of the thousands of people living longer with treatable but not curable cancer. She explains, 'It has been a massive adjustment in understanding that the secondary cancer I have isn't curable and yet it is treatable. So, it is all about what does this mean to my life and how I live each day? How do I plan ahead and yet be realistic about the plans that I make every day, every week and every month?'

People with treatable but not curable cancer can experience great uncertainty, a prolonged, complicated treatment pathway and unpredictable physical and emotional health. It can be much harder for healthcare professionals to say how this type of cancer might progress.

Macmillan research reveals that:

- 77% of people recently diagnosed with, or treated for, treatable but not curable cancer are not getting all the support they need with cancer-related issues.
- More than one in five (22%) say that their healthcare professionals seem to have an unmanageable workload.

Macmillan is campaigning for a fully-funded plan for the NHS and social care workforce. We have also set up a new webpage at macmillan.org.uk/tbnc, which directs people with treatable but not curable cancer to our support services.

To read our brief report on treatable but not curable cancer, visit macmillan.org.uk/tbnc-report

Tailored information and support at diagnosis

Macmillan's national campaign to reach people at the point of a cancer diagnosis.

We know that when someone is diagnosed with cancer, it can be overwhelming, and they may have a hard time absorbing everything. Macmillan's information and support can make a huge difference at this point.

Since October 2018, we have been running a test campaign to reach people living with cancer at diagnosis. We have seen over 23,000 people sign up to receive ongoing information and support in a way that suits them.

Shola, who was diagnosed with cancer in 2013, said, 'The Macmillan information was very simple and easy to read. That's what people need when they're trying to manage a very difficult diagnosis.'

In mid-February 2020, we launched a national campaign. Our goal is to ensure that people receive the right information when they need it, to help with the physical, financial and emotional impacts of cancer. We specifically aim to reach people at diagnosis, including people:

- on lower incomes
- in work
- with dependents at home
- aged over 65 with limited or no digital skills.

The campaign is now live across the UK on television, posters in hospitals and GP surgeries, and online. People who have recently been diagnosed with cancer can sign up to receive ongoing information via email or in the post, with content tailored to their particular cancer type.

This includes information on work and benefits, and support on how to talk to their family about the diagnosis.



Gary, who was diagnosed with cancer in 2008, says, 'I'd encourage anybody affected by cancer to contact Macmillan.'

You can encourage people to sign up online at macmillan.org.uk/diagnosis or by calling us free on **0808 808 00 00** (7 days a week, from 8am to 8pm). 📞

Support for family and friends

Family members, friends and carers often call us to seek information and support on behalf of their loved one with cancer. For this reason, we have also developed a series of printed information packs, which not only provide content to share with the person diagnosed with cancer, but also include information to support those looking after them. You can encourage people to call us free on **0808 808 00 00** and sign up for a pack.

New Macmillan films promote patient engagement

Helen Melling, Macmillan Radiotherapy Advanced Practitioner, and Yvonne Saunders, Patient Information Co-ordinator, on creating two films to promote the benefits of patient engagement.

In 2018, Macmillan brought together a group made up of people living with cancer and health professionals to produce two short films about the importance of patient engagement.

One film is aimed at people living with cancer to encourage them to get involved in shaping cancer services. The other is aimed at healthcare professionals to promote the benefits of patient engagement.

The idea came from two Macmillan engagement leads, but from the beginning they let the group take responsibility for the project.

Following a co-production approach, we met once a month for nearly a year, and together agreed the films' key messages and audiences. We appointed a video producer, who supported us in coming up with a concept for the films. Then we wrote the film scripts as a group.

We wanted to work with people with cancer and their carers to improve patient engagement for others going through a cancer experience.

While we were apprehensive about engaging patients at first, professionally we knew it was the right thing to do. We did not want to inconvenience people living with cancer because they already had enough to cope with. But with a group of willing volunteers to work with, and Macmillan staff to guide us, this project was a chance to gain knowledge and skills to take forward and help others.

When we started the project, the word 'engagement' seemed a bit abstract.

However, it simply involves listening to people and having a conversation. Working together to decide what engagement meant to each of us and producing the film scripts as a group was very important. They needed to be written in our collective voice, embrace our colloquialisms and feel authentic.

Engagement does not have to be overwhelming.

As we moved closer to filming, we collectively agreed to feature in the films. Being filmed seemed daunting, but we were not acting; we were saying our own words. Despite our initial fears, it was a very enjoyable experience and we had quite a lot of laughs along the way. The encouragement that we gave each other, together with the support from Macmillan and our video producer, were invaluable.

The films are available on Macmillan's website at macmillan.org.uk/share-your-experience (for people with cancer) and macmillan.org.uk/professionals (for professionals).

If we had one message for professionals considering involving people living with cancer in their work, it would be 'just do it!' Engagement does not have to be overwhelming – just start small and have a go. 

Further information



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New mindfulness app

Julie Armytage, Macmillan Counsellor, on developing a mindfulness tool at Velindre Cancer Centre in Cardiff.

My colleague Tara Daisley-Devoy, Assistant Psychologist, and I have created an app that we hope is easy to use, and can have huge potential for anyone needing help to manage difficult thoughts, feelings and emotions.

The idea for the app came from mindfulness groups, which we run here at Velindre Cancer Centre, aimed at both patients and staff. The groups are very popular and often oversubscribed.

Feedback from the groups indicated that although the mindfulness workbooks that accompanied the group were a useful resource, one of the barriers to continuing practice was access to the guided exercises. Tara and I talked about how we could solve this, and we had the idea to develop a mindfulness app for people with cancer.

Creating the app

We were keen from the outset to make the app inclusive, so that patients, family members, carers and colleagues could benefit from practising mindfulness. Our Macmillan Supportive Care Lead, Michele Pengelly, secured funding from the Welsh Government Carer's Fund.

The Orchard Media and Events Group Ltd helped us design the app. We are very grateful for the input from patient and staff focus groups, which helped shape the format and voice preference. Our occupational therapy team provided the scripts for the visualisation exercises in the relaxation element of the app.

Potential benefits

We are incredibly proud of what we have created and wanted to let all our Macmillan colleagues know about this valuable resource and self-help tool.

Potential benefits include:

- free to download, easily accessible and simple to navigate
- improved feeling of personal wellbeing and control
- help to manage low mood more effectively, reduce anxiety and develop resilience
- may encourage patients to proceed successfully with treatments that they find distressing or difficult
- help with coping independently as an in-patient
- possible reduction in treatment opt-outs, promoting prudent healthcare
- relaxation element can promote rest and sleep
- encourages self-care
- unlimited potential use within primary care, secondary care and mental health settings, and with other health conditions
- available in English and Welsh.

Since its launch in August 2019, the app has been shortlisted for three awards (including a workforce award) and has been downloaded nearly 2,000 times. It has also been added to iPads used on wards, so that staff can offer the exercises to patients who are experiencing low levels of anxiety and distress. In addition, Velindre Cancer Centre plans to download the app to staff laptops and desktops to support staff wellbeing.

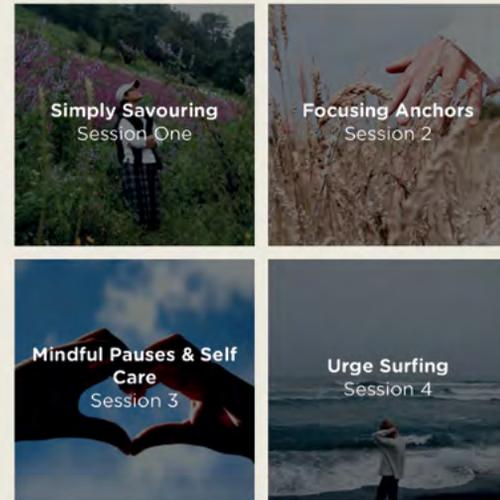
You can download the Velindre Mindfulness App on Google Play or the iTunes App Store. 



Velindre
mindfulness & relaxation

Cy

Mindfulness



The mindfulness app offers different sessions.

Further information



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Q&A: Maggie Wilkieson

Job title

Macmillan Cancer and Palliative Care
Nurse Specialist

Location

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In post

Since 2007

Contact

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What does your day-to-day role entail?

I am a lone practitioner and my role is extremely varied. I generally start the day by visiting the hospital ward and community team to check for any changes, and then my day can be filled with home visits, in-patient care or in clinic. I see people and their families at any stage in their illness, but most often I am involved in palliative and end of life care. I never cease to be amazed by the strength and resilience of the human spirit, despite the most challenging of circumstances. It's a privilege to share such an intimate part of people's lives. I also provide education to a variety of audiences including secondary schools, community groups, home carers,

care home staff, nurses, allied health professionals and GPs, as well as chairing our local palliative care meetings.

Service development is also hugely important, and creativity is needed to ensure changes meet specific rural needs. Most recently, I have been working on a project with the local community to refurbish a small palliative care suite at our local hospital. This was just in time for our 'Macmillan Quality Environment Mark' assessment, in which we scored 'excellent' in all four domains. This year we have also secured a blood analyser to assist in the early detection of sepsis, meaning people can get their neutrophil levels checked without having to travel 130 miles to Glasgow. Through evidencing the impact, and many discussions, we are now better equipped to manage suspected sepsis with a much-improved service.

What does being a Macmillan Professional mean to you?

I am really proud to be a Macmillan Nurse. There is a real trust associated with the Macmillan brand that I think helps to drive forward change and inspire others to become involved in making a difference. The networks that Macmillan offers in terms of education, expert advice, support and project development are fantastic. Despite working in such a rural locality, I am well supported by my Macmillan colleagues in the region.

How did it feel to get the Queen's Nurse Award?

I'm hugely honoured, especially as this is the first Queen's Nurse Award given to a Macmillan Nurse in Scotland. The programme demonstrates that if we are truly to be change makers, then self-care is a necessity, not a luxury. This was very new to all of us, but our journey of discovery over the nine months, supported by our course leaders, residential workshops, inspirational speakers and coaches, has been transformative. I now feel truly confident in using my voice to make change happen – providing truly person-centred care, and seizing every opportunity I can to challenge inequity, to encourage others to come alongside, and to embrace the ethos of nursing and all that it means.

What are the challenges and rewards of working in a remote location?

The peaceful, beautiful surroundings of my rural location help balance the stresses and emotions that come with being a Macmillan Nurse. My 'patch' covers almost the whole of the Kintyre peninsula, stretching across 50 miles of rural countryside, and including the beautiful Island of Gigha, where I live. I work closely with the community team to provide an informal on-call service to those who require additional support at this particularly stressful time. It is important that we provide equity of care, and that those who are more remote are not disadvantaged by a lack of services. I am proud of the fact that we strive to offer the best care, despite the challenges.

It's important that we provide equity of care.

Patients often have to travel around 250 miles for scans, consultations or treatments. We currently offer telephone consultations, and I am also working with IT colleagues to try and set up video consultations. I can also relay information or advice between consultants and patients. Working and living in small communities can mean that we are often caring for people and families that we know well. There is a need for a high level of emotional intelligence in these situations. It can be tough, but we support each other. At times I can feel isolated from other colleagues, but on balance, the positives of rural working far outweigh any negatives.

What are you looking forward to?

I've recently been involved in a local Macmillan-supported project to establish a support worker role. This person will work alongside me and my Macmillan colleague in the next patch, 50 miles away. I am excited to see how this will help improve the support people receive following a cancer diagnosis. It will also be great to have a colleague in close proximity! 🍷



The team enjoy their Christmas party.

Information and support in Edinburgh libraries

Gaynor Stobie, Macmillan Programme Lead, outlines a volunteer-led information and support service across libraries in Edinburgh for people affected by cancer.

Macmillan @ Edinburgh Libraries is a volunteer-led service that was set up in 2016. It provides emotional, financial and practical signposting throughout five geographical areas within Edinburgh, in addition to an Information Hub at the city's Central Library.

The team of trained volunteers are on hand to answer any questions and give confidential information and support to people affected by cancer. This is available for everyone, regardless of whether they are newly diagnosed, have finished treatment or

are a family member, carer or friend.

A listening ear

The service aims to give people affected by cancer a break from medical environments and offer a friendly face and a listening ear.

Each library runs a daily drop-in session from 10.30am to 2.30pm, where no appointment is needed. There is no limit on the amount of time spent with each person.

The libraries are informal, warm and welcoming spaces, with tea and

coffee served. People can find lots of information on cancer and its impact and helpful reading material on a range of topics, such as healthy eating or physical activity.

People affected by cancer often feel disempowered by the condition and by the organisations that support them. This can lead them to withdraw from their communities, not knowing who to turn to for support.

Our team of volunteers offer one of the greatest gifts we can give to people and that is time. They make the time to listen to people and understand their real concerns.

The volunteers then use their skills and knowledge to take a holistic, person-centred approach, providing much-needed information and support. A great benefit of the service is that it is held in a free, accessible community setting open to all.

Volunteer support and training

Our volunteers cover a variety of geographical areas. For this reason, we feel that it is important for them to stay in touch with other volunteers who they may not see on a regular basis. We have frequent peer support sessions for volunteers to learn from each other's experiences. These sessions also have guest speakers from relevant services. The benefits of peer support sessions are that they:

- enhance and expand existing knowledge
- create an opportunity for organisations to engage in cross-functional working
- promote a greater understanding of how other services work.

The service continues to grow, and new volunteers shadow our more experienced volunteers for six weeks. This makes new volunteers feel supported, but also gives them the chance to increase their confidence while learning.

All volunteers are offered training when needed throughout the year, in addition to the Macmillan courses and access to the Learnzone resources.

This ongoing training keeps their knowledge up-to-date. Many volunteers have said that they enjoy volunteering for Macmillan because they feel involved with, and part of, the organisation.

Being there in times of need

The service is now seeing many repeat visits to the libraries. This shows that our 'open door policy' encourages people to come back if they have further questions or concerns.

The volunteers have also seen people return to share good news stories because they have felt supported throughout their cancer experience. In the words of one of our volunteers, 'knowing that we have been there for them, in good times or bad, and for them to then thank me for my time, makes me feel very humble that I can be there for someone when they need it most'.

With thanks also to Angela Davidson, Macmillan Volunteer Manager and Margaret Faichney, Macmillan Programme Officer. 

Further information



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Providing peer support for information service managers

Sarah Grant, Macmillan Patient Information and Health and Wellbeing Manager, on the benefits of a learning and development forum for information and support managers.

Over the past 10 years, a regional forum has been open to information and support service providers across the Yorkshire and Humber region. The forum is funded by Macmillan and run by information and support managers.

Representatives from information services in Airedale, Bradford, Calderdale and Huddersfield, Harrogate, Hull, Leeds, North Allerton, Northern Lincolnshire and Goole Hospitals, Wakefield and York are invited to attend.

Four members must be present at each quarterly meeting to ensure decisions are valid and we adhere to our terms of reference. Administration is kept to a minimum with a rolling chair and deputy, ensuring greater fairness in sharing organisational responsibilities.

The purpose of the forum is to:

- share best practice and information service development
- arrange education and training for members
- support a patient-centred approach to providing good quality information
- promote compliance with information governance principles when providing patient information services
- work collaboratively with multidisciplinary teams to support the National Quality Surveillance Programme
- understand the wider agenda, both strategically and operationally.

Since its inception, the format of the meeting has frequently been transformed to help members meet the challenges of an ever-

changing healthcare agenda. Many of the information managers are also responsible for health and wellbeing services and are involved in delivering and implementing patient education programmes now being developed from the Recovery Package.

The forum allows members to share best practice and provides valuable peer support. This has been increasingly identified as an essential component on the agenda and is appreciated by both new and established post holders.

One or two guest speakers are invited to each meeting. They talk about topics where the group feels more knowledge is needed in order to improve patients' experiences. Recent topics covered include:

- annual welfare and benefit updates
- ethical tissue and organ donation
- funeral planning and choices
- EU immigration and refugee welfare rights
- advances in cancer treatment
- carer support services
- work and employment support
- beauty products and services that are safe for people with cancer.

Information enquiries have become more detailed and demanding, often requiring complex responses and referral to specialised organisations. This has made the forum more aware of the emotional burden and stress experienced by information professionals.

Another common theme emerging from the group has been their role in providing education and emotional support to other healthcare

professionals across multidisciplinary cancer teams. This is an area of work which often takes up a significant amount of time, and the emotional energy required is underestimated as 'it's just done'.

Sadly, only a few of those attending the forum have access to regular clinical supervision. Consequently, the forum approached Macmillan to advise on additional, bespoke resilience, reflection and coaching training.

Over the past two years an extra training day has been added to the annual agenda, provided through an external facilitator. Everyone who has attended this training day evaluated it extremely well, and it is now a fixed part of the annual programme.

Moving forward, the forum has agreed to take on a new challenge in 2020 to create change. Reflective sessions have highlighted the challenges, complexities and barriers experienced by many people with cancer wishing to travel.

Even holidays in the UK can involve difficulties. At our last meeting every

Information enquiries have become more detailed and demanding.

member around the table could recount challenging situations for people with cancer, either witnessed first-hand or told to them by a patient.

Fuelled by our experiences, the forum is committed to undertake work over the next couple of years to explore how some of these issues can be improved and hopefully even resolved. If anyone is interested in joining us on this project, we would be delighted to welcome you.

Thank you to all the members of the Macmillan North Yorkshire, Humber and Lincoln information and support managers' learning and development forum: Hannah Hall, Helen Jones, Helen Murphy, Jane Archer, Joanne O'Mara, Lauren Farrow, Mandy Davies, Margaret Harrison, Nicola Lee, Pat Chennells, Rebecca Foster and Sarah Grant. 



Further information



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Active patients in the West of Scotland

Alun Myers, Clinical Specialist Physiotherapist, on a Macmillan project to boost the physical activity levels of people undergoing cancer treatment.

The Macmillan Physical Activity Project at the Beatson West of Scotland Cancer Centre is a three-year project funded by Macmillan. Its overall aim is to increase and maintain people's physical activity levels before, during and after cancer treatment.

This is an important area of development. Approximately 30–50% of people living with cancer achieve the government's current physical activity recommendations¹, compared to 65% of the general Scottish population². In addition, 43% of people living with cancer do not receive any advice on physical activity³.

The benefits of physical activity

Physical activity is a very effective way to improve someone's resilience before they undergo substantive cancer treatment. This applies whether they are having surgery, chemotherapy, radiotherapy or a combination. It also helps to improve recovery from the side effects of treatment, such as fatigue, muscle loss and deconditioning.

Physical activity is an aspect of cancer treatment where people can have some autonomy and control. It can help to empower an individual and improve their mental health, in addition to their physical health.

Cancer survivorship is now at its highest-ever rate. The focus on optimising an individual's physical function, independence and quality of life is becoming increasingly important. Thankfully, archaic messages of bed rest are being replaced with a greater interest in physical activity to support people living with cancer.

Bridging the gap

It is exciting to be part of this project, which consists of various developments. A new, unique physiotherapy service has been set up to bridge the gap between traditional inpatient, outpatient and community physiotherapy services in the West of Scotland.

Alongside my colleague, physiotherapist Elise Inrig, we have created, developed and overseen specific outpatient clinics. These clinics aim to see people as soon as possible after diagnosis and whenever they require support to be more physically active. We have built up relationships within lung, upper-gastrointestinal, prostate and neuro-oncology teams, who can refer people to us who have been identified as either:

- inactive and in need of specialist support to become active
- at risk of dropping below the minimum recommended physical activity levels during treatment.

Encouraging physical activity

The clinics involve assessing an individual's current function, co-morbidities and overall physical activity levels. We then use a combination of:

- traditional physiotherapy
- exercise prescription
- fatigue management
- physical activity goal setting
- signposting to physical activity referral schemes.

We process referrals, arrange outpatient appointments and maintain a database of outcome measures. This ensures that we can evaluate how

Further information



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effective the interventions were. The measures we use include the Godin Leisure Time Exercise Questionnaire, the six minute walk test and the Oxford Scale of muscle strength.

We are also working hard to develop the physical environment of the Beatson West of Scotland Cancer Centre to help our inpatients and outpatients become more physically active. We also hope to make information more accessible for staff, people living with cancer and their families on the role of physical activity and opportunities to be active.

A wide reach

We treat people with cancer from a large geographical area across the West of Scotland. People attend from Forth Valley, Lanarkshire, Ayrshire and Arran, as well as Greater Glasgow and Clyde NHS Trusts.

We have also been working within the Greater Glasgow and Clyde 'Active Wards' group to develop resources and approaches to reduce 'pyjama paralysis' (endpjaralysis.org). This term describes the negative physical and psychological effects experienced by people who are inactive, and in

their pyjamas, for lengthy periods in hospital. Our work includes the initial trial and ongoing development of 'physical activity menus', which provide information and promote opportunities for inpatients to be more active while staying in hospital.

Improving staff confidence

Before I started this role, staff at the Beatson West of Scotland Cancer Centre did not feel confident in their ability to advise people on physical activity. I have set up workshops to create 'Beatson Activators', who are trained in giving brief physical activity advice to people living with cancer and become champions in their areas. The training is being rolled out to more staff and I will be delivering sessions at the Lanarkshire Beatson satellite treatment centre soon.

It would be great to hear from any other relevant services or professionals to share practice and build links. Please feel free to contact me. 

Read Macmillan's latest prehabilitation guidelines at macmillan.org.uk/prehabilitation

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2. Scottish Government (2019) Scottish Health Survey 2018. Available at: gov.scot/publications/scottish-health-survey-2018-volume-1-main-report/
3. Macmillan Cancer Support (2016) What motivates people with cancer to get active? Available at: macmillan.org.uk/about-us/health-professionals/programmes-and-services/physical-activity#290188

The Macmillan Move More pack includes a copy of the booklet *Physical activity and cancer*, and information flyers about some popular types of physical activity. There is also an activity chart so people can see what they have achieved each day, as well as a Move More DVD, which includes gentle activity videos people can do at home. The pack is available to order at be.macmillan.org.uk



Recognising excellence in cancer care

Aaron Hall, Macmillan Community Facilitator, on a new award scheme for GP practices in Lincolnshire that offer quality cancer care reviews.

On behalf of the Lincolnshire Sustainability and Transformation Partnership, Lincolnshire West Clinical Commissioning Group is working with Macmillan to transform how support is given to people affected by cancer. The Living with Cancer Programme aims to recognise GP practices committed to delivering excellent ongoing cancer care with a new award, to try to address current challenges and achieve more effective outcomes for people living with cancer.

There are currently 27,500 people living with cancer in Lincolnshire, and this number is expected to increase to 45,000 over the next 10 years. Higher numbers of new patients will inevitably create extra demands on primary care providers.

Lincolnshire GP practices play a vital role in the ongoing support offered to people with cancer and their families. One of their roles is to carry out an effective cancer care review, which enables people to talk about their cancer experience and identify any concerns or worries they may have. These reviews enable a practice to provide personalised care, including:

- support with symptoms and side effects after treatment
- care planning
- signposting to offers of support in the community.

Improving standards

Over the past six months, our team has consulted with more than 40 GP practices. We wanted to learn more about how support is offered to patients who return to the community after treatment.

Although all practices recognised the importance of a holistic cancer care review, there were significant unwarranted variations in the quality and consistency of patient care. Some GP practices had effective processes for carrying out cancer care reviews and signposting people to community-based services. However, challenges elsewhere have meant that cancer care reviews are often unfit for purpose.

One of the key issues that GP practices identified is a lack of guidance and structure for providing follow-up care to people living with cancer. With support from Macmillan GPs, a Cancer Care Review Protocol has been developed to reduce variations in the quality of care and support a more standardised model for the future.

In 2020, we are taking the protocol to various Primary Care Networks to support GP practices in transitioning to the new model. Our aim is for people to receive the same quality of care, regardless of their location.

Our community team will also work closely with acute teams to see how we can improve communications leaving secondary care, to support practices carrying out cancer care reviews. This will include looking at IT systems and information sharing. We will also:

- provide a training update for GPs and practice nurses to develop the cancer workforce
- embed robust pathways for practices that refer people into the community.

Rewarding good practice

The Lincolnshire Cancer Care Award is presented to GP practices that can demonstrate excellent ongoing care for people living with cancer. This includes working with Macmillan and the Living with Cancer programme to ensure that quality cancer care reviews are offered to people within the first six months of diagnosis, and using the new Cancer Care Review Protocol.

With support from Lincolnshire's cancer co-production group, comprehensive award criteria have been developed and GP practices can work towards them. This includes the practice nominating a cancer champion to support ongoing developments in the programme.

Dr. James Howarth, Macmillan GP, says, 'The Lincolnshire Cancer Award demonstrates to patients, and the Care Quality Commission, that the practice has been thorough a rigorous process, acknowledging that a standard has been achieved in cancer care.'

The team at Abbeyview Surgery receive their award.

The Abbeyview Surgery in Crowland was the first recipient of the award. Helen Herbert, Practice Manager, says, 'Our dedicated team feel passionately about providing the best possible care to all those affected by cancer.'

In the last six months, four GP practices have achieved the award and eight practices are working towards full accreditation. Macmillan Community Facilitators work with practices to enhance services and identify where changes can be made.

A GP practice in the south of the county has introduced nurse-led cancer care review appointments, supported by a practice care coordinator. These have been well received by people with cancer.

Practices that meet the award criteria are presented with a plaque and Certificate of Excellence from Macmillan. If you wish to hear more about the award, our programme or the Cancer Care Review Protocol, please get in touch. 



Further information



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Promoting health and wellbeing in Nottingham

Ellen Parr, Macmillan Assistant Project Lead, on developing an ambitious local programme of cancer information and support events.

The Macmillan Project Team at Sherwood Forest Hospitals NHS Foundation Trust has developed a cancer information and support event based around the top 10 concerns raised by local people living with cancer. We identified these concerns using data from electronic holistic needs assessments (eHNAs).

The top 10 concerns identified by people living with cancer were:

1. tiredness, exhaustion or fatigue
2. worry, fear or anxiety
3. thinking about the future
4. sleep problems
5. eating, appetite or taste
6. uncertainty
7. changes in weight
8. relationship issues
9. pain or discomfort
10. breathing difficulties

This shows that many people with cancer frequently experience emotional concerns as well as physical symptoms.

A prehabilitation approach

According to the National Institute of Health Research, a person's wellbeing can be affected even before cancer treatment starts. This not only creates increasing anxiety for the person facing treatment, but can also decrease resilience to the cancer and response to treatment.

In turn, there can be increased risks and complications during treatment itself.

Addressing physical and psychological health issues at an early stage can improve outcomes for people with cancer. We reviewed other trusts' health and wellbeing events and found that most use a post-treatment approach. To maximise patient benefit, we wanted our model to be accessible at the earliest possible opportunity.

We engaged with the wider cancer teams at our trust, who were enthused by the opportunity to offer a service that meets people's information and support needs. We soon had a full agenda, with key people willing to give a presentation, and booked 12 months of events at the hospital site.

In January 2019, the first cancer information and support event developed using the prehabilitation model was launched in the East Midlands. The aim was to:

- signpost patients and carers to local support and services
- give them an opportunity to challenge information and make informed decisions
- empower people to self-manage their condition.

We successfully delivered 11 cancer information and support events in 2019, presenting to a total of 147 people living with cancer and 118 carers or family members.

Our model

People are invited to attend an event from diagnosis onwards. We hold

rolling monthly, two-hourly events at the acute trust, with one hour of presentations from healthcare professionals and one hour of informal discussions.

As part of the presentations, the Cancer Clinical Psychology Team gives a visual demonstration. This shows how easy it is to let worries and concerns escalate to a point where they can become quite debilitating and unmanageable if not discussed.

The team delivers psychological training to hospital staff and equips them to assess and support our emotionally vulnerable patients. They can signpost to various support groups and provide valuable one-to-one support. Through these tailored sessions, people with cancer and family members can explore how to live in a way that makes the best of their situation.

Attendees are guided to the supporting website: sfh-tr.nhs.uk/our-services/clinical-psychology-cancer-service

Evaluation

All cancer information and support events are evaluated through a simple questionnaire of 10 questions. All attendees are given this on arrival. The questions are designed to get feedback from both the person living with cancer and their family member or carer. This feedback helps to develop the event for future attendees.

Our evaluation shows that:

- 73.8% of people were extremely likely to recommend the event to others living with cancer.
- 63.2% rated the overall helpfulness of the content delivered as excellent.

The qualitative data that we collect in the form of patient or carer comments is invaluable. One person said, 'The event was brilliant – just enough information to take in', and another described how it 'made an emotional and difficult time seem more normal'.



With the help of the Cancer Clinical Psychology Team and support from social psychologists at Nottingham Trent University, we also carry out a follow-up evaluation after six months. This allows us to find out if the person living with cancer has:

- taken advantage of the services showcased at the event
- adapted to their treatment and symptoms
- been able to 'self-manage' aspects of their own health, either independently or with a healthcare professional's help.

Our team is working with senior staff and commissioners to ensure that cancer information and support events become 'business as usual'. We would like them to be a permanent element of the pathway for all newly-diagnosed patients.

With thanks also to Kate Roggan, Heather McCormack, Helen Nind and Ashlie Burgess for their contribution to this article. For more information about the project, please get in touch with Kate Roggan at kate.roggan1@nhs.net 

The Macmillan Project Team

Further information



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Understanding the cancer navigator role

An explanation of what Macmillan cancer navigators do, and examples of best practice from across the country.

Macmillan cancer navigators work with people who have been diagnosed with cancer to identify their needs and any issues affecting their wellbeing. They can then navigate the local support system to connect them to the appropriate community services available to help them. This might include both practical and emotional support, covering the wide range of needs that people living with cancer may have.

This is very similar to other roles that have been adopted in both primary and secondary care across the UK,

including cancer care coordinators, support facilitators and link workers. Following engagement and co-production with local people and communities, the roles may have different names depending on what resonates most with them.

Macmillan cancer navigators, and those providing a similar service, can free up health and care resources, but it is important to recognise that this is a skilled role that must be understood and valued by all professionals as part of the skilled workforce. It takes time, effort and resources to

keep up to date with local support systems, to build relationships, and to work within communities to ensure relevant support is available to meet people's needs. Cancer navigator roles and services must be adequately resourced to ensure they are feasible and sustainable.

Below are three examples of Macmillan cancer navigators demonstrating best practice across the UK. You can also read more about social prescribing in this month's edition of Sharing Good Practice.

Velindre Cancer Centre, Wales

With the support of Macmillan funding, the Navigator Service was introduced to Velindre Cancer Centre to assist with the non-clinical workload of clinical nurse specialists (CNS).

The aim was to promote a holistic approach in supporting patients, family members and carers, freeing up time for the CNS to provide more specialist care.

This service was introduced following patient surveys, which highlighted concerns that people with cancer could not speak with their CNS in a timely manner due to clinical commitments.

The navigators were introduced to play a crucial role in helping people to get the right support, at the right time. This included support with managing side effects or treatment, help with finances and signposting to a range of services within someone's local community.



L-R: Macmillan Cancer Navigators Diane Rees and Karen Kendall

The team of navigators work closely with the specialist nurses in assisting with patients' telephone queries and referring these to the relevant community teams.

The navigators initiate contact with the patients, completing an electronic

holistic needs assessment (eHNA) to assist the patient in identifying their concerns and feelings. This helps the navigators to provide appropriate information that may support them and offer an empathetic ear. If agreed with the patient, the care plan can then be shared with GPs. The navigators are also on hand to assist the teams with projects such as patient surveys, wellbeing events and initiating patient support groups.

One of the main challenges has been the increase in calls. This has affected our capacity within a working day to support people with an eHNA and spend time with them to discuss their concerns.

Using data collection, the specialist nurses and navigators have reviewed the service and made changes to improve the way we work.

Verbal feedback from patients has been positive, with people saying they

appreciate having someone to listen to their concerns and resolve queries in a timely manner. By developing rapport with patients, navigators can act as the link between them and the specialist nurses for more clinical questions. Verbal feedback from staff has also been positive. Clinical teams have valued our input in offering a holistic approach to supporting people affected by cancer.

For more information contact **VCC. NavigatorService@wales.nhs.uk**

University Hospitals of Derby and Burton

We are part of a team of eight Macmillan Cancer Navigators across the trust. Working within a hospital environment, the navigator's primary responsibility is to identify where a person with cancer is on the cancer pathway, and ensure any potential delays or detours are avoided or managed. This role was introduced to free up cancer nurse specialists' time, allowing them to manage more complex tasks and utilise their time effectively.

As cancer navigators, we aim to ensure a smooth and efficient pathway from diagnosis and beyond. Our responsibilities include:

- booking and changing appointments
- tracking investigations and highlighting results
- being an effective member of the multidisciplinary team
- completing audits and producing data for reports
- carrying out holistic needs assessments and care plans
- producing end of treatment summaries
- triaging telephone calls and signposting effectively.

Examples of services that we might signpost patients to include nutritional support, support groups,



Some of the Derby and Burton navigators at a recent workshop.

complementary therapies, patient information or counselling services.

Cancer nurses face increasing demands every day. The cancer navigator role has been proven to alleviate time pressures for the teams they work in, enabling them to streamline services and offer each person with cancer the complex level of support they require. We advocate for the patients, fostering good relationships and bridging gaps between the patient and the clinical teams.

Introducing the navigator role has been invaluable and allowed better use

of nurse-led clinics and ward visits, freeing up consultant clinic capacity. It has helped to ensure that patients are seen by the appropriate professional required for their needs, at the most appropriate point along their pathway.

For more information contact **sharon.cox9@nhs.net** or **megan.docksey1@nhs.net**

Continues over

Addenbrooke's Hospital, Cambridge

The Macmillan Integrating Cancer Care Project was a Macmillan-funded project to initiate risk stratification and implement the Recovery Package at Cambridge University Hospitals (CUH).

This identified the need for additional resources to integrate electronic holistic needs assessments (eHNA) into the patient pathway.

Following closure of the project, the Macmillan CUH Cancer Support Team was formed, and the Macmillan navigator posts were introduced.

This role has helped to embed the eHNA earlier in the pathway, which can prompt patients to think about non-clinical or holistic concerns that come when they are diagnosed with cancer.

The navigators are site-specific in line with the Cancer Alliance current target sites (prostate, colorectal and breast) and have integrated with their relevant clinical teams and pathway. The induction period for the role included Trust e-learning and Macmillan LearnZone, spending time in the Macmillan Cancer Information and Support Service to learn about cancer support information and resources, and shadowing nurse specialists.

The navigators offer a responsive service, making first contact with a patient to offer an eHNA within 31 days of a decision to treat. The navigator's contact details and role description are included in patient packs, while others have identified an appropriate clinic for patient to see the navigator after their appointment. Patients are also seen on the ward.

The navigator role has led to increased delivery of eHNAs, and navigators saw 877 patients in the six months from May to October 2019. By responding to concerns early, fewer patients are reaching crisis point



L-R: Breast Navigator Fiona McGachen, Prostate Navigator Christopher Squires and Colorectal Navigator Sarah Goodman.

and concerns that may have been a barrier to treatment are overcome. The majority of patients are being reached when their complexity level is still low.

Navigators have demonstrated that uncovering concerns and highlighting the medical issues to the relevant team allows staff to refocus and prioritise their clinical workload. There is a clear demand for the service to continue and expand in order to address patients' needs.

The navigator service has proven to be a success: patient feedback is positive, unmet needs have been addressed and there is better collaboration with the multidisciplinary team.

For more information contact **laura.abbas@addenbrookes.nhs.uk** 

In focus: Seldom heard groups



In this section

- 26 **Cancer listening events in Manchester**
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Community engagement in transforming cancer care

Macmillan Living With and Beyond Cancer Programme Lead, Jane Brown, and Macmillan Service User Involvement Facilitator, Salma Hashmi, on engaging the local community to improve cancer services.

The importance of community engagement and co-production in creating successful, sustainable changes to healthcare services has been recognised for some time¹. But how can we better involve the local population to achieve more equitable and diverse service user engagement?

The population of Greater Manchester has increased by nearly one-third since 2001 and there has been considerable economic growth². However, there has been no corresponding significant decrease in health inequalities, leaving the area with some of the worst health outcomes in England³.

More people are living with and beyond cancer (LWBC) and transformation of cancer care is essential for better experiences and outcomes. We also know that social isolation is a key driver in poor health and being part of a community can drastically improve health outcomes.

Engaging with our local community

Traditional approaches to recruiting and engaging service-users through hospital-based cancer services do not always accurately represent the needs of people affected by cancer. At the Manchester University NHS Foundation Trust, we decided to reach out to the local community. Our initial scoping considered:

- diversity
- community groups and activities
- cancer support groups
- employers
- cancer prevalence/incidence
- local knowledge.

Social media was invaluable in identifying opportunities and contacts.

Our Macmillan LWBC Service User Involvement Facilitator then engaged with community groups, who are typically viewed as hard to reach. The success of this project was due to:

- raising awareness of our LWBC programme with a 10-minute ‘taster’ session before a longer, more interactive event
- meeting with key figures and group members
- using existing local venues and community groups and activities
- co-production of content for a Cancer Listening and Information Event, including promotional materials
- building trust
- offering a mixture of activities, including information sharing, listening exercises and social opportunities
- funding (through a Macmillan Support Grant for refreshments, venue hire, etc.)
- tenacity and patience from the facilitator.

We used our Trust’s ‘What Matters to Me’ Patient Experience toolkit as the basis of the listening activities.

Our achievements

Over the last 18 months, we have engaged 31 community groups and held six co-produced Cancer Information and Listening Events. We have also attended nine general or targeted community events or festivals.

Further information



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WHAT MATTERS TO ME

Tell us about cancer support, where to go & who to speak to

More focus on afterwards and asking questions

| Sharing stories

| Targeting BAME men

Culturally aware support groups that include physical activities and spiritual needs

Advocates to help us understand and ask questions

Information in different languages ... tailored to our culture

We have collected feedback, which we are using to drive and underpin our Macmillan-funded LWBC programme activities. These include a co-produced leaflet promoting the local Macmillan Cancer Information Centre, a peer-to-peer support project and a local newsletter written by people affected by cancer to help meet LWBC needs.

Wider benefits

The wider benefits of our community engagement work include:

- connecting people and developing networks; for example, our local Macmillan cancer information centre, Macmillan cancer care support co-ordinators and community grocers (an alternative to foodbanks) are now signposting to each other
- raising awareness about LWBC and cancer prevention or screening
- developing insight into how to tailor support to community needs
- informing our LWBC programme, including the content of our Health and Wellbeing Event and how and where it is delivered.

Next steps

The next steps are to maintain key relationships and continue to engage, listen to and connect local people, groups and communities. We also want to engage more diverse groups, such as younger people, the lesbian, gay, bisexual and transgender (LGBT) community, individuals with learning difficulties and offenders. We hope to achieve more focused engagement on specific areas, such as assessment and care planning or health and wellbeing information and support.

Our ultimate goal is to embed the 'community voice' fully into our service transformation. This should lead to more tailored care and support for people living with and beyond cancer. 

Feedback has highlighted key issues for local people.

Being part of a community can drastically improve health outcomes.

Addressing the cancer awareness gap in ethnic communities

Liz Riddle, Macmillan Information Centre Manager, on a project to raise cancer awareness in ethnic minority and deprived communities in South Reading.

A Macmillan-funded project has trained 25 volunteers from culturally-diverse populations and deprived communities in South Reading to become cancer champions. So far, they have run 44 awareness sessions, reaching more than 1,900 people since March 2017.

The project was set up in response to:

- poor screening uptake in ethnic minority communities within the South Reading area
- poorer one-year survival rates in the area compared to the national average
- a higher than average incidence of late stage cancer at diagnosis.

Data collected over the past five years by the Macmillan Information Centre at Berkshire Cancer Centre also showed that local people from ethnic minority communities were not accessing information and support through our centre.

A community-first approach

Our volunteers are reaching people from a wide range of community groups including Polish, Nepalese, Punjabi, Sudanese, Afro Caribbean, Pakistani, Zambian, White British people living in deprived areas, people who are deaf and members of the LGBT (lesbian, gay, bisexual and trans) community. They underwent a 12-week Macmillan training programme to become cancer champions, and now reach out to their own communities to spread the word.

Berkshire West Clinical Commissioning Group, Macmillan and Rushmoor Healthy Living worked together to deliver the project. They turned the traditional method of raising cancer awareness – through

promotion and leaflets – on its head by using a community-first approach. The project started by talking to different communities to learn about their knowledge of cancer, people's fears, myths and aspirations, and what stopped them engaging with cancer services. We then developed the cancer champions service to address these findings.

This was achieved by working with communities, engaging through different activities, events and meetings, using formal and informal networking with organisations, groups, professionals and carers, sharing information through educational events, and always working in partnership.

Achievements so far

The champions are now familiar faces at 16 GP practices in South Reading, where they provide a range of support for people with cancer. This could be translating during consultations, accompanying them to chemotherapy or radiotherapy, or visiting them on the wards or back at home after treatment.

Local publicity has helped to promote the project, with some champions taking part in radio and TV interviews. This has empowered people to volunteer as cancer champions for their community, leading to increased demand for cancer champions to work together with professionals, attend community events and talk about cancer locally.

Following on from a poster presentation at the National Earlier Diagnosis Event in Manchester (October 2019), an interest to replicate this project in several areas across the UK is growing.

Further information



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Dr Kajal Patel, Berkshire West Clinical Commissioning Group Cancer Clinical Lead, said, 'We know there is a lack of awareness and understanding of cancer among ethnic minority and deprived communities in South Reading. Too often this means that people from these communities are diagnosed with cancer at a late stage, leading to poorer survival rates. Furthermore, they tend not to access the care that they need and is available to them.'

However, the impact this project has had with professionals working within the Berkshire Cancer Centre and the Macmillan Cancer Information Centre is very positive.

We are starting to link people who are newly diagnosed and going through treatment with a cancer champion from their community, so they can be more readily supported and signposted to the information and help they require, such as benefits advice and knowing where to go for symptom management support.

As a result of this project, the communities have told us they now feel they have a voice regarding a better understanding of cancer and its treatment, and they are more engaged with health professionals and services. This makes them more likely to take up screening opportunities and speak to GPs about their concerns, which in turn makes an early diagnosis more likely, and should improve survival rates.

Dr Kajal Patel adds, 'Health professionals have also embraced the

Communities now feel they have a voice.

project, and it has given them a much better knowledge of the barriers these communities face. We are extremely pleased with the successful way the project has been implemented and the way communities have worked together with us.'

Gosia, from South Reading, is one of the cancer champions for the Polish community and has completed her training with Macmillan. She said, 'I was diagnosed with breast cancer in 2011 and had to undergo very long, hard treatment. I'm still experiencing the side effects today. But I also found it tough emotionally.

'Trying to raise three small children whilst coping with cancer was really isolating. I just wanted someone to talk to who would understand my feelings, who would help me understand the cancer journey and the support that's available.

'A lot of people in my community don't understand cancer symptoms and don't get the healthcare they need because they don't know what's out there. Often the language barrier prevents them from receiving the right professional help. Living in a foreign country without your family makes it even more difficult to cope emotionally. That's why I volunteered to be a cancer champion for the Polish community. I know what it's like, I've been there.

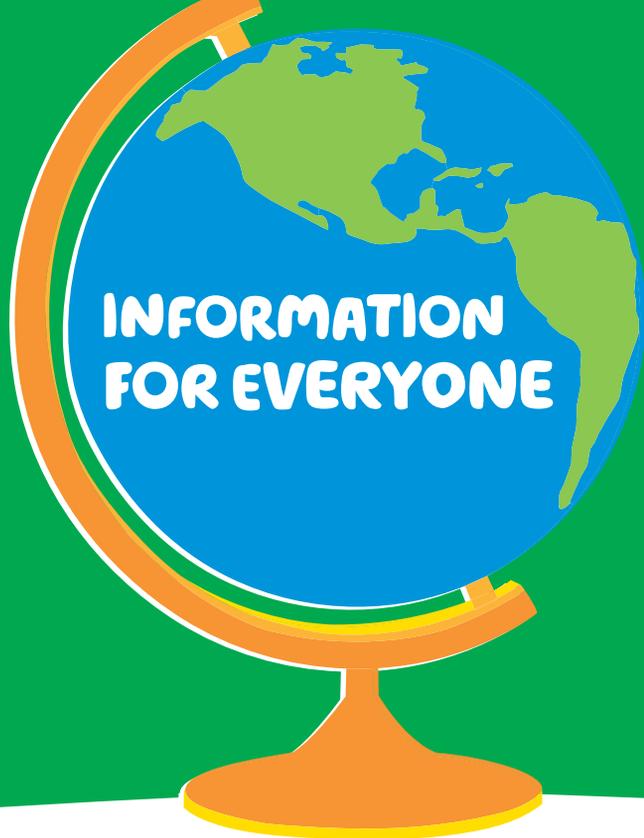
'I'm already using my personal experience and my training from Macmillan to raise awareness of cancer and healthcare services to Polish people in South Reading. If I can help someone get diagnosed earlier by making sure they're aware of the signs and symptoms and they get the treatment they deserve, then it'll all be worthwhile.'

Future ambitions

We're expecting that this approach will help increase survival rates in South Reading over the coming years, and it may even save lives. Due to its success, this project has been

extended for a further two years, funded by Macmillan, to take in the whole of Berkshire West. Work has already started to identify those hard to reach communities where cancer information and support are lacking and links are being made with local services and groups to support this.

The aim is to have a self-supporting and sustainable service that ensures cancer information and support is more accessible to all our local communities. 



Have you seen our accessible information?

Macmillan produces a range of resources to help you support people with accessibility needs. This includes information in different languages, formats such as easy read and British Sign Language videos.

Translations

We have a range of factsheets in 11 languages available on our website, including Arabic, Bengali, Polish, Romanian and Welsh. These cover a range of topics, from the signs and symptoms of cancer to financial support and healthy eating. If you require another language or topic, please let us know at cancerinformationteam@macmillan.org.uk and we will try help.

The Macmillan Support Line also has an interpreter service, which enables people to speak to a cancer support specialist in their own language. Call **0808 808 00 00** and say, in English, the language you want to use.

Easy read

Our easy read booklets use simple language and pictures, and cover a range of topics. They can be useful for anyone who finds it hard to read. You can read, order or download the booklets at macmillan.org.uk/easyread You can also see easy read

information about cancer produced by other organisations.

British Sign Language (BSL) videos

Our British Sign Language (BSL) cancer information videos cover what cancer is, signs and symptoms of cancer, what to expect if you are diagnosed, living with cancer, diet and cancer, coping with side effects, and cancer treatments. They are available at macmillan.org.uk/bsl or on our YouTube channel.

Audio

You can listen to or download audio information about cancer online. We have over 50 audiobooks covering cancer symptoms, cancer types, treatments and living with cancer.

Visit be.macmillan to download cancer information as PDFs or eBooks. If you would like any information in Braille or large print email cancerinformationteam@macmillan.org.uk

If you have any feedback or suggestions about our different formats, we are very keen to hear them. Please email us at cancerinformationteam@macmillan.org.uk

This will help us grow and develop our range of accessible information. 

Do you work in information?

Can you spare five minutes to complete our short survey? We want to know more about how you keep up-to-date with our range of cancer information and if there's anything more we can do to support you in your role. To complete the survey visit smartsurvey.co.uk/s/infoprofs

Working with seldom heard communities across the UK

The map below provides a snapshot of some of the work Macmillan is doing across the UK to build trust and relationships with seldom heard communities. Our aim is to understand the additional barriers they face and what change needs to happen. For more information about these projects and many others, please contact the Engagement and Volunteering Manager in your region.

Scotland: Focusing on developing and improving services for people living in the Western Isles.

Northern Ireland: Engaging with women from the Polish community who have breast cancer, to hear about their experiences of accessing practical and emotional support.

North West: Engaging with people from BAME communities to enable commissioners to better understand their needs in relation to cancer, in particular end of life and palliative care.

Wales: In-depth engagement is underway with farming and rural communities after attending rural shows across the summer.

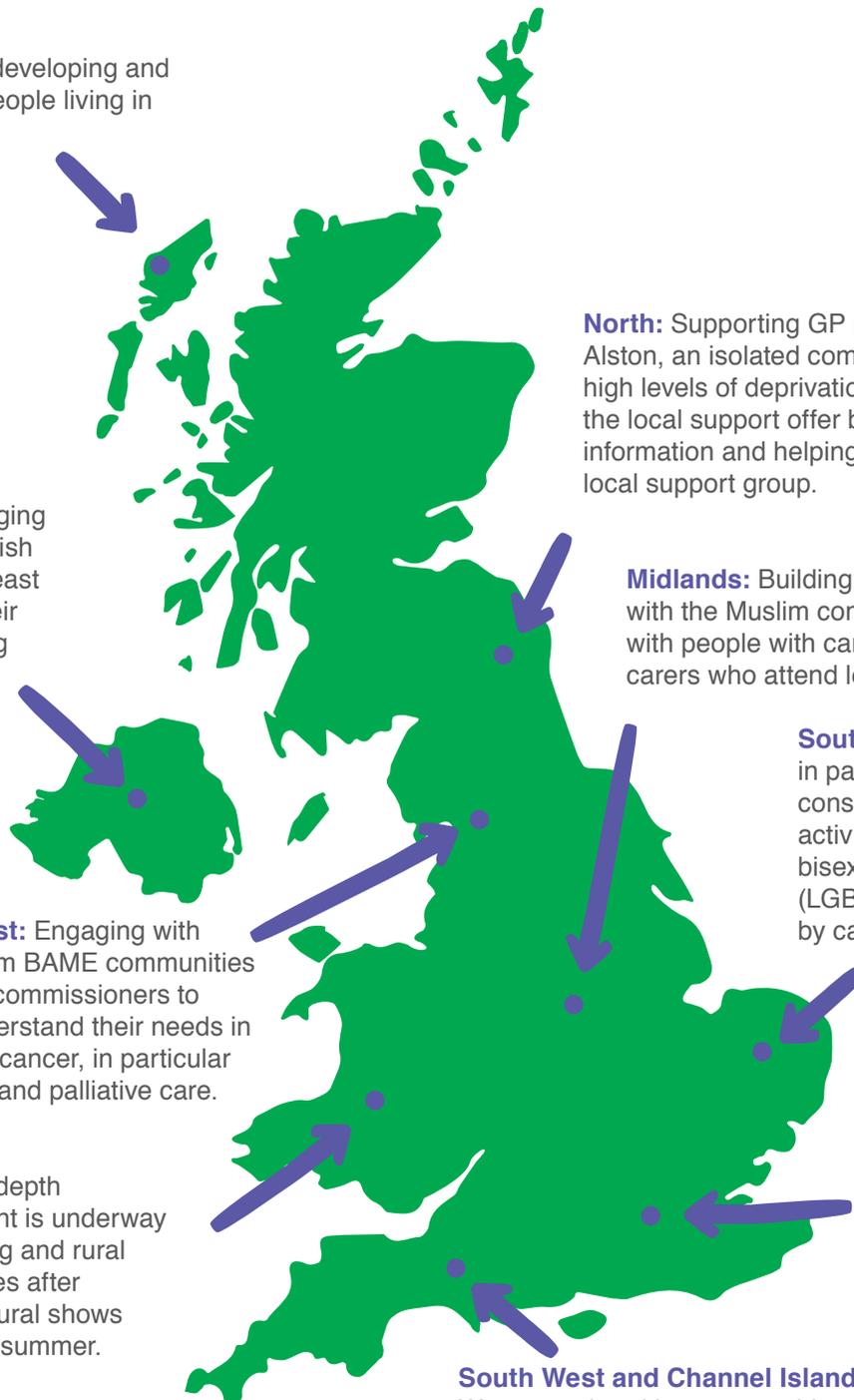
North: Supporting GP practices in Alston, an isolated community with high levels of deprivation, to enhance the local support offer by providing information and helping to develop a local support group.

Midlands: Building on existing links with the Muslim community to engage with people with cancer and their carers who attend local mosques.

South and East: Working in partnership on a series of consultation and engagement activities with lesbian, gay, bisexual, trans and queer (LGBTQ) people affected by cancer.

London: Engaging with the male Afro-Caribbean community, and upskilling barbers in South West and North West London to become confident in having conversations about cancer.

South West and Channel Islands: We are undertaking partnership working with Dorset Police to increase engagement with homeless people who have cancer.



Updated



Cancer and complementary therapies

MAC11645_E10_N
Edition 10

This booklet is about complementary therapies. It talks

about the most common types of complementary therapy used by some people with cancer. The booklet provides a balanced view of the different complementary therapies available and what is involved.

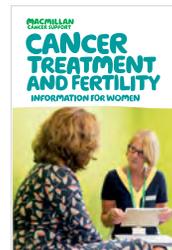


Cancer and your sex life

MAC17968_E01_N
Edition 1

This booklet is about how cancer and its treatment can affect someone's sex

life and relationships. This booklet replaces our two previous booklets: *Cancer and your sex life – information for women*; and *Cancer and your sex life – information for men*.



Cancer treatment and fertility – information for women

MAC12156_E05_N
Edition 5

This booklet is about how cancer and its treatment can affect

a woman's fertility. The information is relevant for people whether they are in a relationship or not, and whatever their sexual orientation. We also have a booklet for men: *Cancer treatment and fertility – information for men*.



Managing your energy costs

MAC11290_E04_N
Edition 4

This leaflet is about managing your energy costs if you have cancer. It explains the

payments, schemes and grants that could help with energy costs, and how to get more support.



Housing costs

MAC14650_E04_N
Edition 4

This booklet is about managing housing costs if you are affected by cancer. These costs could

include mortgage payments or rent. It gives tips on talking to a mortgage lender or landlord, applying for benefits and getting help with energy bills.



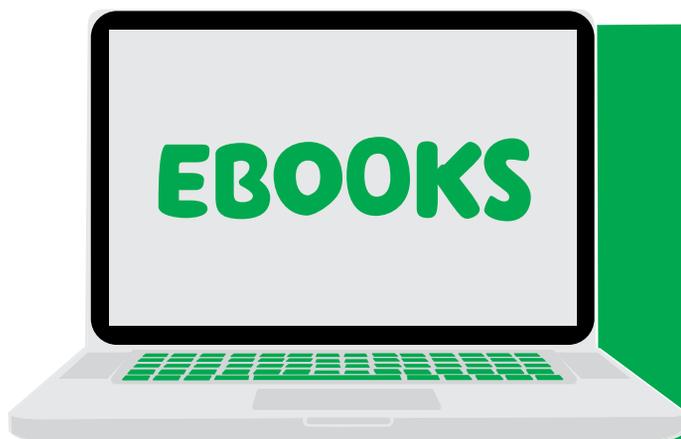
Travel and cancer

MAC11667_E07_N
Edition 7

This booklet is about travelling when you have cancer. It explains important issues to think about

before travelling and includes tips on finding travel insurance and taking care while away.

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



Did you know that all our cancer booklets are available online as eBooks?

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