Mac Voice

For Macmillan Professionals | Issue 95 | Spring 2021

Dessie Aresti

Macmillan Dietitian

In this final issue:

Palliative and end of life care, mindful compassion, rapid diagnosis and supporting family members, as well as several Macmillan projects

In Focus:

Pharmacy

MACMILLAN
CANCER SUPPORT

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Mac Voice is available to download as an interactive PDF at **macmillan.org.uk/healthcare-professionals/macmillan-professionals/newsletters-for-health-professionals**

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Some of the photos in this issue were taken before the government introduced the rules on social distancing.

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Welcome

Welcome to the Spring 2021 issue of *Mac Voice*.

In this issue, we highlight the work of several projects across the UK, including the creation of Warrington Integrated Palliative Care Hub, the success of a pilot Rapid Diagnosis Centre in Wales and the Family Support Team initiative at Wirral University Teaching Hospital NHS Foundation Trust.

We also explore the benefits of mindful compassion and share details about several Macmillan projects – the Telephone Buddy service, Macmillan at Work Masterclass Webinars and our campaign to change Universal Credit for people living with cancer.

This issue features a Q&A with Dessie Aresti, Macmillan Dietitian at Kingston Hospital NHS Foundation Trust. Dessie talks about the importance of her role, the skills needed and what she values most about her work.
Find out more on page 10.

Our In Focus section looks at three different aspects of pharmacy – the work of a virtual Boots Macmillan Information Pharmacist, introducing an integrated pharmacist within a palliative care team and a Macmillan-funded research project on people having targeted cancer treatment.

We also provide an update on the impact of the coronavirus (COVID-19) pandemic on *Mac Voice* magazine, and the future of professional engagement at Macmillan (read more on pages 4 and 5).

Spring 2021 will be the last issue of Mac Voice magazine. We'd like to take this opportunity to thank you all for engaging with the magazine over the years, and to everyone who has contributed articles sharing their work.

Elissia Albertella-Howell
Managing Editor

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Impact of the coronavirus (COVID-19) pandemic on Macmillan and *Mac Voice*

Derek Nott and Lynda Thomas speak about the impact on Macmillan and *Mac Voice* magazine.

Message from Derek Nott
The devastating impact of the coronavirus pandemic has meant that as an organisation, we've had to prioritise our resources. This is to ensure we are delivering the services and support needed most by people living with cancer as efficiently as we can.

As a result of restrictions on our activities and a struggling economy, we have seen a significant decline in our income. We made the incredibly difficult decision to restructure to protect our critical cancer services, and are now a significantly smaller organisation. Macmillan's cancer information provides a critical source of support, but we need to ensure that our smaller teams can continue to deliver the information that's needed most, now and in the future.

With this in mind, we'll be streamlining the information we deliver to our professional audiences, to make sure it's fit for purpose and more accessible.

This means that this issue, Spring 2021, will be the last edition of *Mac Voice* magazine.

We will of course continue to engage with Macmillan professionals, and this will be done through our new online learning and communications hub that will launch to Macmillan Professionals this spring. This will be managed and delivered by the Professional Development and Knowledge team within Macmillan. You can read more about this on page 5.

We'd like to take this opportunity to thank you all for your engagement with *Mac Voice,* and hope you will continue to engage with Macmillan in the future.

Derek Nott
Director of Direct Services
Macmillan Cancer Support

Message from Lynda Thomas
Macmillan's priority throughout the coronavirus (COVID-19) pandemic has been to maintain our support services for people with cancer and their loved ones. However, in common with other charities, we have seen a substantial decline in our income. It meant that last year we made the incredibly difficult decision to make redundancies across the organisation, in order to protect our vital frontline cancer services and meet the needs of people living with cancer, now and in the future. It was not a decision taken lightly.

As a result, we will, sadly, be stopping the production of the *Mac Voice* magazine.

Despite this change, I'd like to assure you that Macmillan will continue to do whatever it takes to be there for you, as we recognise our professionals may need our support more than ever. Our emotional and wellbeing hub is now live, with resources to support you in your role during these very challenging times. Visit **macmillan.org.uk/coronavirus/healthcare-professionals/wellbeing** And our new online learning and communications hub will be your go-to place for all cancer-related information, learning opportunities, and to connect with fellow health and social care professionals.

I'd personally like to also take this opportunity to celebrate the years of hard work that have gone into delivering a staggering 95 issues of *Mac Voice* magazine, and say a huge thank you to all of you who have taken time out of your busy jobs to contribute articles sharing best clinical practice. A very special thanks also goes to the *Mac Voice* Editorial Board, a dedicated group of professionals who have given their precious time over many years to help shape the magazine, review content and share their expertise.

Mac Voice could never have been the success it has been without the hard work of each and every person involved, and I am so grateful for the dedication and commitment you have all shown to this invaluable resource.

Lynda Thomas
Chief Executive, Macmillan Cancer Support

New learning and communications hub launching for Macmillan Professionals

An update on the future of professional engagement at Macmillan, as we plan the launch of a learning and communications hub.

We know that, as a Macmillan Professional, you are passionate about delivering the best outcomes for people living with cancer. We also know that with the cancer workforce facing an unprecedented number of challenges – including the ongoing impact of the coronavirus (COVID-19) pandemic – being able to access digital and remote learning is more important than ever.

That's why we have created our brand new learning and communications hub that will launch to Macmillan Professionals this spring. Designed with busy health and social care professionals in mind, the hub allows you to grow your skills and knowledge by tapping into Macmillan's trusted educational and professional development content whenever you need it. No matter where you are in your career and whatever your role in caring for, supporting or treating people living with cancer, the hub offers a wide range of education to suit your learning needs.

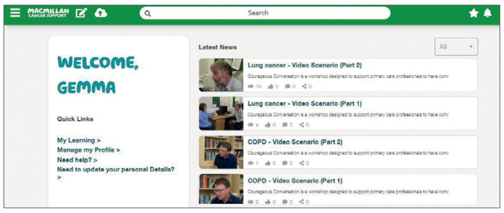
The offer ranges from bite-sized e-learning pieces to in-depth modular courses, and ranging from foundation level, non-clinical content to evidence-based degree and Masters level qualifications. The evidence-based qualification is a 30-credit module, accredited through our partnership with the University of the West of England (UWE) in Bristol. Some projects are clinically focused, and others are to develop a new service or evaluate ways of working. And, because some of our e-learning and virtual classroom modules are CPD accredited, they could count towards your professional revalidation too.

Within the hub, you'll find a wealth of educational content and learning opportunities to support you in the clinical understanding of cancer and its management. If you're a new Macmillan Professional, you'll be able to complete our updated digital induction and access foundation level courses designed to build your skills and knowledge from day one in your new role. If you're an experienced Macmillan Professional, we've created an advanced level educational programme to enhance your communications skills, leadership and professional development, so that you can confidently handle any situation in a person's cancer journey.

But we also appreciate everything you do for people living with cancer and we want to help you be in the best place to do this, so you'll also have full access to our emotional health and wellbeing tools and resources.

The Macmillan learning and communications hub is your go-to place for all things cancer-related, helping you stay up to date with the ever-changing cancer landscape and putting all the information you need at your fingertips. You can tailor your dashboard to show topic-related information, latest learning and conversations relevant to your role and areas of interest. Plus, within the hub communities, you'll be able to connect with fellow health and social care professionals to share best practice and discuss challenging issues, latest health developments and much more. And of course, the hub offers information and links to Macmillan's vital services that could help the people you support.

You should shortly receive your personal email invitation and link to access the Macmillan learning and communications hub. All you'll need to get set up is your work email address.



WELCOME, GEMMA

Quick Links

My Learning >
Manage my Profile >
Need help? >
Need to update your personal Details? >

Latest News

Lung cancer - Video Scenario (Part 2)
Courageous Conversation is a workshop designed to support primary care professionals to have conv
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Lung cancer - Video Scenario (Part 1)
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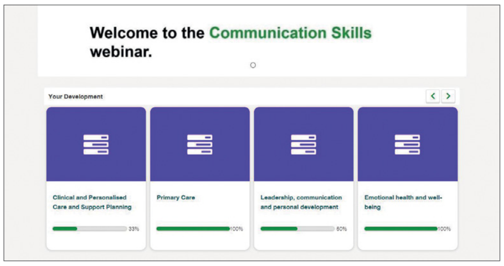


Welcome to the Communication Skills webinar.

Your Development

Clinical and Personalised Care and Support Planning 33%

Primary Care 100%

Leadership, communication and personal development 50%

Emotional health and well-being 100%

In brief

Fast-track benefits applications in Wales for the terminally ill

Terminally ill people in Wales can have their benefits applications fast-tracked online, following a successful campaign by Macmillan. Previously, individuals with less than six months to live had to apply for certain benefits by post. Due to delays, some applicants sadly died before receiving their benefits. A digital process existed in England, but the computer systems in Wales were not compatible with those used by the Department for Work and Pensions. Macmillan campaigned for change and an increasing number of professionals in Wales now submit the DS1500 forms online. Richard Pugh, Macmillan Head of Partnerships in Wales, reflects, ‘By sending these forms digitally, people with less than six months to live can apply for their benefits more quickly, speeding up the process at a time when they shouldn’t be worrying about money.’ Visit **gov.uk/terminal-illness-benefits** for more information.

Emotional support provided by pets

Pets can be a major source of comfort for people living with cancer. This is according to initial research findings from the Macmillan-funded HORIZONS study, led by the Macmillan Survivorship Research Group at the University of Southampton. Looking at the support networks for young women diagnosed with breast cancer, pets (along with partners, friends and close family) were an important source of emotional support. Previous research has shown a link between social network support and the recovery of people’s health and wellbeing after cancer treatment. However, there is a lack of understanding in these studies about who the social network members are and how they are each affected by cancer. The HORIZONS study aims to explore patterns of illness and practical and emotional support over time. This will allow the HORIZONS team to identify gaps in support and develop interventions to enhance and build upon existing structures of support. Visit **horizons-hub.org.uk/index.html** for more information.

Results of the Scottish Cancer Patient Experience Survey

A survey reveals what people think about the cancer care and support they receive in Scotland. 5,001 people living with cancer took part in the Scottish Cancer Patient Experience Survey, which was funded by Macmillan and the Scottish government. The survey participants made almost twice as many positive (4,176) than negative (2,285) comments about their experiences. A third (33%) of the negative comments related to a lack of personalised cancer care or insufficient help with non-clinical issues. Janice Preston, Macmillan Head of Partnerships in Scotland, says, ‘This new analysis highlights once again why people’s emotional, financial and practical support needs must be recognised as just as vital as good clinical care.’ Visit **macmillan.org.uk/about-us/what-we-do/evidence/using-cancer-data/cancer-patient-experience-survey.html**

New guide for talking about advanced cancer

The Advanced Cancers Coalition (ACC) publishes 'A guide for talking about advanced cancer'.

The ACC, a group of cancer charities including Macmillan, has issued advice for people living with advanced cancer, and their family members and friends. 77% of people with treatable but not curable cancer feel that they are not getting the support they need, according to research from Macmillan[1].

Developed with Dr Mary Burgess, Lead Consultant Clinical Psychologist, the short guide aims to encourage more productive conversations about advanced cancer. It explains how the emotional and psychological consequences of living with the later stages of the disease can impact communication with others. Often, communication barriers arise because people are not sure what to say, how to say it and when to say it. This can leave individuals living with advanced cancer feeling isolated and unsupported.

Dr Helen Bulbeck, Director at the brain tumour charity Brainstrust, reflects how avoidance or denial is a common response to advanced cancer: 'Denial is an important coping mechanism for some, as it allows the person time to process distressing information. However, continued avoidance usually increases our fear and can leave us feeling stuck and increasingly isolated.'

Other barriers that can prevent people from speaking openly are fears of:

- change
- upsetting loved ones
- facing the unknown
- feeling vulnerable.

Different factors can influence how people cope with an advanced cancer diagnosis. These include their personality, social and cultural environments, understanding and previous experience of cancer, and the level of support available.

Despite the complexities, the guide sets out simple, practical tips to aid communication. It offers a constructive approach to encourage open conversations about advanced cancer.

For the person affected by cancer, this involves:

- writing down any specific concerns or worries before the conversation
- pacing the discussion and taking a few deep breaths to keep calm
- prioritising concerns or worries to agree on an action plan.

For healthcare professionals, or others involved, tips include:

- choosing a convenient time for everyone involved and not rushing the conversation
- being non-judgmental and checking how an issue or problem is making the person feel
- helping to prioritise concerns and agreeing on an action plan.

People affected by advanced cancer are referred to the Macmillan Support Line for further help in handling emotionally charged conversations.

The ACC is dedicated to raising awareness of the unique needs faced by people with advanced cancer and improving their quality of life.

Read the guide at **brainstrust.org.uk/advancedcancerguide**

The guide sets out simple, practical tips to aid communication

References

1. Macmillan Cancer Support (March 2020). *Treatable but not curable cancer.* Available at: www.macmillan.org.uk/_images/tbcn-research-summary-march-2020_tcm9-355791.pdf

Macmillan at Work Masterclass Webinars

Macmillan at Work Masterclass Webinars help managers and HR professionals feel confident in supporting employees affected by cancer.

The coronavirus pandemic has had a huge impact on people's work lives. For employees who are, or have been, shielding due to cancer, this is an even more challenging time. And we know from our research that only a third of line managers feel well equipped to support employees with cancer.

The Macmillan at Work programme has been running since 2014. Its aim is to help managers and HR professionals feel confident and equipped in supporting employees affected by cancer, using our resources and face-to-face training.

However, the coronavirus pandemic and social distancing meant we had to suspend face-to-face training for employers at the beginning of March 2020. At the same time, we knew that employers needed our expert training now more than ever, to make sure they could support their employees affected by cancer in unprecedented times.

It was a long-term objective of the Macmillan at Work programme to provide an online offer for employer training. We know that attending face-to-face training can cause issues for participants due to the time commitment, so suspending this provided an unexpected opportunity to focus on developing our new offer online.

In July 2020, we launched our new Masterclass Webinars for line managers and HR professionals, which offer a level of expertise that is simply not available anywhere else in the UK.

Employers can choose from a range of Masterclasses, including our 'Cancer in your workplace' in-house and open sessions, or bespoke training.

Just like our face-to-face training, each Masterclass is highly interactive and features a range of activities, including the analysis of real case studies, small group sessions and whole class discussions. We have also limited class sizes to 15 participants, to ensure the best learning experience.

As part of our Masterclasses, we help employers to develop tailored action plans, as we know that it's not one-size fits all. We also know that it's helpful to have further support after the training which is why we offer all participants lifelong access to our e-learning course.

We are proud to be at the forefront of providing vital support to line managers and HR professionals, especially during such worrying times. Our training and expert resources can help employers provide the best support to an employee diagnosed with cancer, or a colleague who is caring for someone with the illness.

For more information, visit **macmillan.org.uk/atwork**

Our training and expert resources can help employers provide the best support to an employee diagnosed with cancer, or a colleague who is caring for someone with the illness

All Wales online training for Cancer Care Reviews

Susan Llewelyn, Macmillan Lead Nurse, Macmillan Primary Care Cancer Framework Programme, on introducing online training for Cancer Care Reviews in primary care during the coronavirus (COVID-19) pandemic.

We are a team of three nurses at the Macmillan Primary Care Cancer Framework Programme, who work with primary care health professionals and cancer specialists in secondary and tertiary care. Our work includes offering a range of training and education opportunities to enhance the cancer care skills of primary care nurses.

To improve processes along the whole cancer pathway, we work with:

- nurses, GPs and reception teams
- paramedics
- pharmacists
- physiotherapists
- secondary and tertiary care.

We have introduced innovative pilots and produced a guide for practice nurses to taking a more person-centred care approach through Cancer Care Reviews.

Quality improvement

One output of our work is the Macmillan Cancer Quality Toolkit for Primary Care (Wales) to support primary care professionals in Wales. It is a quality improvement tool made up of five learning modules. They are designed to support the whole primary care team to review and improve cancer care services for people living with cancer.

A key objective for the nursing team in 2020 was to provide educational workshops across Wales to support module four of the toolkit. This is a mandatory module on ‘Cancer Care Reviews and long-term consequences’. Several face-to-face Cancer Care Review workshops were delivered. However, in March 2020 coronavirus (COVID-19) descended, and planned events were cancelled due to the Welsh government’s restrictions.

New ways of working

Where there are challenges, there are sometimes also opportunities and new ways of working can arise. The nursing team responded with inspiration and innovation. We have designed a series of five online Cancer Care Review educational modules, which are aimed at primary care professionals across Wales. These modules include podcasts and patient stories.

Due to clinical demands and working patterns in primary care, we anticipated some people would not be able to attend all live sessions. Therefore, all modules were pre-recorded, and were available online for two weeks after the live events.

Results

- 70 people attended the first module. Over 50% attended all five modules.
- From September to October 2020, over 159 participants watched and listened to the pre-recordings.
- 70 attendees completed the pre-training survey. Most identified that they were not currently doing holistic cancer care reviews (92.8%). Over half of the participants (57%), were practice nurses.
- A good representation of participants were seen from each Health Board across Wales.
- On completion of the training, almost three-quarters of attendees reported that they were intending to start doing cancer care reviews in their GP surgery.

Conclusion

At a time where COVID-19 changed the way we all practice in health care, the team took the lead to adapt to the circumstances and create a positive and effective development opportunity for Primary Care. The impact of COVID-19 can make people living with cancer feel lonely, frightened and isolated. The training was quick to address this. Potential impacts of the training include better support for patients with cancer, their carers and family, with a significant strengthening of the ‘quality’ of a Cancer Care Review across Wales. Participants of the training have now formed the basis of a Community of Practice to support and share knowledge around holistic Cancer Care Reviews. To date, over 200 clinicians have completed the CCR training online or via the recordings. We hope to repeat this training further across Wales this spring.

L–R: Juliet Norwood, Macmillan Regional Nurse S.E. Wales, Sue Llewelyn, Macmillan Lead Nurse and Hayley Phillips, Macmillan Regional Nurse S.W. Wales.

Further information

Susan Llewelyn

Macmillan Lead Nurse, Macmillan Primary Care Cancer Framework Programme

NHS Wales Health Collaborative

susan.llewelyn5@wales.nhs.uk

Q&A: Dessie Aresti

Job title
Macmillan Dietitian

Location
Kingston Hospital NHS Foundation Trust

In post
Since 2017

Contact
dessie.aresti@nhs.net

Can you tell us about your career so far?
My first role was as a general dietitian at King's Mill Hospital in Mansfield. I worked on the wards, in clinics, and conducted home visits to build my knowledge of dietetics in hospital. I moved onto Queen's Medical Centre in Nottingham, specialising in hepato-pancreatico-biliary and colorectal surgery. There I started working with cancer patients, which led me to my current role.

Last year I also graduated with a Masters. My dissertation looked at dietary misinformation on online cancer forums, to establish the rate of misinformation, any common themes and to evaluate how it is currently targeted. The research found that online forums play an extremely important role in supporting someone with cancer, and are generally a reliable source of dietary information when moderated.

This has increased my confidence in directing my patients to reliable online information.

What does being a Macmillan dietitian involve?
Dietitians are the only health professionals qualified to assess, diagnose and treat dietary nutritional issues, at an individual and wider public-health level. As a Macmillan dietitian, I follow and support patients through their cancer pathway and get involved from pre-diagnosis where needed.

I frequently encourage a high-energy and high-protein diet, to help patients meet their nutritional needs. I also use oral nutritional supplements and sometimes recommend tube feeding. This is because many of the patients I see have already unintentionally lost weight at the point of diagnosis.

My role is to identify and prevent, or treat, malnutrition. Someone who is malnourished may struggle to tolerate their cancer treatment. This can lead to delays in treatment, and a significant impact on quality of life due to a number of factors.

I also support people living with and beyond cancer with clinic appointments and patient talks. I aim to address common myths on diet and cancer, remove stigma around particular foods or food groups, and encourage eating a healthy and balanced diet.

In addition to clinical knowledge and expertise, what else is important for your role?
Seeing patients as people, with lives that aren't defined by their diagnosis. I love getting to know patients and feel very privileged to do so. If one of my patients goes into hospital, I try to visit them so they see a familiar face and receive continuity of care. I get a lot of joy from the human aspect of my role. Offering someone a bit of comfort in what is probably one of the darkest times of their life is as important, if not more so, as the clinical side of the role for me.

I love getting to know patients and feel very privileged to do so

What are the biggest challenges of your role?
The biggest challenge this year has been not seeing as many patients face to face because of the coronavirus (COVID-19) restrictions. I am largely conducting telephone clinics, which is hard as it helps to physically see patients to assess them. But I understand that patient safety is the number one priority. Virtual appointments have also been beneficial for some patients, as they don't have to come into hospital between treatment cycles.

We are trying to do as much as we can despite the limitations. We are developing a video on healthy eating for our living with and beyond cancer groups, to reach more patients virtually. Attend Anywhere also lets us see patients in their own home. I try to meet patients on their first day of treatment, as I'm still able to go to the chemotherapy suite. Another challenge is being the only Macmillan dietitian in the department – I feel the responsibility of representing my role.

What are the biggest rewards of your role?
The biggest reward for me is seeing patients throughout treatment, especially when nutrition is so important to their tolerance of it. In my current role, I conducted an audit on the nutritional management of people with oesophageal cancer, where I compared the weights of patients who received RIG (radiologically inserted gastrostomy) tubes for nutrition, to those without a tube. It found that artificial nutrition is so important, as some patients have a physical obstruction that means they can't eat or need food with a modified consistency, on top of the already known barriers to eating for someone with cancer. The prospect of tube feeding can be worrying for patients, so I explain that it's a part of their treatment. I show them models of what the tubes look like and find out what their concerns are.

The audit won an award for the best abstract at the British Dietetic Association Research Symposium.

What does being a Macmillan professional mean to you?
The brand of Macmillan carries great credibility and trust with people. You don't have to be living with cancer to have heard of Macmillan. They are everywhere in the community and my job fills me with pride. I feel a responsibility to represent the charity well and uphold the Macmillan values.

Creating Warrington Integrated Palliative Care Hub

Diane Evans, Palliative and End of Life Programme Manager, on creating Warrington Integrated Palliative Care Hub as a single point of contact for advice, support and rapid response for those receiving palliative care.

Identifying a need

In the past, we know patients have experienced issues with palliative and end of life care being poorly coordinated. The NHS Warrington Clinical Commissioning Group has a registered population of approximately 217,500, with an increasing number of residents aged 65 and above. Cancer has been the leading cause of death in Warrington (Cheshire, England) since 2013. This is due to a number of factors, including age, lifestyles, deprivation and uptake of screening. Research revealed that Warrington was in the highest quintile nationally for emergency admissions of circulatory and respiratory patients in the last year of life.

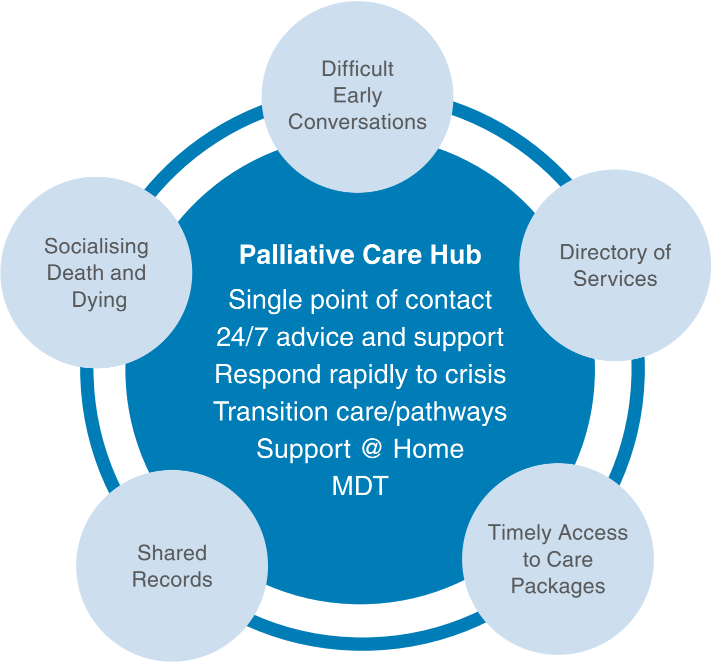
These patients, as well as those with dementia, were also in the lowest quintile nationally for achieving death in usual place of residence. However, cancer patients had a better experience. In Warrington, they were in the lowest quintile nationally for emergency admissions during the last year of life and were only slightly below average for deaths in usual place of residence. Inequalities exist where many frail, older people with complex conditions, of which cancer is commonly one, do not receive tailored services.

An integrated service

To address this issue of poorly coordinated care, NHS Warrington CCG, in partnership with Macmillan Cancer Support, funded a two-year programme of work to integrate palliative and end of life services. The transformational programme was to be delivered within existing resources.

Support for primary care

In addition, a specific primary care project was funded to support GP practices to identify patients potentially in their last year of life, regardless of their palliative condition.



Data showed that these patients often experience unplanned, emergency admissions and long stays in hospital. These situations may not be necessary, and are often not conducive to good quality living, dying and normal grieving.

To improve services, we knew it was vital to understand the views of patients and their families, local charities, and community and voluntary organisations. Patients told us they did not want to have to repeat their story to different people involved in their care. Practices were encouraged to use an Electronic Palliative Care Coordination System (EPaCCS) to identify, communicate and share an individual patient's wishes and preferences with other professionals.

Working with GPs improved relationships and focussed the workstream, supporting better outcomes and experiences for everyone involved.

Using Experience Based Co-Design

The overall programme used Experience Based Co-Design (EBD) to enable staff, patients, carers and voluntary services to co-design services and pathways together. Over 500 individuals participated. There were also 10 in-depth 1:1 patient and carer interviews. An engagement feedback event was held, and participants voted on the areas most important to them.

Creating the Palliative Care Hub

Central to the co-designed model was the creation of a Warrington Integrated Palliative Care Hub. The Hub was designed to act as a single point of contact for advice and support, with the ability to respond rapidly if required and enable individuals to be supported at home. The Hub is based at St Rocco's Hospice in Warrington and delivered in partnership with Bridgewater Community Healthcare Trust. Individuals and their families can phone the Hub and speak to a triage nurse. The nurse can help with any concerns and work with them, their GP and community and hospice services. The Hub operates 9am to 5pm, 7 days a week, in order to keep it within existing resources.

Through the project, a diverse working group have helped to support the work of 'socialising death and dying'. They have developed useful information and links for the NHS Warrington CCG web page **'Dying to Talk'** and for the **'Death as part of life'** page of the local authority website, My Life Warrington. Bereavement support has been developed collaboratively by Warrington and Halton CCGs, Public Health and local authorities. A palliative care 'directory of services' has also been developed to make it easier to find information. The directory is promoted on the NHS Warrington CCG and provider web pages.

Successes of the programme

Patients are now proactively managed through the GSF (Gold Standards Framework) Supporter Care Register, where team meetings with different healthcare professionals address individual needs for care. Before the project, 361 people in the borough were offered this enhanced care. Now, after making these changes, this has increased to 2,004 people.

The findings at the beginning of the project were compared to a random sample from August 2020. There were 221 patients who were 'expected' deaths. Of these:

- 17% had advance care planning in place – this has increased to 61%
- 50% were in hospital – this has reduced to 36.6%
- 0 patients had an EPaCCS 'shared care record' – this has increased to 50%
- 43% of people were achieving their preferred place of death – this has increased to 86.2%.

We are really proud of how successful the programme has been. It is now being rolled out to Halton (a neighbouring town in Cheshire) with further support from Macmillan.

References

1. National Institute for Health Research. Annual Report 2015

Further information

Diane Evans

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Strengthening end of life care

Claire McFall, Macmillan Community Service Improvement Facilitator, and Mary O'Kane, Macmillan End of Life Care Facilitator, outline their work to achieve best practice in end of life care within Northern Ireland.

Claire McFall on her role as Macmillan Community Service Improvement Facilitator

My nursing career spans 31 years and I have been a clinical nurse specialist in palliative care for 22 years. I have worked for community hospices and in the Macmillan team at acute hospitals.

My current role is to support collaborative working across the Northern Health and Social Care Trust (NHSCT), with a focus on local community hospitals, primary care and nursing homes. The aim of my work is to develop, strengthen and enhance palliative and end of life care service provision and delivery.

Improving services

To achieve the best patient-centred care, I use service improvement tools to ensure that evidence-based practice guidelines are implemented, and outcomes are monitored. My role includes leading on palliative and end of life care audits and, as appropriate, contributing to research. This will enable sustained improvements in service provision across all care settings.

I facilitate training for generalists in community settings and nursing homes. I also help other specialist practitioners to develop their knowledge, skills and expertise in relation to palliative and end of life care.

To improve palliative care services, I work in partnership with a wide range of stakeholders including voluntary, statutory, independent and community groups. I also support the ongoing developmental work and implementation of a public health approach for palliative and end of life care.

Responding to the coronavirus (COVID-19) pandemic

When the coronavirus pandemic started, I could no longer deliver face-to-face training. I managed to develop a programme of palliative care training through Zoom in a very short time frame. We delivered various training sessions to over 600 staff covering COVID-19 and the changes to providing care, such as:

- visiting arrangements
- sensitive communication by telephone
- managing the symptoms of patients with end-stage COVID-19.

As a result of my work, I was recognised within the Trust as a 'Northern Trust Star'. This is a public recognition made by Trust senior management to staff who have made a significant contribution during the pandemic.

Reflections

Macmillan has funded my role until May 2021 and I am proud to include the name in my professional title. My main goal for future practice is to ensure that all patients at the end of life can be looked after in their preferred place of care.

> **The aim of my work is to develop, strengthen and enhance palliative and end of life care service provision and delivery**

References

1. National Institute for Health and Care Excellence (NICE) guideline [NG31] (16 December 2015) *Care of dying adults in the last days of life.* Available at: www.nice.org.uk/guidance/ng31

Mary O'Kane on her role as Macmillan End of Life Care Facilitator

I started my nursing career in Belfast in 1981. Later I worked in London on an oncology ward, where I developed my passion for palliative and end of life care. On return to Ireland, I worked in the Foyle Hospice for many years before joining the Hospital Specialist Palliative Care team at the Northern Health and Social Care Trust (NHSCT). I was then given the opportunity to work as a Macmillan End of Life Care Facilitator.

Striving for best practice

My role is to provide clinical leadership on all aspects of end of life care across the NHSCT, focusing on care in the acute hospitals. I lead on the implementation and evaluation of the End of Life Care Model, working in partnership with multi-professional colleagues within the acute hospital setting.

I work collaboratively with the Hospital Specialist Palliative Care Team to promote best practice. Another duty is to demonstrate effective leadership in palliative and end of life care education and the associated documentation.

Like my colleague Claire, I use service improvement tools, lead palliative and end of life care audits, and engage with research projects. I also act as a visible role model, providing clinical support and practical guidance on every aspect of end of life care (including bereavement care) for designated wards.

There are four main areas of my work:

- Recognising when a person may be in the last year of life using best practice tools, such as the Gold Standards Framework or Supportive and Palliative Care Indicators tool.
- Key performance indicators for the dying phase have been developed locally, based on the NICE guidelines for the care of dying adults. This enables services to be benchmarked against best practice guidelines.
- Ascertaining the experience of bereaved relatives through an audit.
- Education and training.

Reflections

One of my proudest achievements was being nominated for the Royal College of Nursing Northern Ireland Nurse of the Year award in 2019. I reached the final four and received a commendation for my present work and career in palliative care.

Macmillan has funded my role until February 2021. My ambition is to ensure that all patients at the end of life experience equal care. I passionately believe that standards should not vary, despite being cared for on a busy acute ward in a general hospital.

> **My ambition is to ensure that all patients at the end of life experience equal care**

Further information

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Transferable skills of Macmillan staff during the coronavirus pandemic

Dawn Miller, Macmillan Lead Cancer Nurse, outlines an initiative to help families stay in contact when a loved one is in hospital during the coronavirus (COVID-19) pandemic.

In line with government guidelines on managing the COVID-19 pandemic and social distancing, Wirral University Teaching Hospital NHS Foundation Trust (WUTH) restricted visiting except under exceptional circumstances. However, we realised the impact upon both patients and families of being unable to see and speak to each other. The Family Support Team was therefore established to help them stay in contact and get support.

Communication skills

We recognised that excellent communication skills would be required at this emotive time, and that the staff working within the Family Support Team would be the key to its success. Macmillan nurses and support workers regularly have complex communications with people living with cancer and their families. For this reason, we were best placed to provide the necessary support.

Cancer referrals reduced dramatically during the pandemic, with diagnostic tests and surgeries often being suspended. It was vital that people diagnosed (mostly shielding) still had support mechanisms in place. WUTH ensured that services had a skeleton staff supporting people with cancer. At the same time, they tapped into an established workforce who had skills that could be transferred to the Family Support Team.

Implementing the new service

The Macmillan Lead Cancer Nurse and Dementia Matron led the initiative to create a shared vision and engaged senior management from the outset to support the proposal. As the public perception of 'normal' hospital visiting was challenged, there was a need for the service to be implemented immediately. An action plan was devised with very tight time frames for producing pathways and policies, reviewing staff roles, and recruiting and orientating the new Family Support Team workforce.

Macmillan Cancer Support Workers were redeployed as coordinators. Their role included:

- responding to calls from the public and relatives
- facilitating communication (including sharing photos and children's drawings) through a preferred method of technology, such as email, mobile phone, FaceTime, WhatsApp, Skype or video call.

Macmillan Clinical Nurse Specialists (CNS) acted as caseworkers, contacting and supporting families with suspected COVID-19. With ward staff working to full capacity, extra phone calls were challenging. It was therefore essential that families had contact with a key caseworker to provide timely updates and advice. The CNS had the skills, knowledge and experience to respond to the families' distress and refer them to community services for further support.

Offering emotional support

Sadly, many patients died without their loved ones being able to visit due to visiting restrictions or shielding issues. The Family Support Team worked with the bereavement and palliative care teams to identify relatives who needed additional support following the loss of a loved one.

Macmillan Cancer Information Staff provided an 'aftercare service', which involved contacting relatives after an often rapid and unexpected death. They offered emotional support and made onward referrals for counselling or practical services.

The Macmillan Deputy Lead Cancer Nurse worked alongside the Dementia Matron and played an essential role in the daily operational management of the service. Another aspect of their role was to support staff with frequent challenging situations.

Evaluation

The feedback from families has been overwhelming and humbling. As staff have gradually returned to their substantive roles, we can reflect on the lessons learnt from this project. We are tremendously proud of the Family Support Team initiative and the new skills that we have gained as individuals. Each of us is part of an NHS team and, in a time of crisis, we ultimately work together for the greater good.

Some of the feedback from relatives helps to demonstrate the impact of the service and the transferable skills of the Macmillan staff. One person said, 'I can't tell you how much you helped me through this dreadful time in my life.' Another commented, 'The Family Support Team is an amazing service, linking families together when their loved ones are in hospital. I will always be grateful for your support.'

A relative described the support that they received and what it meant to them: 'When I had a phone call from Joanne in the Family Support Team, it all started from there. She gave me information and reassurance knowing that Mum would not be alone and we were able to speak to her. There was an opportunity for the family to send in photos and have FaceTime.'

L–R: Sue Milling, Kelly Patient Experience Officer, Dawn Miller, Macmillan Lead Cancer Nurse, and Margie Davies, Dementia Matron.

Finally, someone reflected, 'I received a call from Jenny in the Family Support Team today. She was extremely helpful and really assisted in helping me know how we could maintain contact whilst [our loved one] is in hospital and how best to support him. Jenny had a lovely manner and we are very appreciative of the service the team is offering at this challenging time.' Ⓜ

Further information

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Macmillan’s campaign to change Universal Credit

Melissa Cradock, Senior Public Affairs Officer, on the work the organisation is doing to change Universal Credit for people living with cancer.

Why is Macmillan campaigning to change Universal Credit?

People living with cancer tell us a diagnosis is a ‘financial wrecking ball’, as it can result in reduced income, rising household bills and mounting transport costs to get to hospital appointments. One in three people living with cancer also lose their job or reduce their hours, losing on average £860 a month from their income.

What is Universal Credit?

There are currently 60,000 people living with cancer in the UK claiming Universal Credit. Universal Credit is a benefit for people under retirement age who are out of work, unable to work due to an illness or caring responsibilities, or on a low income. It replaced six separate welfare benefits including Employment Support Allowance.

What needs to change?

The amount of Universal Credit

The amount of Universal Credit is too low. At the start of the coronavirus (COVID-19) pandemic, the government took the swift and correct action to increase Universal Credit payments by £20 a week. This uplift was vital for people living with cancer as costs increased due to the pandemic.

Unfortunately, this uplift is due to end in April. We are calling on the Government to make this vital lifeline permanent. We do not think support should be reduced at a time when people living with cancer are facing huge uncertainty about what the ongoing pandemic and upcoming recession will mean for both their health and their finances.

> ‘I had to take taxis to treatment. The extra £20 a week helped significantly. If I didn’t have it, I would have to play Russian roulette with public transport.’
>
> **Judith, diagnosed with terminal cancer in 2018**

The 5-week wait

Once an application is made, Universal Credit is paid monthly. This is meant to mirror a salary and prepare people for the world of work. This means there is a 5-week waiting time before the first payment is made. Managing during these 5 weeks is hard for thousands of claimants, from those who are moving from another benefit, to new claimants, 58% of whom were paid weekly or fortnightly previously in their job.

A Macmillan benefits adviser said: ‘One of my clients has now fallen into rent arrears due to the waiting time for Universal Credit to be processed.’

Further information

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Access

Universal Credit is a digital system, with people expected to make and manage their claim online. People who are in and out of hospital, or have to travel to access the internet, can find applying really difficult. If you are in hospital having treatment, you are unlikely to have access to the internet. Many people living with cancer also experience severe consequences from their treatment, such as cognitive impairments or memory loss after chemotherapy, which can make accessing their application online difficult.

Before the COVID-19 pandemic, most people also need to attend a Jobcentre, either to complete their application or to meet with a work coach. For people living with cancer, especially those having treatment, going to a Jobcentre can be distressing, and could put them at risk of infection.

During the pandemic, these rules have been relaxed to allow people to give evidence without going into a Jobcentre. We are calling on the government to keep this flexibility in the system.

Support

When people apply for Universal Credit, they have to give ‘explicit consent’ at every stage if they want another person to talk to the DWP (Department for Work and Pensions) on their behalf about their application. This mean it’s often difficult for support services, such as Macmillan’s benefits advisers, to directly help people with their claim.

We know that applying for Universal Credit can be confusing and complicated. Many people have multiple issues that need to be resolved before completing their claim, so aren’t able to submit their application all in one go. Providing consent for each issue can be difficult, particularly for someone who is ill or in hospital.

Macmillan is calling on the government to relax the consent rules within Universal Credit to allow advice services to support people at every stage of the process.

What is Macmillan doing to make this happen?

Our most urgent aim is to keep the £20 uplift to Universal Credit, and we have joined with the Joseph Rowntree Foundation (JRF) Keep the Lifeline campaign to ensure this happens. We will continue to bring the voices of people living with cancer to politicians of all parties and ensure they are mentioned in Parliamentary debates. We will keep campaigning until we get the changes people living with cancer need.

Visit **macmillan.org.uk/get-involved/campaigns/money-and-cancer/universal-credit**

> **‘After my treatment I went to the Jobcentre to apply for Universal Credit. I had to sit in front of the computer for six hours to fill the whole form in. It was embarrassing. You feel like you’re being penalised for being unwell.’**
>
> **Neil, diagnosed with a brain tumour in 2016**

Mindful compassion for everyone

David Oldham, former Macmillan Counsellor, describes how learning mindful compassion can benefit both people living with cancer and Macmillan professionals.

Mindful compassion training group.

Developing the mindful compassion course

I developed and facilitated a mindful compassion course at Blythe House Hospice in Derbyshire. I describe mindful compassion as ‘a way of living our lives with care, attention, kindness and compassion to alleviate suffering and benefit ourselves and everyone else’.

The course was part of a range of education and support groups in the hospice’s Living Well Service. People reported many benefits and one individual reflected that the course:

- made them realise their inner potential to recover
- gave them strength in difficult times
- helped them to cope with their life and illness better
- made them feel better equipped to face the challenges ahead.

Macmillan education package

Macmillan asked for the mindful compassion course to be part of their education package. Following a well-received pilot weekend retreat, hundreds of Macmillan professionals benefited from learning mindful compassion at retreat weekends across the UK. This offered them a new approach to care for themselves, and the realisation that this also benefitted those around them.

When my colleague Ann Burgoyne joined the hospice, she began to develop her own mindful compassion practice until she felt ready to help facilitate groups. We then ran workshops, courses and retreats and participated in national conferences.

We were also asked to train professionals to facilitate courses. To date, we have trained 30 professionals nationwide and many of them continue to hold courses and workshops.

Facing the unknown

During the coronavirus (COVID-19) pandemic, we recognise many similarities between the current difficulties and the challenges faced by those with cancer or other life-threatening illnesses. Common emotions are:

- fear and anxiety
- anger
- confusion
- stress or feeling overwhelmed
- grief, a low mood or a sense of loss.

These are all very human responses to life-threatening or life-changing events.

While living through the pandemic, we are all dealing with the unknown. People experience a similar feeling when they undergo pre-diagnostic tests, are diagnosed or live with cancer, prepare for death or go on to recover.

Many of us find it hard to cope with uncertainty and tend to adopt unhelpful ways of thinking, which only add to our difficulties.

Benefits of mindful compassion

The mindful compassion approach focuses on different aspects of being human and the challenges they bring. It borrows concepts from neuroscience, ancient practices, philosophical understandings and a wealth of current research.

The mindful compassion approach focuses on different aspects of being human and the challenges they bring

Here are a few ways that people have described the value of learning mindful compassion:

- ‘Meditation calms my soul.’
- ‘I enjoyed meditation and found peace. I developed heightened sensitivity to day-to-day experience, which has shaped my way of being.’
- ‘Having cancer has allowed me to be more self-compassionate. The course opened my mind to self-compassion and living in the now rather than worrying about what has gone and what will be.’

The Mindful Compassion Partnership

A couple of years ago, changes in the Macmillan education programme coincided with myself and Ann leaving our roles at the hospice. We decided to set up The Mindful Compassion Partnership. Our intention was to:

- continue developing the mindful compassion approach
- protect its essence as a way of living (not just an intervention)
- support the facilitators.

Since then, we have run weekly groups, workshops and various retreats. Mindful compassion has been taught to thousands of patients, carers, healthcare professionals, organisations, companies, charities and the public.

With ongoing feedback, the mindful compassion approach continues to evolve. We are grateful to every participant for what they have shared and how this has helped to enrich the course over the years. Our own personal practice and the input from our teachers has contributed to this ongoing development.

Getting involved

When the coronavirus pandemic arrived, our events had to be cancelled. However, we began to lead online meditation sessions twice a week to support people.

At the time of writing, those sessions are still popular and will continue until we can meet in person again. We have also run sessions for a few organisations.

As human beings we will continue to face difficult times, life-threatening illnesses and the loss of loved ones. We will keep looking for things that can help us deal with these difficult aspects of life. Mindful compassion is one approach that can bring us peace and comfort. We will also continue to find compassion, love, kindness, joy, happiness, a sense of wonder, understanding and wisdom. Learning mindful compassion can help us appreciate and be grateful for those experiences, too.

If you or your organisation would like to learn the mindful compassion approach, please visit **themindfulcompassionpartnership.uk** and get in touch. You can also download free meditations.

Further information

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The Mindful Compassion Partnership

Successes of the Rapid Diagnosis Centre at Neath Port Talbot Hospital: A one-stop shop for vague symptoms

Catherine Lloyd-Bennett, Macmillan Clinical Nurse Specialist; Dr Heather Wilkes, GP Lead; Dr Martin Bevan, Unit Medical Director; Helen Gray, RDC Coordination Manager and Kim Beddow, Senior Service Manager, on the success of the Rapid Diagnosis Centre at Neath Port Talbot Hospital.

Scope of the project

Diagnosing cancer shouldn't have to be so hard. The Rapid Diagnosis Centre (RDC) at Neath Port Talbot Hospital was one of two pilots commissioned by Wales Cancer Network in 2017. The aim was to understand whether investigating patients with vague symptoms, where the GPs had a suspicion of cancer, would be beneficial.

The RDC provides a pathway where patients are examined and investigated to obtain a diagnosis and to make sure they are referred on the correct pathway for any onward management. It also ensures that the patient and GP are reassured if no cancer is detected.

How it works

GPs refer patients with vague symptoms, following a clinical examination and detailing their suspicion of cancer. The GP also requests blood tests, in preparation for the clinic. The referral is received and triaged by the RDC, and the patient is booked for the next available appointment. Once the referral is triaged, the Macmillan Clinical Nurse Specialist (CNS) creates a 'data profile' for the patient. This includes the patient's medical history, investigations and any ongoing follow-up pathways.
On clinic day, after investigations and clinical examination, impressions are brought together in an MDT setting.

Overall outcomes of the pilot

- 11% of patients were diagnosed with a cancer (of which 85% were radiologically diagnosed on the day of clinic).
- 37% of patients were diagnosed with a significant, non-cancer diagnosis.
- 49% of patients were reassured that there was no diagnosis.
- 3% of patients of patients required other investigations to obtain a diagnosis.

Benefits to patients

This approach is beneficial to the patients for many reasons:

- They only need to attend one appointment instead of many and are seen in a timely manner.
- the physician and radiologist discuss the findings of the investigations so that the majority of patients have a diagnosis on the day.
- The clinic looks at the patient as a 'whole' and helps with the holistic needs at the earliest possibility
- They have the full support of a CNS at the point of referral.

The RDC service has been successful with both patients and GPs, with 96% scored in satisfaction surveys.

Further information

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Quotes from patient feedback include:

‘To be offered every courtesy and hospitality turned what could have been a stressful experience, into a very pleasant day.’

‘I felt cared for as a person not just a number.’

‘Being told I didn’t have cancer was such a big relief. Everyone here was wonderful and the service was marvellous. It was all done so quickly.’

Quotes from GP feedback includes:

‘Very happy, thanks once again, excellent service and extremely useful for those gut feeling cases.’

‘It is a great service. It is really reassuring to know that we have a pathway to refer patients that do not necessary fit into the traditional USC pathway.’

Role of the Macmillan Clinical Nurse Specialist

The RDC team was very grateful for support from Macmillan in the recruitment of a Macmillan Clinical Nurse Specialist. This has improved the way the clinic supports patients. As well as providing emotional and practical support to patients and their families, the CNS also manages patients’ expectations and ensures the concept of the clinic is explained and understood.

Patients who have a cancer or non-cancer diagnosis on the day of clinic will have a keyworker from this point, until they are transferred to the relevant speciality. Knowing there is someone looking after their interests and providing support has a big impact on reducing the anxiety of patients and family members.

The CNS has also helped develop pathways and inter-professional relationships with other departments. This has led to the creation of a biopsy pathway for patients where the origin of cancer is unknown.

The aims of the RDC are in keeping with the Macmillan strategy for Wales.

The RDC also received the Macmillan Professional Award for Innovation in 2019.

Where are we now?

Since October 2019, the RDC has been embedded into core services in Swansea Bay Health Board.

The RDC team in Neath Port Talbot Hospital are working with the Wales Cancer Network to roll out the concept of the service across Wales.

Further information

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Macmillan Telephone Buddies

The Macmillan Telephone Buddy team explains the service and how it is supporting people living with cancer during the coronavirus (COVID-19) pandemic.

Scope of the project
An estimated 200,000 of the 1.5 million people who were advised to shield by the government in March 2020 were people living with cancer. Loneliness and isolation among this group were expected to increase due to shielding and social distancing.

To respond to the unprecedented public health emergency, Macmillan launched a national telephone befriending service in April 2020. The service involves Macmillan volunteers called Telephone Buddies delivering regular and ongoing emotional support. The model was based on existing Macmillan face-to-face services. It was scaled up to provide a UK-wide offer to people living with cancer. A number of our Direct Volunteering Schemes had already moved from face-to-face to telephone support. We also used learnings from existing internal and external telephone befriending schemes to ensure that good practice was implemented and maintained.

How can Telephone Buddies help?
Living with cancer can be an isolating experience at any time, but especially when shielding and social distancing. Our volunteer Telephone Buddies offer a listening ear and are ready to talk about how people feel and their support needs. The free service provides regular emotional support, typically for a period of up to 12 weeks, for people living with cancer. One of our volunteers said 'During the lockdown we switched to supporting people by phone. It's good to feel that you can still make a difference.'

Our Telephone Buddies service is here to support people living with cancer. It offers a weekly call from a volunteer buddy, who is trained to understand what people living with cancer are going through.

One of our Telephone Buddy service users said 'It really helps to speak to someone you don't love. I know that sounds strange. But you don't have to be guarded with your words. I feel like I can say everything.' The Telephone Buddies can also signpost the person they support to other Macmillan services.

Individuals can refer themselves to the service, or be referred through a health professional, family member or friend. Referrals can be made through our website or the Macmillan Support Line. A member of the Telephone Buddy support team will then contact them to discuss the support in more detail and find an appropriate match with one of our volunteer Telephone Buddies.

Looking to the future
The Telephone Buddies service has been a great success during the coronavirus pandemic, and has enabled Macmillan to offer this support on a UK-wide scale. The service allows us to support people living anywhere in the UK and avoids the postcode lottery people sometimes face when accessing healthcare. Our volunteers have been incredible at supporting people living with cancer, and we have seen a real need for this service to continue.

Telephone Buddies has been operational for almost a year, and is now a Macmillan business as usual service. In 2020, Telephone Buddy volunteers supported 2,455 people with cancer, with more than 17,775 calls. It will continue to support people living with cancer across the UK. during the pandemic and beyond

For more details, visit **macmillan.org.uk/telephonebuddies** or email **telephonebuddying@macmillan.org.uk**

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In focus: Pharmacy

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Accessing a pharmacist remotely during the coronavirus (COVID-19) pandemic

Matthew Rewbridge, Boots Macmillan Information Pharmacist, on setting up a virtual information and support service for people living with cancer during the coronavirus (COVID-19) pandemic.

The traditional pharmacist role
Boots Macmillan Information Pharmacists (BMIP) are Boots pharmacists who have completed extra training developed by Macmillan and Boots. This extra training better enables the pharmacist to understand the needs of the patient, which may not always be medical. The pharmacist can also act as a link by signposting the person with cancer or their carer to other sources of information or support, locally and nationally.

Traditionally, a person living with cancer would have accessed their local BMIP through their Boots pharmacy. For example, this might have been when they were picking up a prescription for their medication. The individual could start a conversation with the pharmacist themselves, or the pharmacist may have identified that they would benefit from a conversation by looking at their medications.

However, the COVID-19 pandemic has greatly changed the situation.

The challenges of the pandemic
Sadly, the opportunities to have a conversation with a Boots Macmillan Information Pharmacist in-store have reduced due to several factors. The pandemic has required the vast majority of people having cancer treatment to shield in their homes. This precaution is needed to reduce the risk of infection to their susceptible immune systems. Therefore, family members, friends or delivery services are often used to get people living with cancer their medications.

People having cancer treatment or experiencing delays in treatment are understandably anxious. They may have many unanswered questions during normal times. However the pandemic and the requirement to shield and self-isolate has made an already difficult time much harder. Many people are suffering from loneliness due to reduced face-to-face contact with others.

The growth in online services
During the pandemic, there has been an increase in people accessing online services. Some people are doing this for the first time, for example ordering a supermarket delivery of groceries to their home or seeing their GP via a remote consultation. To help keep in touch with family and friends, many people have organised video calls, virtual coffee mornings or quizzes. These activities have helped ease the isolation to some extent.

At the start of the pandemic, Boots approached a group of shielding Boots pharmacists (myself included) to help ease the burden on the NHS. We did this by setting up a remote NHS 111, COVID-19 assessment service. This involved taking calls from the NHS 111 service, and after establishing people's needs, we either:

- closed their calls after giving them help, information or advice
- referred them to a suitable healthcare professional or service.

This service proved very popular with patients, as it gives them access to a pharmacist's knowledge and skills from the comfort of their own home.

Personally, as a pharmacist, I found it professionally fulfilling to help run the service. It allowed me to develop skills in remote consultations, and gain knowledge in a variety of clinical areas.

A new virtual pharmacist role

Boots has a longstanding and well-renowned partnership with Macmillan. As Boots had access to pharmacists who were familiar with remote consultations, a new role was created in response to the coronavirus pandemic.

The role of the store-based BMIP was combined with the opportunity for people to access a pharmacist remotely. This resulted in a new virtual Boots Macmillan Information Pharmacist role, to help combat some of the barriers to information and support during the pandemic. People living with cancer can book an appointment with a virtual BMIP at a time that suits them, in the comfort of their own home. A link is sent to their mobile phone and with one click they are face to face with the pharmacist.

I feel so privileged to have been involved with the project from the early days

Evaluation

Feedback about the service so far has been positive. People living with cancer value its accessibility, ease of use and the ability to talk face to face with someone. The service has covered a wide variety of topics, but a few common themes are:

- helping people deal with a new cancer diagnosis
- nutrition and food supplements during or after treatment
- identifying side effects of medications and how to cope with them.

Apart from providing health information and advice, the role also involves offering people living with cancer emotional support and the opportunity to talk to a friendly, sympathetic face. If an individual needs more help beyond the scope of the consultation, they can be signposted to further services or information.

Overall, I have found the role of the virtual Boots Macmillan Information Pharmacist rewarding and fulfilling. I feel so privileged to have been involved with the project from the early days. I'm proud of the difference that my colleagues and I can make to people living with cancer by offering this virtual service.

Boots Macmillan Information Pharmacists (BMIP) are Boots pharmacists who have completed extra training developed by Macmillan and Boots.

Further information

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Targeted treatments for cancer

Dr Adam Todd, Reader in Pharmaceutical Public Health, and Professor Linda Sharp, Professor of Cancer Epidemiology, explain their Macmillan-funded research project on the experiences and unmet needs of people having targeted cancer treatment.

Revolutionising cancer treatment

Therapeutic advances in oncology have revolutionised the management of cancer, with more and more people now surviving this devastating disease. Perhaps one of the most significant areas of progress is the discovery of molecular targeted therapies, and the concept of personalised medicine.

We now better understand the different genetic and biological processes that go ‘wrong’ in cancer development. This means that we can test for these mutations and target them with different types of medicines. Collectively, these types of therapies are called targeted treatments.

The new targeted treatments provide additional options for people with cancer. They may promote survival with certain types of cancers compared to traditional treatment. Some cancers, which were previously treated as acute illnesses in hospital, are therefore now managed like long-term conditions. In these cases, people can live with cancer and have daily treatment to control it.

A gap in understanding

In this new age of treatment, it is important to understand the experiences of people living with cancer and their needs for support and care. As targeted treatments are so new, little is known about how people experience their treatment, and what their individual needs are during or after treatment.

It is well established that people receiving traditional cancer treatment may need support with:

- physical problems, such as treatment side effects
- emotional problems, such as worries about the future
- social problems, such as relationships with family and friends.

There are various tools available to help clinicians assess people’s needs when they are undergoing cancer treatment. However, these tools are based on the needs of people having traditional treatment. Given the differences between traditional chemotherapy and targeted treatment, we cannot assume that peoples’ needs are the same. Drug research and development are progressing rapidly. It is important that other research into ways of supporting people during and beyond their treatment also develops quickly.

Assessing unmet needs

In our Macmillan-funded research project, we will assess for the first time the experiences and unmet needs of people who have targeted therapy. Based on these experiences, we will develop a tool to capture these needs. We hope that doing so will lead to the development of appropriate services and support, which in turn will improve people’s experiences and outcomes.

Improving compliance with treatment

The research complements our ongoing work in cancer survivorship. We are trying to develop ways to support people through their cancer treatments.

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The new targeted treatments provide additional options for people with cancer.

At present, we are developing a package of care to improve adherence to endocrine therapy in women with breast cancer. The study, known as SWEET (Improving outcomes for women diagnosed with early breast cancer through adherence to adjuvant endocrine therapy), will hopefully start recruiting patients in late spring 2021. Unfortunately, we know that cancer treatments, including the new targeted treatments, can cause unpleasant side effects that may contribute to people stopping their treatment prematurely. When using endocrine therapy for adjuvant breast cancer (treatment given in addition to breast surgery to kill any remaining cancer cells), stopping treatment prematurely increases the chances of the cancer returning.

Ensuring fair access to treatment

Another important consideration is that although targeted treatments have many benefits, there is a significant cost involved. For example, some targeted treatments can cost many thousands of pounds every month. Even though patients in the UK never have to pay these costs directly, we are interested in finding out if people have fair and equitable access to the new treatments. This is the focus of another of our research studies. Previous research has shown that when new technology is discovered, people in a higher socioeconomic position can navigate the system better and get preferential access.

In the field of cancer care, we still see preferential uptake according to socioeconomic position for:

- screening programmes
- diagnostic testing
- some of the traditional treatments.

It is possible that these inequalities in cancer care contribute to the gap in overall cancer survival, where people from more deprived areas are less likely to survive the cancer. It is therefore important that access to the new targeted treatments is fair and equitable for everyone.

Summary

In recent years, there has been considerable progress in cancer drug development. Many new targeted treatments are now licensed and available to people on the NHS. It is essential that we understand how best to support people during and after these treatments, while also ensuring that everyone in society has fair access to them. We hope that our research will fill this important gap.

Innovative Macmillan palliative care pharmacist roles

Emma McDougall and Clare MacGregor, Macmillan Palliative Care Pharmacists, explain the importance of their roles.

Introduction

The role of pharmacists has evolved in recent years and their skills have been utilised in novel ways, including prescribing within primary care networks, care home services and specialist input into acute trusts. Pharmacists have expert knowledge on all aspects of medicines, and this makes them ideally placed to advise, support and make decisions about medication-related issues.

What does a Macmillan palliative care pharmacist do?

Our roles, Macmillan palliative care pharmacists, have been developed to integrate us within the clinical palliative care team. Our roles work across healthcare boundaries in Northumberland and Gateshead, seeing patients at home and in specialist palliative care inpatient units. We work with patients, specialist nurses, doctors, dieticians, physiotherapists and occupational therapists to help manage patients' symptoms. This includes advising other team members, assisting patients in the shared decision-making process, counselling patients on new medications and working together to develop management plans. Symptom management is a major part of the role, in combination with reviewing polypharmacy and rationalising medication. We are both independent prescribers, which allows timely symptom management and deprescribing (safe and effective withdrawal of medicines that are no longer providing benefit to the patient) as part of the patient's pharmaceutical care.

Education

Our roles allow us to provide specialist education and training to staff of all grades and disciplines. This ensures safe, effective use of high-risk medications and use of medications in a different manner to their licensed indications – where doing so adds value to symptom control and any risks are outweighed by benefit to the individual. The training allows staff outside the palliative care team to learn palliative care principles, which in turn leads to higher quality care for patients. More advanced training within the palliative care team also improves understanding of complex medication regimes and leads to optimisation of pharmacological management.

Patient care

Working across healthcare boundaries, we can provide seamless care for patients who started medication as an inpatient. Our roles allow us to regularly review patients once they are at home, to check for efficacy and side effects. These reviews are also an opportunity to look at other aspects of their care. We can refer patients to services such as occupational therapy and psychology, and provide regular updates to their consultant. This enables high-quality, seamless care from everyone involved, across primary and secondary care.

Further information

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Working across healthcare boundaries, we can provide seamless care for patients who started medication as an inpatient

Complex polypharmacy
Polypharmacy is the concurrent use of multiple medications by one individual, often defined as 10 or more medications. It is a complex issue that can increase the chance of adverse effects, which could lead to hospital admissions. In patients with an advanced illness, polypharmacy and tablet burden are associated with higher symptom burden and reduced quality of life. As pharmacists within the palliative care team, we are ideally placed to identify and address polypharmacy, and advise on safe and effective withdrawal of medicines that are no longer providing benefit to the patient. This process is called deprescribing. It is a stepwise, patient-centred approach that aims to reduce the risks and burden of ineffective or problematic medication, such as medications that are causing the patient intolerable side effects.

Response to the coronavirus (COVID-19) pandemic
During the initial COVID-19 outbreak, there were multiple concerns regarding medication. These included availability of medicines and access to healthcare professionals who could give injectable medicines to patients approaching end of life. In addition, we needed to review emerging evidence and learn about the best way to treat refractory (difficult to manage) symptoms in people with COVID-19.

We were both involved in rapidly writing multiple procedures and guidelines for patients in primary and secondary care, in collaboration with other professional groups.
The value of our cross-sector roles was demonstrated, as we could advise and consider options within both settings, ensuring best practice was shared. We regularly reviewed access to essential end of life medication and provided expertise to ensure stock lists across the region were updated to allow timely symptom management.

Staff feedback
Feedback has been gathered from other professionals, to understand the impact of our roles. Here are some of the highlights:

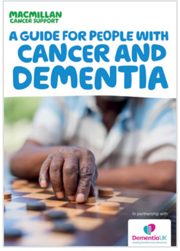
- 'We couldn't now manage without your expertise.'
- 'A wealth of knowledge when it comes to prescribing drugs in specific conditions and ensuring safe prescribing.'
- 'Consistently demonstrates the value of clinical pharmacists embedded within a highly specialist setting and paving the way for future pharmacists.'
- 'Actively engages in local, regional and Network discussions on prescribing and availability of palliative and end of life medications in a variety of settings.'

Next steps
Future aspirations for our roles include establishing a regional forum for palliative care pharmacists, in order to build a support network, share best practice and encourage learning opportunities. As our roles progress, it is anticipated that we will gain enough experience and skills, to enable our development into consultant pharmacist roles.

References

1. Schenker, Y. Park, S.Y. Jeong, K. et al. *Associations Between Polypharmacy, Symptom Burden, and Quality of Life in Patients with Advanced, Life-Limiting Illness.* J Gen Intern Med. 2019 Apr;34(4):559-566. doi: 10.1007/s11606-019-04837-7. Epub 2019 Feb 4. PMID: 30719645; PMCID: PMC6445911

New and updated



A guide for people with cancer and dementia

MAC16126_E02 (Edition 2)

This booklet is for anyone who has both cancer and dementia. We have written it in partnership with Dementia UK.

A guide for young people looking after someone with cancer

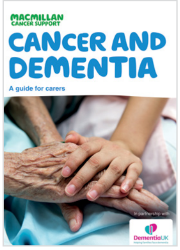
MAC13009_E05 (Edition 5)

This booklet is for people under the age of 18 who are looking after someone with cancer.

Bone health

MAC12169_E04 (Edition 4)

This booklet is for people who have cancer treatments that may affect their bones. It talks about bone health and how to help maintain healthy bones. It also explains drug treatments that can improve bone strength.



Cancer and dementia – a guide for carers

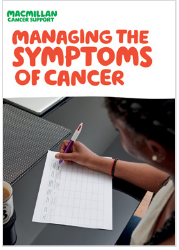
MAC16834_E02 (Edition 2)

This booklet is for anyone who looks after a friend or family member who has both cancer and dementia. We have written it in partnership with Dementia UK.

Cancer treatment alert card and leaflet

MAC18344

These new resources were developed in partnership with UKONS and NHS England. They are for anyone who is having anti-cancer treatment that can cause serious, life-threatening side effects. The card can be shown to healthcare professionals to make sure the person is seen immediately if needed.



Managing the symptoms of cancer

MAC11671_E10 (Edition 10)

This booklet is about some of the symptoms of cancer. It describes ways to help manage them.

MSCC alert card and leaflet

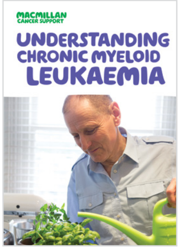
MAC15457_E03 (Edition 3)

These resources are for people with cancer who are at risk of developing malignant spinal cord compression (MSCC). They explain what MSCC is, what symptoms to look out for and what to do if symptoms develop.

Side effects of cancer treatment

MAC12921_E05 (Edition 5)

This booklet is about the possible side effects of cancer treatment. It is for anyone who is having, or thinking about having, treatment for cancer.



Understanding chronic myeloid leukaemia

MAC11620_E10 (Edition 10)

This booklet is about chronic myeloid leukaemia (CML). It explains how CML is diagnosed and treated.

Understanding lung cancer

MAC11632_E17 (Edition 17)

This booklet is about cancer that starts in the lung (primary lung cancer). It explains what lung cancer is, and how it is diagnosed and treated.

You can order our booklets and leaflets at **be.macmillan.org.uk** We also have a range of audiobooks at **soundcloud.com/macmillancancer**

To find out more about our full range of information, including translations and easy read, visit **macmillan.org.uk**

If you have any questions about our information resources, please contact the Cancer Information Development team at **cancerinformationteam@macmillan.org.uk**