Mac Voice

For Macmillan Professionals | Issue 93 | Summer 2020

Justin Trewren

Macmillan End of Life Care Facilitator

In focus

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Writers wanted

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Welcome

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

The past few months have been a difficult time for healthcare professionals as the coronavuris pandemic has significantly impacted the treatment and care they are able to provide for people with cancer. On page 4, we outline some of the support available for you during this time. Do look out for further updates on our website and in the next edition of *Mac Voice*, which will now be published in October.

This issue also features a Q&A with Justin Trewren, Macmillan End of Life Care Facilitator, who won a Macmillan Professionals Excellence Award last year for his important work to help speed up discharge processes for people at the end of life. Find out more on page 10.

You can also read about new ways that Macmillan is working to support health and social care professionals, including our new pilot programme to support staff and residents in care homes on page 5, and the latest edition of our Competency Framework for Nurses on page 9.

Our **In Focus** section looks at how professionals are working with people affected by cancer to ensure that their voices are heard when developing new services and improving existing ways of working.

Sharing Good Practice explores what we mean by personalised care, and the different ways that professionals are integrating these principles into their services.

Rachel Hunter
Managing Editor

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COVID-19 pandemic: support for staff

How Macmillan can help you and your patients cope during the coronavirus pandemic.

The global outbreak of the coronavirus COVID-19 has been extremely worrying for many people with cancer and placed huge pressure on the services and professionals who care for them.

Macmillan's priority has been to support people with cancer, the NHS and the health and social care workforce. We know there have been major changes to the way in which services are being delivered, and to many of your roles. Please keep in touch with us through your local Macmillan team, particularly if you have any questions or require support.

Courses and events

Macmillan has postponed all planned face-to-face professional development courses and events. We will keep you informed as to when courses and events will be rescheduled. You can also access resources and guidance on COVID-19 and cancer on our dedicated Learn Zone page at **learnzone.org.uk/coronavirus** This includes a wide range of topic areas including emotional health and wellbeing, and end of life and bereavement. Each topic area includes useful resources, such as the COVID-19 Courageous Conversations, which provide examples of words or phrases that can be used to have conversations virtually.

Clinical resources

You can find key clinical resources at **learnzone.org.uk/coronavirus**, which are updated daily. Here we provide guidance and FAQs for cancer treatment modalities and regimes and for different cancer types. These include:

- **guidance for SACT and radiotherapy**
- **guidance for stem cell transplants**
- **FAQs by tumour site**
- **acute oncology guidance**
- **guidance around surgery.**

Working with volunteers

Macmillan has issued guidance to our volunteers in line with government advice and are working with them to explore different ways of supporting people living with cancer that does not involve face to face contact and minimises risk to everyone.

Managing your mental health

The Mental Health Foundation has produced some excellent guidance on how to safeguard your mental health in these trying circumstances at **bit.ly/3cG7QZh** You can call the NHS mental health hotline for NHS staff, delivered by Hospice UK and Samaritans, 0300 131 7000 (7am – 11pm, 7 days a week) or text FRONTLINE 85258 for 24/7 text support. You can also access wellbeing support from Macmillan on Learn Zone at **learnzone.org.uk/courses/course.php?id=400**

Additional resources for Macmillan professionals include our four-week Be.Mindful course at **learnzone.org.uk/macprofs/283** and access to the Employee Assistance Programme, provided by Health Assured. This offers a wide range of 24/7 confidential services, from legal advice to counselling. Call the confidential freephone number **0800 030 5182** or access via the Health e-Hub app or the Health Assured website (username: Macmillan, password: Support).

Patient resources

Our dedicated cancer and coronavirus webpage is continuously updated with tools and resources that professionals can signpost people to. Find out more at **macmillan.org.uk/coronavirus**

You can also signpost people to the Macmillan Support Line on **0808 808 00 00.**

For the latest government advice, go to **www.gov.uk/coronavirus**

Supporting people with cancer in care homes

Macmillan has worked with care providers to raise awareness and strengthen support for care home staff and residents.

More than 400,000 people are living in care homes. Many will have a cancer diagnosis and are highly likely to have a comorbidity.

Macmillan has identified an opportunity to widen and strengthen our support for people living with cancer within the care homes sector. To help scope people's needs, we convened a group of major private care providers, representatives from regulatory bodies and Macmillan colleagues, and held two workshops in London in November 2018 and February 2019.

These workshops helped us to develop an offer for care home staff that the providers believe is practical to implement and deliver and will add value for staff and residents. The initial proposition is based on promoting our professional development offer for care home staff, by signposting to our learning and development resources on both Learnzone and Be.Macmillan. This will enable staff to access training, information and support to improve their knowledge of cancer care and help provide better outcomes for residents living with cancer.

Learnzone courses identified as being of most value include:

- Cancer in the Workplace for Managers
- Working with Cancer
- Cancer Awareness.

These resources are available for care homes staff through a dedicated landing page on Learnzone at **learnzone.org.uk/carehomes** We are also signposting to the Macmillan Support Line, so that care home staff can make use of this valuable resource.

We are currently piloting this approach with four care home groups: HC-One, Care UK, Bupa and Barchester. Initial feedback has been very positive, and we hope this offer will eventually be available to all 23,000+ care homes in the UK. The pilot was due to end in May 2020, but due to the coronavirus outbreak, it has been extended with a phased regional roll-out commencing later in the year.

For more information, please contact Alan Taylor, Business Engagement Adviser, at **alantaylor@macmillan.org.uk**

In brief

Changes to hospital parking charges

From April 2020, all hospital trusts in England must provide free 24-hour parking to Blue Badge holders and outpatients who attend regular appointments to manage long-term conditions. In addition, free parking must be available at specific times of day for parents of sick children staying in hospital overnight and staff working night shifts. Macmillan's Director of Policy, Dr. Moira Fraser-Pearce, describes free hospital parking as 'a game-changer for many, allowing them to attend appointments and focus on their health without the extra worry about their finances'.

Apply now for fatigue research workshop

Macmillan and the National Cancer Research Institute are hosting a three-day residential research workshop on cancer-related fatigue this autumn. This event aims to generate innovative and multidisciplinary research ideas that seek to understand the causes of fatigue in people living with and beyond cancer, and the best ways to manage it. The best idea will be awarded £5,000 to fund the successful team to develop the idea into a full grant proposal and submit it to an appropriate funder. We welcome applications to attend from anyone looking to collaborate and explore new ideas, including academics, healthcare professionals and patient and carer representatives. The costs of attending will be met by the organisers, including travel, accommodation and full board. Find out more at **ncri.org.uk/ncri-macmillan-fatigue-sandpit**

Update on travel insurance

The Financial Conduct Authority (FCA) has announced that from 5 November 2020, travel insurance companies must signpost people with certain pre-existing medical conditions to a directory of specialist providers. Companies must also tell consumers whether and how any exclusions for pre-existing medical conditions can be removed, and assess the risk associated with these conditions using reliable, relevant information. Macmillan's Head of Campaigns, Eve Byrne, described the new rules as 'a step in the right direction'. See the FCA Policy Statement at **www.fca.org.uk/publication/policy/ps20-03.pdf.**

What's coming up?

July

Public Health England's Cancer Data Conference
1-2 July
ndrs.nhs.uk/cancer-data-conference-2020

Ethnic Minority Cancer Awareness Month
cancerequality.co.uk

Sarcoma Awareness Month
sarcoma.org.uk

Health Information Week
6-12 July
kfh.libraryservices.nhs.uk/health-information-week-2020

August

Douglas Macmillan's birthday
10 August
macmillan.org.uk/about-us/who-we-are/organisation-history.html

September

Blood Cancer Awareness Month
bloodcancer.org.uk

Childhood Cancer Awareness Month
childrenwithcancer.org.uk

Head and Neck Cancer Awareness Week
21-25 September
makesensecampaign.eu

World's Biggest Coffee Morning (30th anniversary)
25 September
coffee.macmillan.org.uk

New health literacy guidance

Five tips to help professionals support better communication and understanding.

The Health Literacy Place, a website run by the NHS in Scotland, has published new guidance for professionals. The organisation defines health literacy as having enough knowledge, understanding, skills and confidence to use health information, be an active partner in your care, and to navigate health and social care systems.

Anyone can be vulnerable to poor health literacy, particularly when hearing new or distressing information. This can make it easy for professionals to underestimate the support that people require to process health information.

The guidance sets out five communication techniques that healthcare professionals can use each time they provide information to their patients:

- **Teach back:** This method involves asking people to 'teach back' what you have discussed and any instruction you have given them. You can use a similar tool called 'show me' when showing people how to carry out actions, such as applying a cream or giving an injection.
- **Chunk and check:** This technique requires you to break down information into smaller, more manageable 'chunks' throughout a consultation. At key points, you can use methods such as 'teach back' to check people's understanding. The technique is likely to be more effective than giving people all the information that they need to remember at the end of the consultation.
- **Use simple language:** A lot of jargon, confusing terms and acronyms are often used when communicating health information. It is best to choose simple language whenever possible and try to explain things to people as you would to a family member or friend.
- **Use pictures:** Some concepts are difficult to express, both for patients explaining what is wrong with them and for professionals giving advice. When communicating new or complex ideas, images and pictures may help to improve people's understanding. Ideally, pictures should be used to assist and support explanations rather than to replace them.
- **Routinely offer help with paperwork:** It is recommended that staff routinely offer people help with completing forms and paperwork.

You can read the full guidance at **www.healthliteracyplace.org.uk/tools-and-techniques/techniques**

Searching online impacts mental health

Macmillan reveals the mental health effects of searching online for information about cancer.

More than a quarter of a million people with cancer say they have been left feeling anxious, depressed or confused after looking for health information online, according to new research from Macmillan.

This research is based on a 2020 YouGov survey of 2,000 people living with cancer in the UK. The survey found that:

- two in five people with cancer (39%) search online for information about their diagnosis
- of these people, more than one in four (27%) report a detrimental impact on their mental health after doing this.

Dr. Rosie Loftus, Macmillan's Chief Medical Officer, says, 'In today's digital society, it is understandable that people look up their diagnosis online when they're told they have cancer. However, it is extremely concerning that such a high number of people who turn to the internet for support are presented with such a seemingly negative outlook.'

Macmillan attributes the habit of seeking health answers online to the confusion and information overload that people often experience after a diagnosis. This is despite the best efforts of frontline staff amid record NHS vacancies and unmanageable workloads. We are campaigning for a sustainable cancer workforce, who have the time and capacity to give people a full explanation of what their diagnosis means.

More than 50,000 people with cancer thought that they were going to die after looking online. Ben, a nurse who was diagnosed with stage 3 oesophageal cancer in December 2019, explains, 'Even as a nurse, I was tempted to research online. 'At first, I tried to stay away but I ended up finding survival rates which scared me. I soon learnt to go to reputable sites because these rates were actually for men who were double my age.'

Looking for health information online can leave people feeling anxious or depressed.

Our research underlines the importance of professionals referring people to reliable information.
Over 50,000 people also found online information or adverts for 'bogus' non-prescription products, which claimed that they could cure cancer.

This year we have launched a tailored information and support service from the point of diagnosis. It aims to help recently diagnosed people cope with the physical, financial and emotional impact of cancer, and make sense of the information overload they may face.

You can encourage people to sign up for our diagnosis support offer at **macmillan.org.uk/diagnosis**.
People affected by cancer can also call the Macmillan Support Line on **0808 808 00 00** or visit **macmillan.org.uk** for evidence-based information. Our booklets are available to order or download at **be.macmillan.org.uk**

Exploring inequalities in cancer care

NHS England has produced new videos to highlight key issues with care experienced by black and minority ethnic (BME) people with cancer.

Three short videos have been published by NHS England to help healthcare providers and commissioners learn from the experience of black and minority ethnic (BME) people with cancer. The videos explore three key issues – perceived bias, communication and dignity – that can result in a poorer cancer care experience for BME people compared with white British people.

According to the NHS Cancer Patient Experience Survey 2017, 79% of white respondents felt fully involved in decisions about their care and treatment. This compared with 70% of Black and Asian respondents. To understand the difference in survey results, NHS England and NHS Improvement commissioned qualitative research from human rights charity brap (**brap.org.uk**). Three videos were then produced featuring interviews with people who took part in focus groups.

Peter Williamson, Senior Insight Account Manager at NHS England, says, ‘Video can be powerful in telling the stories of individuals whose very personal experiences can sometimes be lost sight of under layers of statistical data.’

Implicit bias

The first video explains that implicit bias refers to attitudes or stereotypes that affect our understanding, actions and decisions in an unconscious manner. By taking responsibility for our biases, we can diminish their impact. Darshna Soni, an Asian lady who participated in a focus group, describes how she and her husband could have been put at greater ease during a cancer diagnosis: ‘All it takes is for someone to treat you equally, to shake your hand, to look you in the eye – little things like that can have such a big impact on the way that you feel.’

Communication barriers

The second video examines communication barriers that can arise when interacting with patients, especially if English is not their main language. It emphasises how a patient’s ability to make informed decisions alongside a supportive healthcare professional is part of the healing process. GPs are specifically urged to initiate conversations about prostate cancer with black men, given that race is a significant risk factor.

Preserving dignity

Finally, the third video highlights that prostheses, lymphoedema sleeves and wigs are not always available in skin tones or hairstyles that are appropriate for the BME community. Della Ogunleye was given a white prosthesis in 2018 following her cancer treatment and did not know that she had the option to ask for a black one. Experiences like this can adversely affect people’s dignity and underline the importance of tailoring healthcare services to individual needs.

You can watch the videos on YouTube by searching for **‘Learning from the experience of BME cancer patients’.**

Implicit bias refers to attitudes or stereotypes that affect our understanding, actions and decisions in an unconscious manner.

New Macmillan Competency Framework for Nurses

The competency framework for all UK nurses caring for adults living with and beyond cancer has been updated.

A new edition of the Macmillan Competency Framework for Nurses (MCFN) has now been published. It builds upon the 2014 framework, which was the first to identify core domains of care relevant to the needs of people after cancer treatment and those at risk of developing consequences of cancer and its treatment.

The updated document now includes a toolkit that uses short case studies to help make the framework feel relevant to implement and easy to use for all nurses working in frontline clinical practice, education, management or commissioning.

The intention of the MCFN is to support individuals, teams and managers, by identifying the appropriate competencies in seven specific domains that apply to most nurses supporting people living with cancer.

The seven competency domains are:

- **Clinical nursing practice** – the broad, comprehensive range of knowledge which underpins the need for clinical interventions to support the complex needs of people living with cancer.
- **Personalising the care pathway** – the role of the nurse in coordinating and integrating person-centred care, including care planning that ensures multiple disciplines can be accessed.
- **Proactive management** – supporting self-care, self-management and enabling independence: the knowledge and skills nurses need to provide fully participatory person-centred care to help people make informed choices.
- **Psychosocial wellbeing** – the skills and knowledge nurses need to effectively communicate, assess and provide appropriate strategies to support people living with cancer with their psychosocial wellbeing.
- **Promoting health among high-risk individuals affected by cancer** – the role of nurses in the care of high-risk patients who require close monitoring and complex care plans for a variety of reasons.
- **Multi-disciplinary, interagency and partnership working** – complex care delivered across agencies by effectively managing relationships and facilitating professional cooperation.
- **Professional practice and leadership** – recognising the need for nurses to maintain continuing professional development and use current best practice to achieve optimal outcomes for people living with cancer and their families.

The competency framework describes the knowledge, skills and performance that professionals require to be effective in their role. This means ensuring that people living with cancer receive safe, appropriate, effective, high quality and accountable care, regardless of the care setting.

The competency framework will:

- assist individuals and organisations to extend skill sets and support recruitment, workforce planning and career progression
- aid new and emerging role design and help determine individual and team needs to ensure that people affected by cancer are being supported
- support the development of competencies that contribute to the provision of personalised care for people affected by cancer, including the use of holistic needs assessments and personal care plans.

With special thanks to the project group (Professor Diana Greenfield, Clare Warnock, Libby Potter, Joanna Fairhurst, Kathryn Cooke, Annette Gillett), all those acknowledged in the first edition and the many nurses who contributed.

You can view the framework at **www.macmillan.org.uk/_images/competency-framework-for-nurses_tcm9-297835.pdf.**

MACMILLAN COMPETENCY FRAMEWORK FOR NURSES (MCFN)

Clinical Nurse Specialist,
Sheffield Teaching Hospitals NHS FT

The Macmillan Competency Framework for Nurses (MCFN) supporting people living with and affected by cancer

MACMILLAN CANCER SUPPORT

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

Q&A: Justin Trewren

Job title
Macmillan End of Life Care Facilitator

Location
Pinderfields Hospital, Wakefield

In post
Since 2017

Contact
justin.trewren@nhs.net

Can you tell us about your career so far?
I qualified as a nurse around 10 years ago, after looking after my Grandad at the end of his life. He didn't have the best death in hospital, but there was an end of life care facilitator there who made everything easier for us as a family. She inspired me to train as a nurse and care for people at the end of life.

I worked on medical and rehabilitation wards in Berkshire, and then in Brighton, with a focus on end of life care and care for the elderly, which has always been a passion. I then joined the discharge team at Royal Sussex County Hospital, and loved being involved in complex discharge planning for patients. I relocated to Yorkshire, working in the discharge team at Pinderfields Hospital, which is part of the Mid-Yorkshire

Hospitals NHS Trust. I always knew that I wanted to come back to end of life care. About three years ago, the Trust applied to Macmillan to fund an end of life fast track discharge facilitator, who would develop a rapid discharge process for people at the end of life. The role came at the right time for me and encapsulated everything from my previous experience. We developed the process working with stakeholders from across the district, including hospices, nursing homes, pharmacists and ward managers. We stripped back lots of inefficiencies and made the process much simpler and more streamlined.
That experience led me to apply for the role of end of life care facilitator for the Trust. We still have a fast track facilitator in place, and we work closely together.

What is the main focus of your work at the moment?
My role is to try to improve care for people who are dying in hospital, and this can involve lots of different projects. For example, I'm excited about the 'Taste for Pleasure' project, which aims to dispel 'nil by mouth' culture and introduce some of the patient's favourite tastes if appropriate when providing mouth care. We're also looking into using volunteers in end of life care, who can spend time with people who are dying on the wards, and also offer respite for friends and families.

What achievement are you most proud of?
Research conducted prior to the fast track facilitator project found that, from the time someone was diagnosed as dying, it took about 13.8 days to discharge them from hospital to their preferred place of care. Of the sample of patients I looked at, 80% died on day 8 in a hospital bed. I'm very proud that, as a result of our new pathway, people at hospital in Wakefield who are diagnosed as dying and want to be at home with carers can now get home within 6 to 8 hours.

This was a really successful project and we were runners up at the Patient Experience Network National Awards last year. I also won the Macmillan Quality Improvement Excellence Award in November. This national recognition helped secure continued funding for the role from the Trust, to embed this work further across our hospital and two others. But the real achievement is the fact that the project is working, and the impact for people at the end of life is immediate.

What does being a Macmillan professional mean to you?
I think the public often have Macmillan in their hearts, so that affiliation helps us gain patients' trust and make sure they feel safe. We have also used the training available from Macmillan, and received the grant funding to pay for some advanced communications skills courses.

What changes do you hope to see in future practice and end of life care?
I think the thing that really matters to people is communication. If you know what you are facing, you can face it.

The impact for people at the end of life is immediate.

The main thing for me is offering hospice care within the hospital, and I think having volunteers will help with that. For example, volunteers who can spend time doing extra things, such as hair and nails or providing complementary therapies. We are also currently embedding the Gold Standards Framework for end of life care (**goldstandardsframework.org.uk**) into four wards, and I would like to see that rolled out across the Trust. We know that the NHS is under such huge pressure, but in an ideal world I would like to see end of life care given greater recognition as a key priority.

You can watch a video by the Shrewsbury and Telford Hospital about their Taste for Pleasure initiative at **youtube.com/watch?v=3g9KyQCx27Q**

Raising awareness of welfare benefits

Jelena Nenadic, Macmillan Benefits Adviser, explains how making people with cancer aware of potential financial support can help to tackle health inequalities.

One question in the latest National Cancer Patient Experience survey, published in September 2019[1], was particularly striking for me as a Macmillan Benefits Adviser. People with cancer were asked: 'Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?' 60.5% of people responded 'yes' to this question, which is a significant increase from 58.2% during the previous year.

While the improvement in survey results is encouraging, it is also clear that people with cancer are much more likely to be given advice in other areas. For example, 81% said that hospital staff told them they could get free prescriptions. This suggests that more can be done to ensure that individuals are aware of potential benefits they may be able to claim.

The cost of cancer

Evidence shows that people living with cancer often have considerable expenses, which many struggle to afford. Research commissioned by Macmillan in 2012, based on a survey of more than 1,600 people with cancer, revealed that 83% were on average £570 a month worse off as a result of the illness[2]. The survey also showed that the financial burden is distributed unequally, with a higher than average impact on:

- people aged under 60
- employed people
- people who have undergone chemotherapy or surgery in the past six months.

As a result of these costs, people must frequently rely on help from family and friends. For those who do not have this network, financial support from the government becomes essential.

Macmillan has commissioned up-to-date research on the financial impact of cancer and the findings will be reported in a future issue of Mac Voice. We also recognise that the recent coronavirus pandemic has had a severe financial impact on millions of people, including those affected by cancer, resulting in an even greater need for financial support.

Socio-economic impact

There is now a significant body of top-level research on the socio-economic determinants of health. One of the pioneers in the field, Professor Sir Michael Marmot of University College London, has written extensively about how poverty and inequality are fundamental causes of stress, and associated with poor health[3]. He has also explored how survival rates for cancer and other serious illnesses are linked to people's socio-economic position.

Professor Marmot has argued convincingly that those who feel they do not have control over their lives often cannot make healthy choices. In the 'Marmot Review'[4], he shows that there is a stark difference in life expectancy of seven years between people living in affluent areas compared with those in deprived parts of the country.

The former Chair of the London Cancer Alliance, Dr. Neil Goodwin, has raised similar issues about the links between social deprivation, lifestyle choices and incidence of cancer[5]. For example, incidence of all cancers varies across London boroughs, from 283 per 100,000 people in one borough to 450 per 100,000 in another. The major health inequalities in London and other parts of the UK are closely linked to social inequalities.

Further information

Jelena Nenadic

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Need for awareness

In my role as a benefits adviser at a Macmillan Support and Information Service, I see some people who are hesitant about starting treatment. They are anxious about the financial consequences of reducing their working hours or giving up work and incurring other cancer-related costs. Many people worry about how they will pay rent, gas and electricity, and how they will support their children if they reduce or stop work. I will never forget someone telling me that he would rather not have treatment because he feared losing his home if he stopped working.

I believe it is vital that we come together as professionals and do all we can to raise awareness about financial help and benefits. The benefits system is complex and subject to frequent changes, and people living with cancer often appreciate expert advice in navigating it. If we can help get financial support to those most in need, this may go some way towards addressing the health inequalities that we see all around us.

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Macmillan has more information about benefits for people affected by cancer. You can signpost to our booklet *Help with the cost of cancer* at be.macmillan.org.uk or the welfare rights advisers on the Macmillan Support Line. You could also speak to your local Macmillan Information and Support Centre to find out if benefits advisers are available in your area.

rowcroft hospice

Testing an advance care planning brief intervention in practice

Catherine Hughes, Rowcroft Advance Care Plan Project Lead, on a pilot project to encourage better conversations around future plans and wishes at end of life.

Lack of time is a recognised barrier to advance care planning (ACP).
ACP is a conversation that allows the person to specify preferences in relation to end of life care, and state their wishes and choices.

In 2017, Rowcroft Hospice was given funding from Health Education England to work with people from different care settings to develop a brief intervention in ACP.
The aim was to open up conversations with patients, and give staff prompts to help guide them. A brief intervention is a short, evidence-based, structured conversation, which was originally designed for reducing alcohol consumption or smoking cessation.

Too often, timely and honest conversations about what people want for the future do not happen[1], so it was deemed judicious for the intervention to be tested in practice.

A 15-month project to pilot the intervention was funded by Macmillan in partnership with Rowcroft Hospice. A project lead was employed for two days a week, and 24 staff members were recruited to test the intervention in practice from Torbay and South Devon NHS Foundation Trust and nursing homes in the Torbay and South Devon area.

The project aimed to test the advance care planning brief intervention (ACP-BI) for:

1. usability by healthcare professionals

2. acceptability by patients as reported by health professionals.

The next stage was to then refine the training programme and brief intervention, based on staff feedback.

A steering group provided direction and support to the project.
The intervention was tested in 16 different workplaces, including acute wards, community nursing, hospitals and nursing homes.
A self-assessment tool was developed for the health professionals testing the intervention. Bespoke training was delivered and evaluated, with data on staff learning, including a reflective piece, collected through a learning management system called The Hive. Focus groups with health professionals were held midway and at the end of the project.
Each conversation with patients was written up anonymously by the professional on The Hive.

Results

Not every person will engage with these conversations, including health professionals. However, the use of an ACP-BI, with training and mentorship, gives professionals a building block to broach conversations focusing on the person's future plans and wishes.

Qualitative feedback from nurses suggests it is possible to use an ACP-BI, and as the median time of conversations was just 12.5 minutes, time can no longer be seen as a barrier.

The project only looked at patient outcomes through the lens of the professional, and there was no direct feedback from patients. For example, one professional observed that completion of an ACP enabled one patient 'to let go of her expectation of returning home to be cared for by her

References

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daughter – accept this stage of her life, take back control and empower her to make decisions improving the quality of her life.'

As would be expected, some people did not engage with the conversations, and 10 out of 47 people declined a conversation, which was respected by the professional. Reasons given included not being ready, being too unwell or that the timing was wrong. This supports other studies that have found not everyone will choose to plan ahead and that the timing of such conversations is important given a patient's declining condition[2].

Professionals felt satisfied after instigating conversations with the 37 people who went on to explore the different options that advance care planning offers, with many examples of positive impacts for those patients. For example, one community hospital nurse used the ACP-BI to explore wishes around artificial feeding with a person following a stroke.
This person decided to continue with artificial feeding, despite having an Advance Directive to Refuse Treatment which stated she did not want to be fed though a tube. The conversation allowed the person to indicate using a picture board, highlighting the need to check stated wishes.

Initial findings indicate that confidence and competence to initiate an ACP conversation improved throughout the project. One professional said, 'The whole experience has given me more confidence and more enthusiasm to raise these kinds of conversations around ACP.'

Future plans

We recommend that the ACP-BI is further tested through research, focusing on patients' and professionals' experiences and the impact of having these conversations.
Consideration should be given to the cultural impact on a healthcare setting if all staff are trained in the ACP-BI. The ACP-BI could be considered for use by all professionals.

Share your story

The coronavirus pandemic has significantly impacted the way that professionals are able to provide palliative and end of life care. It may also have changed the way that many people think about planning for the end of life. If you would like to share how your service has had to adapt or your experiences of caring for people with cancer during this time, please get in touch at **macvoice@macmillan.org.uk**

Further information

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Supporting people with cancer through podcasts

Podcasts are increasingly popular and offer a new way to get support and information about cancer.

Research commissioned by Macmillan has shown that more than one in four people with cancer have difficulty talking honestly about how they feel about cancer. We also know that it can be hard to discuss common side effects that are often seen by the UK public as taboo. These include, depression, sex and relationship issues and bowel and bladder problems.

Hearing someone else tell their story can be a real help, as is demonstrated by Macmillan's Online Community, and other forums where people can find comfort and reassurance from others who have had a similar experience to them.

Earlier this year, Macmillan launched its first national podcast, called Talking Cancer, to offer a different kind of support to the growing numbers of people living with and affected by cancer.

Hosted by Radio DJ and Macmillan supporter Emma B, Talking Cancer covers important topics from diagnosis and treatment to end of life and living with cancer. In each episode Emma has honest conversations with people about their experiences.
This is followed by a chat with Macmillan Specialist Adviser (Treatment and Recovery), Dany Bell, who shares advice and information to help listeners find their best way through.

The podcast launched in February 2020, and episodes include:

- a chat with Chloe talking about how she dealt with her leukaemia diagnosis as a new mum
- meeting Adam, who was diagnosed with a brain tumour during a work trip to New York and is now living with a treatable but not curable cancer
- talking to Errol, who has made it his life's work to educate men about prostate cancer, as well as touching on the side effects of prostate cancer that some consider a taboo.

Podcasts are rapidly rising in popularity. According to Ofcom, around 7.1 million people in the UK listen to podcasts each week, and half of listeners only started to use podcasts in the past two years.

The Talking Cancer podcast has had more than 2,000 downloads so far and includes six episodes.
We hope to launch a second season in the near future.

Podcasts are free, you can listen to them whenever you like, and they can provide useful information, a chance to hear someone tell their story or an opportunity to practise mindfulness and relaxation techniques.

You can subscribe to series one of Talking Cancer on a podcast platform from your mobile phone, or access the podcast from your desktop at **macmillan.org.uk/talkingcancer**

As well as Talking Cancer, there are many other cancer-related podcasts out there that may be interesting for you or your patients to try. Examples include:

- **You, Me and the Big C** – a BBC podcast taking a candid look at cancer.
- **Breast Cancer Now** – personal stories and talks with professionals about living with and beyond breast cancer.
- **In conversation with George Alagiah** – a Bowel Cancer UK podcast featuring personal stories and expert interviews about living well with bowel cancer.
- **The Stupid Cancer Show** – giving a voice to young adults with cancer.
- **The Dying Matters Podcast** – talking about death and dying.

Talking Cancer presenter Emma B (right) with her first guest Chloe.

In focus: Patient and public involvement

In this section

Making public involvement everyone's business

Jo Mackintosh, Engagement and Co-Design Project Manager for the Northern Cancer Alliance, on developing an approach to involving the public in their work.

In 2017 Macmillan provided the Northern Cancer Alliance with funding to support the development of our approach to effective public involvement. We view people with cancer, carers and members of the wider community as equal and essential partners in all aspects of our work.

We are absolutely committed to involving people and demonstrating the value that this can bring. However, we recognise that to be effective we require a culture shift where public involvement is everyone's business, and not just that of an individual or team.

We embarked on a two-year project to develop a framework for public involvement to support and inform all involvement activities across the Alliance. The project was led by myself as project manager and supported by a steering group. Membership of the group consisted of health professionals, members of the public and representatives from the third sector including Healthwatch, Macmillan and Cancer Research UK.

The project was developed using a co-designed approach based on a cycle of partnership working. This involved the steering group and a small working group consisting of two Alliance Lay Representatives and the project manager. This approach established a collaborative process for the life of the project.

The project included three initial phases:

1. Setting up the project by identifying key stakeholders and project steering group members, and embarking on a comprehensive communication programme to raise awareness and the profile of the project.
2. Listening to others to develop our framework for involvement, by engaging with key stakeholders from the Alliance support team, members of the public and community organisations.
3. Developing our framework with members of the project steering group and the Alliance support team who came together for a one-day event to identify key elements, using learning gained from engagement with key stakeholders. In addition to developing the framework, the group identified key actions that would support the integration of the framework into the day-to-day business of the Alliance.

By the end of the session, the group had produced a draft version of the Northern Cancer Alliance framework for public involvement. This was later signed-off by the project steering group. We then shared the framework with people who had been part of the engagement process to get their views.

The fourth and final phase was to establish a sustainable approach and celebrate our success. Throughout the life of the project, the steering group had many discussions regarding their responsibility to create a sustainable approach to public involvement across the Alliance.

There was an acknowledgement from the group that completing the framework and workstream

Further information

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Representatives from local Healthwatch groups, CCGs and third sector organisations at a community partners engagement event.

actions would mark the end of the project. They wanted to ensure that the Alliance continued to develop a culture where public involvement was ‘everyone’s business’. This led to the introduction of the Northern Cancer Alliance Public Involvement Accountability Forum to the Alliance governance structure. The overall purpose of this forum is to review and scrutinise public involvement activities across the Alliance work plan.

The steering group also arranged a learn and share event to celebrate the great work occurring right across the Alliance and reinforce the positive impact of involving people in health services. The event was attended by 90 delegates from NHS services, local authorities, third sector organisations and patient and carer groups.

Where are we now?

The legacy of this project is visible within the strategic and operational business of the Alliance, and development of this important work continues to evolve. The newly formed forum has now met four times and has recently produced a set of quality standards and key performance indicators for involvement activities.

> **We are absolutely committed to involving people.**

These standards and indicators will create a reporting framework, which will support the forum to scrutinise involvement activities across the Alliance work plan and provide assurance or challenge to the Alliance Board.

Additional plans for the forum include influencing the development of the Alliance annual work plan and overseeing performance in the National Cancer Patient Experience Survey. The forum will also explore how they connect with, and support, place-based and cancer local group involvement activities in the future.

An inclusive approach to developing local support

Macmillan GI Oncology Cancer Nurse Specialists, Tracey O'Nions and Sophie Woolford, on working with patients and families to set up a support group.

Evidence suggests that attending a support group can improve a patient's quality of life [1]. After attending a national Pancreatic Cancer UK Summit, we felt that we were doing our patients a disservice by not providing a local support group in Swindon specific to pancreatic cancer.

We discussed ideas about how, what, where and when we could make this happen with the rest of our team. It became clear that we needed to provide local support for people with pancreatic cancer and those with an upper gastrointestinal cancer, such as stomach or oesophageal.

Due to the nature of these diagnoses, treatments and the need for referral to a tertiary centre, this can be a very distressing time for both patients and families. The nearest support groups to Swindon for these people were an hour or more away in Oxford, Bristol or Cardiff.

Our first objective was to gather information and contact other groups. We observed one group called the Oxfordshire Oesophageal and Stomach Organisation (OOSO), which allowed us to gather essential information on setting up a support group, involvement and feasibility. One trustee of the charity, Matt Carter, has continued to support and guide our team regularly.

We included setting up a support group as one of our objectives at our Macmillan service review. Anne Morris, Macmillan Engagement Lead for Gloucestershire and Swindon, kindly agreed to share her experiences of setting up similar groups. She suggested that we develop a survey to determine interest, and then organise a focus group to ascertain exact support needs.

Once a survey was developed, we spent many hours trawling through oncology clinic lists and new patient data. Before posting a survey to an individual, we needed to check that this was appropriate, due to the nature of the diagnoses and rapid progression of the disease.

We sent out 45 surveys over a period of a few weeks, with 31 responses. Of those who responded, 14 people said they would like to attend a support group, 4 said they didn't know and 13 said no. Of the 14 patients that said yes, 10 indicated that their family member or partner would also be interested in attending. All the respondents said they would be happy to attend monthly or bi-monthly meetings, with the majority preferring an afternoon session rather than evening.

We gave people the opportunity to add free text about what they would like to hear professional speakers talking about at the group. Responses included:

- diet
- pain relief
- inspirational speakers
- managing symptoms
- handling a terminal diagnosis
- chemotherapy
- information for carers.

Other people said they would like 'an opportunity to discuss experiences with like-minded patients' and that 'it can be lonely without support'.

We arranged a focus group with people who had responded to the survey and their relatives. We led the session with Anne Morris, which was extremely well attended and a testament to how much people needed extra support services.

Further information

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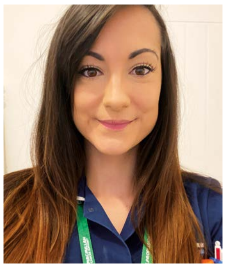

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The focus group revealed that most people wanted a secure and safe place to meet on a regular basis, where they could share experiences with like-minded people. After the focus group we also decided the group needed a name. Feedback from attendees told us that they wanted something unrelated to cancer. After much deliberation we came up with the name Community Café.

> **Most people wanted a secure and safe place to meet on a regular basis.**

Using data from the survey and focus group, we decided to set up three group dates, on the last Wednesday of each month at the same time in order to make it memorable. A free venue was sourced outside of the hospital, as many people felt they spent enough time there already. From our database, we sent out invites to all appropriate individuals for the first three sessions.

We plan to gain feedback at the second and third sessions. If this evaluates well we plan to develop this into a permanent group led by patients and their families, with our continued support as and when required.

During our planning and development we also contacted Pancreatic Cancer UK for support and guidance. We spent time developing and planning a Living Well With Pancreatic Cancer session with Dianne Dodson, Pancreatic Cancer UK Specialist Nurse. This was extremely well attended and evaluated.
We plan to offer this session every six months and feel it is an extremely beneficial additional service that we can offer to this group of people.

References

1. Hogan BE, Linden W, Najarian B 2002. *Social support interventions. Do they work?* Clin Psychol Rev 22:381-440

L-R: Sophie and Tracey with two relatives who helped organise the sessions.

Pancreatic
Cancer
U
K

Living with Pancreatic Cancer Support Day

We warmly invite you to join us for a supportive and informative day for people living with pancreatic cancer.

This free event includes refreshments and you will be able to:

- Meet and chat with others diagnosed with pancreatic cancer
- Listen to short talks exploring different ways of living well
- Meet one of our specialist pancreatic cancer nurses

The day is open to anyone affected by pancreatic cancer and you are very welcome to bring a friend, carer or family member with you.

Date
Tuesday 19th Nov 2019

Time
12pm - 5pm

Venue
Community Room, Sainsbury's, Oxford Road, Swindon, SN3 4EW

If you plan to attend or have any questions please get in touch via our Free Support Line or email below.

0808 801 0707
nurse@pancreaticcancer.org.uk
pancreaticcancer.org.uk

L-R: Philippa receiving her Macmillan Integration Excellence Award with awards host Larry Lamb, nominator Liz Price and awards judge Nikki Cannon.

Representing patients’ views on psychosocial support

Dr Philippa Hyman, Macmillan Mental Health Clinical Lead and Clinical Psychologist, on co-designing a psychosocial support pathway across London.

I have worked as a clinical psychologist for 20 years, with roles in community mental health teams, primary care and acute hospital services. My experience of working closely with service users and the third sector has taught me how valuable these partnerships can be in improving clinical outcomes.

I was delighted to be given the opportunity to lead a project with the Transforming Cancer Services Team for London, funded by and in partnership with Macmillan. The aim was to co-design a pathway to improve psychological wellbeing and quality of life for people affected by cancer in London.

Psychological impact of cancer

Over the past three years, I have seen the significant impact that cancer and its treatments can have on mental health, physical health and socio-economic status. A service user who contributed to this project, Lauren Mahon (founder of the GIRL vs CANCER online community, broadcaster and cancer activist), was diagnosed with breast cancer at the age of 31. She explains:

‘The physical impact of cancer was terrifying, but I was in no way prepared for the emotional upheaval I was about to face. As somebody who has always been the life and soul of the party, I began to feel completely isolated and lonely, no longer able to be the person I know myself to be.’

According to research from Macmillan, 58% of people with cancer feel that their emotional needs are not looked after as much as their physical needs[1]. Our focus on early diagnosis and survivorship must also recognise that people are now living longer with the psychological consequences of cancer.

Patient and public involvement

When designing the new pathway, it was important to consider national strategies and map psycho-oncology services in London. At the same time, patient and public involvement was an effective way of ensuring that a wide range of views were represented.

Three stakeholder events were organised, bringing together service users, healthcare providers, commissioners and the third sector. Focus groups and qualitative interviews were also held with people living with cancer.

Key themes were identified to be incorporated into a new pathway:

- The importance of improving psychologically informed cancer care across the whole pathway.
- The need to prevent distress and promote adjustment.
- The impact of wider factors on mental health following a cancer diagnosis, such as financial difficulties or fertility concerns.
- The wide variation across London in what support services are available, how easy it is to access them and when to refer people to these services.
- The gap in specialist cancer psychological support after treatment.

- The expert services of psycho-oncology teams, which should be available across the whole pathway.
- The education and training needs of the wider workforce to integrate physical and mental health support.

An integrated pathway

Having gathered feedback from multiple parties, I published a report in May 2018 setting out recommendations for an integrated London pathway for psychosocial support [2]. This pathway covers services from diagnosis through treatment, long-term survivorship and end of life care. In February 2020, I published a suite of documents to support the implementation of the pathway and the development of psycho-oncology services.
All these documents are available at **healthylondon.org/resource/psychosocial-support**

A patient's needs are placed at the centre of the new pathway. Services are encouraged to take a responsive, flexible and person-centred approach whenever someone affected by cancer needs support. A distinction is made between universal, enhanced and specialist support. While most people will cope using their own inner resilience and external support, others may experience varying degrees of distress and require psychological intervention.

Within the pathway, there is a clear role for both psycho-oncology teams and Improving Access to Psychological Therapies (IAPT) services. They both provide vital support at different points along the pathway. Psycho-oncology teams should share their expertise across health settings and there needs to be a 'whole system' approach to providing psychosocial support.

Award-winning work

Several clinical commissioning groups in London have now adopted the new London Integrated Pathway for Cancer Psychosocial Support. Funding has been agreed across two sustainability and transformation partnerships in London to develop psycho-oncology services. This will benefit thousands of people affected by cancer.

> **'I was in no way prepared for the emotional upheaval I was about to face.'**
>
> **Lauren Mahon, diagnosed with breast cancer.**

It was a huge honour for my work to be recognised with a Macmillan Integration Excellence Award in 2019. People affected by cancer have been meaningfully and actively involved in service co-design to deliver psychosocial support. I hope that this project will enable integrated care systems to be developed and improve patient experience, quality of life and clinical outcomes across the cancer pathway. Ⓜ

References

1. Macmillan Cancer Support (2006). *Worried sick: the emotional impact of cancer.* Available at: https://www.macmillan.org.uk/documents/getinvolved/campaigns/campaigns/impact_of_cancer_english.pdf
2. Macmillan Cancer Support (May 2018). *The psychological impact of cancer: commissioning recommendations, pathway and service specifications on psychosocial support for adults affected by cancer.* Available at: www.healthylondon.org/wp-content/uploads/2018/05/Psychological-support-for-people-affected-by-cancer-May-2018.pdf

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Transforming Cancer Services Team at Healthy London Partnership

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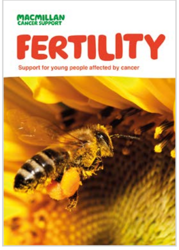
Updated



Fertility – Support for young people affected by cancer

MAC15118_E03_N (Edition 3)

This booklet is for teenagers and young adults who are worried about how cancer and its treatment may affect their ability to have children. It has information on preserving fertility, having fertility tests, fertility treatments and other options for having a child.

Sorting out your financial affairs

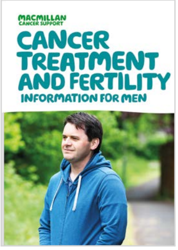
MAC14286_E06_N (Edition 6)

This booklet is for people affected by cancer who want to make plans for their money and belongings in the future. It includes information on making a will, inheritance tax, asking someone else to manage your affairs and power of attorney.

Signs and symptoms z-card

MAC17348 (Edition 3)

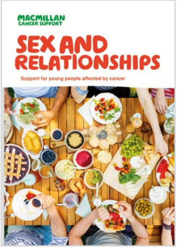
A credit-card-sized resource that opens out to a double-sided A3 poster. The front page explains the general symptoms of cancer and the back page has information about talking to your GP. Features a new gender-neutral figure. Also available in other languages.



Cancer treatment and fertility – Information for men

MAC12155_E05_N (Edition 5)

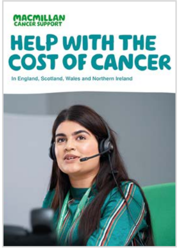
This booklet is about how cancer and its treatment can affect men's ability to have children. It has information on preserving fertility, testing fertility, fertility treatments to start a pregnancy and other options for having a child.



Sex and relationships – Support for young people affected by cancer

MAC15117_E03_N (Edition 3)

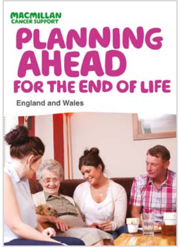
This booklet explains how cancer and its treatment may affect teenagers' and young people's relationships, including their sex life. It has information about coping with any changes and how to get more support.



Help with the cost of cancer

MAC4026_E18_N (Edition 18)

This booklet is about getting benefits and other financial help if you are affected by cancer. It is for anyone living with cancer and their family, friends and carers. The booklet explains the types of financial help available, how to claim support and who to contact for further help.



Planning ahead for the end of life

England and Wales: MAC13616_E03_N (Edition 3)

Scotland: MAC14480_E03_N (Edition 3)

These booklets explain how people can plan ahead and make choices about their future care. They replace two previous booklets: *Your life, your choices: plan ahead - England and Wales; and Your life, your choices: plan ahead - Scotland.*

Impact of coronavirus on our information resources

We're working hard to continue producing cancer information and updating our website and be.Macmillan with all new and revised content. You can see the latest stock updates at **be.macmillan.org.uk/be/s-1004-stock-updates.aspx** At the time of going to press, our printers and distributors are still able to fulfil orders.

Inside Information, our monthly e-update, is currently paused. If you have any questions about our information resources, please contact the Cancer Information Development team at **cancerinformationteam@macmillan.org.uk** where you will be redirected to further information or support.

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**