‘People with head and neck cancer can be hugely vulnerable after leaving hospital.’

Cherith Semple
Macmillan Head and Neck Cancer Nurse and Northern Ireland Nurse of the Year

In focus:
Creating patient information for everyone

Sharing good practice:
Psychological support
Contents

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Help us shape your magazine

Thoughts about Mac Voice? We’d love to hear them. Comments on reading the magazine, contributing to it, the content and the design will all help us improve. Just email Graham Pembrey at macvoice@macmillan.org.uk

News
4–11 Celebrating 40 years of Macmillan professionals and winners from the 2015 Macmillan Excellence Awards

Q&A
12 Cherith Semple, Macmillan Head and Neck Cancer Clinical Nurse Specialist

Features
14 Creating a Scottish community of influence
15 ‘We don’t talk any more’: linking generalist and specialist professionals
16 Pancreatic cancer
18 Welfare rights
20 Arts for well-being
21 Understanding clinical trials

Sharing good practice pull-out

Psychological support

In focus: Creating patient information for everyone
23–27 How do we provide cancer information to people with particular needs, such as those who are deaf or whose first language is not English?

Resources
28 New and updated information from Macmillan
The first National Macmillan Alumni Congress
A successful launch for the scheme.

Celebrating 40 years of Macmillan professionals
The first Macmillan nurse came into post in 1975. Forty years on, Macmillan CEO Lynda Thomas looks at how things have changed.

Welfare rights
A Macmillan Citizens Advice team leader on supporting people affected by cancer though welfare cuts.

Q&A: Cherith Semple
The Royal College of Nursing's Northern Ireland Nurse of the Year.

Arts for well-being
Supporting recovery through art workshops.
News

From 1975 to 2015: 40 years of Macmillan professionals

Macmillan CEO, Lynda Thomas, marks the occasion.

This year we have been celebrating 40 years since the introduction of the first Macmillan professional posts.

In 1975, the first team of Macmillan nurses helped around 250 people with cancer. It is astonishing that we now have almost 3,500 Macmillan nurses reaching over 550,000 patients, alongside a range of Macmillan professionals in other vital health, social care, information and advice roles.

An incredible breadth of roles

Over time, the introduction of other types of roles meant Macmillan professionals supported more people, right across the cancer pathway. This expansion began in the 1980s, when Macmillan started to offer bursaries, fellowships and training to doctors.

By 1995 there were 22 Macmillan GP Facilitators. Throughout the 90s and early 2000s, the number of Macmillan healthcare posts steadily increased, with the introduction of new roles including physiotherapists and dietitians. We also began to work with increasing numbers of information and social care professionals.

Today, there are almost 8,000 Macmillan professionals working in 90 different roles. This incredible breadth means that together, you allow patients and their families to receive support in the community as well as in clinical settings, no matter where they are in their cancer journey.

Building teams for the future

The story of cancer continues to change. People need different forms of care to support the fact that they are living longer with the disease, its after effects, and co-morbidities.

I know we will continue to work together to build the cancer care teams of the future.

Recognising your contributions

It was wonderful to be able to attend the fourth annual Macmillan Professionals Conference and Excellence Awards last month. On pages 8–11 you will find a special feature on the 2015 Macmillan Professionals Excellence Award Winners. These awards celebrate and recognise the outstanding contribution Macmillan professionals make to cancer services.

Thank you all for your hard work and here’s to the next 40 years!
There is strong evidence that work can have a positive impact on health and recovery for people with cancer. More than 750,000 people of working age are living with cancer in the UK, who may face difficult decisions about work.

Having discussions about work early can be vital in preventing problems. Not everyone knows, for example, that if you have cancer you are protected by law from unfair treatment. Employers also have a duty to make reasonable adjustments to help you stay in or return to work.

Order our free Work Support Route Guide to help you guide people who are in employment, on long-term sick leave, self-employed or out of work and want to discuss work options. It suggests relevant questions for you to ask, recommends responses and lists further sources of support.

Personalised information for Scotland: an update

As reported in the summer issue of Mac Voice, NHS 24 and Macmillan have been developing a test website that demonstrates how people in Scotland can personalise information they find online. We are pleased to say that NHS inform’s Cancer Zone Beta site is now online. It includes the unique Info For Me personalisation tool, which allows users to pull information that is relevant to them into their own cancer information leaflet. Visit the test site at nhsinform.co.uk/cancer

Ongoing feedback will be used to make improvements to the site until the end of March 2016. The wider NHS inform website will also be redesigned to better meet the needs of the population, with a launch planned for summer 2016.

In brief

Older people and cancer
Evidence suggests people with cancer aged 65 and over are less likely to be given life-saving treatment than patients aged 55–64. But a new Macmillan report suggests older people are not more likely to refuse treatment. The findings will help to challenge judgements made towards age rather than a person’s capacity or choice to receive treatment. Order the report, Exploring the attitudes and behaviours of older people living with cancer, from be.macmillan.org.uk

OPERA – cancer genetics tool
OPERA (Online Personal Education and Risk Assessment) is an online self-assessment tool for those concerned that they may be at risk of developing breast or ovarian cancer through an inherited gene. OPERA asks 10 questions about personal and family history and summarises the answers to give personalised information and support. To find out more, visit opera.macmillan.org.uk

How we use data
Macmillan’s Evidence team has put together a short animated video. The video shows some of the ways we use research to get a better understanding of the numbers, needs and experiences of people affected by cancer. We then use this data and knowledge to influence and improve the development of cancer services. For more information please visit macmillan.org.uk/research
Your thoughts on writing for Mac Voice

We asked professionals who have written for Mac Voice and Sharing Good Practice in the past three years to complete an online survey about their experiences.

Hundreds of Macmillan professionals have contributed to Mac Voice since it was launched in 1997. We wanted to know more about recent experiences of working with the Mac Voice team, and the benefits to professionals of their articles being published. One of our main aims was to find any improvements we could make to our processes.

A positive experience
Almost all 50 contributors who responded were happy with their finished article and 96% said that they would recommend the experience of contributing to Mac Voice to their Macmillan colleagues. Most felt that they had a straightforward knowledge of how to write their article and enough guidance with doing so.

The benefits
The survey highlighted the way in which articles published in Mac Voice can help develop relationships with other professionals and organisations. 56% said they were contacted by other professionals after their article was published. 58% said their article helped them to promote a project or a service, such as local counselling services and courses; which ultimately has benefits for people affected by cancer.

Some also said that their article helped them in terms of their career development. One respondent said that following an application for a promotion, their article helped to demonstrate their dedication to their profession as well as to Macmillan.

What we have learned
The findings from the survey suggested contributors are largely happy with our processes and that they found benefits in writing for the magazine. However, there were some good suggestions about how we could do things differently. For example, one respondent suggested we should promote the online versions of articles (available at macmillan.org.uk/macvoice) more widely using social media. Some responses suggested contributors would like more guidance about how to write their articles. These are both suggestions we’ll be looking to follow up on.

More information
If you are interested in writing Mac Voice or have feedback, please email macvoice@macmillan.org.uk
The first Macmillan Alumni Congress

The first National Macmillan Alumni Congress was held in Manchester on 10 September, and started in true Macmillan fashion with a slice of cake to celebrate the 40th anniversary of Macmillan professionals.

Once down to business, the call to action for the former Macmillan postholders was made clear: to help the public gain a better understanding of what Macmillan does. Alumni members were then welcomed by a video message from CEO Lynda Thomas in which she emphasised a desire to see members working together with people who are ‘like you and different from you’.

Keynote speakers included two Alumni Patrons: Heather Tierney-Moore, CEO of the Lancashire Care NHS Foundation Trust and Bridget Johnston, Professor of Palliative and Supportive Care at the Sue Ryder Centre, Nottingham University. Charles Campion-Smith, Linda Atter and Jan Morrison spoke about their activities so far as Alumni members and the benefits they have experienced.

‘The thought that went into the event definitely paid off.’
A delegate

Alumni members also had the opportunity to participate in workshops covering topics such as coaching skills, making an impact, being a Macmillan Ambassador, speaking about Macmillan, volunteering and using volunteers.

Feedback from the event showed 100% of attendees gained a wider understanding of different projects happening across Macmillan, and 100% felt they took away useful tools and information that they could use. A great launch for the Macmillan Alumni.

Do you know someone who used to be a Macmillan professional?
If you know someone who might be interested in joining the Alumni, please ask them to email alumni@macmillan.org.uk
The Macmillan Excellence Awards 2015

The Excellence Awards recognise and thank pioneering teams and individuals who deliver the highest standards of care for people affected by cancer. The winners, chosen by a specialist panel, demonstrate excellence in their field.

The winners received their awards during a ceremony hosted by Olympic silver medallist and motivational speaker Roger Black MBE. To find out more about the winners, you can watch their videos at macmillan.org.uk/professionalsawards

Service Improvement Excellence Award winners

Professionals whose vision and commitment has made a lasting difference to the quality of services.

Shez Holmes
Macmillan Neuro-oncology Clinical Nurse Specialist, Northampton General Hospital

Shez has set up nurse-led initiatives that respond to the changing needs of patients and their families. This includes nurse-led clinics and nurse-led telephone support – of which 80% of calls come from family members and carers who are worried about their loved ones. She has built excellent partnerships with key services to benefit patients.

Judith Smith
Macmillan Nurse Consultant in Cancer and Palliative Care, NHS Borders

Judith undertook a service review that has led to substantial change in the care pathways for acute oncology admissions. This work has seen the establishment of a nurse-led model of care. The results are there to see. It has improved patient experience, reduced delays and increased productivity. And there were 25% fewer admissions over a three-month period, and 80 less bed days.

Fiona Haston
Macmillan Clinical Nurse Specialist Head and Neck Cancer, NHS Lothian

Fiona identified that poor patient outcomes were caused by delayed diagnosis and poor compliance. She then put comprehensive plans in place to address these issues, which included approaching Macmillan with a bid for service improvement. The service now sees 800 patients a year compared with 200 in 2003. 97% of all patients are now supported by the same clinical nurse specialist throughout their cancer journey.

The Macmillan Excellence Awards 2015

The Excellence Awards recognise and thank pioneering teams and individuals who deliver the highest standards of care for people affected by cancer. The winners, chosen by a specialist panel, demonstrate excellence in their field.

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**News**

### Innovation Excellence Award winners

Professionals who have improved the quality and experience of care through innovations.

**Professor Rosemary Richardson**  
Macmillan Nutrition Volunteer  
Project Lead, NHS Greater Glasgow and Clyde

Rosemary realised there were not enough dietitians to look after people with head and neck cancer. Working with Queen Margaret University, Rosemary set up a quality-assured, accredited programme to give patients the confidence and skills to support others with nutritional queries and concerns. In doing so, the programme also empowers them to give something back.

**Dr Neil Smith**  
Macmillan GP, NHS East Lancashire Clinical Commissioning Group, NHS Blackburn with Darwen Clinical Commissioning Group

Neil has made a significant impact with a simple message – ‘think cancer’. Through the delivery of large scale events and engagement with the two clinical commissioning groups and other partner organisations, all 89 practices now have a lead cancer GP and practice nurse. As a result, more than 800 new patient reviews have been undertaken, 72% using the Macmillan template.

**Dr Gerry Millar MBE**  
Macmillan GP Facilitator, Southern Health and Social Care Trust

Gerry has led a project to improve early detection of lung cancer through education of both professionals and the community. Following extensive media coverage, more than 300 people went for an x-ray over a three month period. He has also delivered a successful project to give people with learning disabilities better access to screening services — an initiative that has now been replicated by 95% of GP practices in the Southern Trust.

### Integration Excellence Award winner

Professionals who have developed integrated services that greatly improve experiences of care.

**Tanya Humphreys**  
Former Macmillan Senior Project Manager, Bolton Hospice

Tanya has developed an information and support service that really puts users at its heart. She has co-designed a board consisting solely of people affected by cancer. This ensures that people using the service are engaged in genuine collaboration and meaningful user involvement. She has also developed excellent partnerships with the clinical commissioning group, local hospices, public health, and Healthwatch, to name a few.

Professor Rosemary Richardson and Dr Gerry Millar MBE have also been selected as Macmillan Fellows for their outstanding achievements. As Fellows, they can access grants of up to £10,000 to continue improving services.

Rosemary plans to continue embedding her dietitian service and expand its influence beyond Beatson Cancer Centre. Gerry is keen to facilitate the rolling out of several of his successful projects across the other health and social care trusts in Northern Ireland.
Team Excellence Award winners

High-performing and innovative teams providing an outstanding level of support.

Macmillan Pharmacy Service
NHS Greater Glasgow and Clyde

This team has developed a resources folder that is endorsed by the Royal Pharmaceutical Society. The folder provides comprehensive palliative care information for community pharmacy staff, GPs and district nurses. The team has also developed links with all 291 community pharmacies, which all have access to the resources folder. Through an evaluation by the University of Strathclyde, the team were able to provide evidence that supports further development of their project. Successful outcomes have included improved speed and access to appropriate palliative care medicine in the community.

Macmillan Head and Neck Cancer Team
Mid Yorkshire Hospitals NHS Trust

This team has developed its practice, building on years of multi-professional working. Holistic pre- and post-treatment clinics are now consistently provided for all head and neck cancer patients. And as traditional consultant follow-up was unsustainable, the team now provide follow-up clinics – including nasoendoscopy. Working to a risk stratification model, and with the support of the clinical commissioning group, these new clinics have managed to reduce waiting times, improve quality of care, and free up time for consultants to see more new referrals.

Macmillan Lung Cancer Project Team
Mid Cheshire Hospitals Foundation Trust

Through educating GPs and practice nurses, this team has worked together across multiple organisations, increased referrals and reduced the volume of cancers diagnosed through emergency admission from 21% to 13% in one year. Since the project began, access to a lung cancer clinical nurse specialist at diagnosis has also increased from 46% to 85%. This ensures patients have access to all available support and have the best possible experience.
Lifetime Achievement winner

A professional who has made a tireless and inventive contribution to the development of cancer care over the course of their career.

Liz Henderson OBE
Macmillan Redesigning the System Special Advisor, Macmillan Cancer Support

Liz has held several Macmillan roles during the course of her distinguished career, which saw her become Lead Cancer Nurse at the NI Cancer Network (NICaN). Liz has promoted Macmillan’s work for more than 15 years, including early diagnosis, patient involvement, access to information, survivorship and palliative care.

Liz was the first nurse from Northern Ireland to undertake specialist training in oncology. She was influential in the development of the tripartite agreement between health authorities in Northern Ireland, the Republic of Ireland and the National Cancer Institute in Washington. She was also the driving force behind the success of the Transforming Cancer Follow-Up project in Northern Ireland. Her integrity, humanity and humour inspire everyone she comes into contact with.

Henry Garnett Award winners

Inspirational professionals who have made an exceptional contribution to working directly with Macmillan beyond their core role, and in promoting and supporting Macmillan through media work, fundraising, policy development and educating across networks.

Debbie Smith, Macmillan Information and Support Manager, University Hospital of South Manchester

Florence Doran, Macmillan Palliative Care Nurse Specialist, Southern Health and Social Care Trust

Helen Tyler, Macmillan Therapy Services Manager, Velindre Cancer Centre

Jenny Steen Macmillan Palliative Care Nurse Specialist, Southern Health and Social Care Trust

Nicola Neale, Macmillan Cancer Information and Support Manager, Frimley Health NHS Foundation Trust (Wexham Park)

Vikki Jones, Macmillan Advanced Nurse Practitioner Gynae-Oncology, University Hospital Coventry and Warwickshire

Give your colleagues the recognition they deserve with a nomination.

Being nominated for an award is the biggest compliment you can give a Macmillan professional.

You can nominate anyone who’s been a Macmillan professional for at least a year, whatever their role or level. You can also nominate any team which includes at least one Macmillan professional.
Cherith is the Royal College of Nursing’s Northern Ireland Nurse of the Year for 2015.

Tell us about your professional background.
I trained at the University of Ulster from 1991–1995. After that, my first job was in a plastic and maxillofacial unit based at the Ulster Hospital in Belfast. It was there I was first introduced to patients newly diagnosed with head and neck cancer who were having surgery as their main treatment. In 2000, I was appointed to my current role as a Macmillan clinical nurse specialist in head and neck cancer. I have also done intermittent research over the last 15 years.

What are the aims of your current role?
I work with newly diagnosed head and neck cancer patients and their families. As their key worker, I provide support and advice, and coordinate the patient’s pathway. It’s a very important role which includes providing psychological support and helping patients have as good a grasp as possible of what treatment will mean for them, along with the post-treatment impact.
Tell us about your Nurse of the Year award.
I was nominated for my involvement in a series of initiatives leading to improvements for head and neck cancer patients. It really feels a privilege and an honour as there are lots of nurses doing excellent roles and providing excellent care. I also want to share the award with my extremely supportive team.

What improvements did you make?
I realised there was very little evidence surrounding the key factors that contribute to post-treatment psycho-social difficulties for people with head and neck cancer. So I commenced a full-time three-year doctoral fellowship exploring this area. An important learning point was the huge vulnerability of patients post-discharge. A resulting initiative was to implement a telephone support aftercare service. Another recent project has been redesigning the surgical follow-up clinic as part of the Transforming Cancer Follow-Up (TCFU) initiative.

The redesign of the clinic included the introduction of an educational leaflet on the signs and symptoms of reoccurrence, electronic holistic needs assessments (eHNA) to assess patient needs and empowering patients to develop their confidence and skills for self-management. This enabled self-referral or rapid access back into the clinic when necessary. A nurse-led clinic was also established for the low-risk patients who were in year three of their cancer follow-up.

How have you used eHNAs?
Patients come to the follow-up clinic and, alongside a Macmillan volunteer with an iPad, complete a holistic needs assessment specific to head and neck cancer. In real time, the consultant and I have the findings and can focus the consultation around patient concerns rather than clinician concerns. We can also signpost patients to services that can help them. People with head and neck cancer can often have low self-esteem. The eHNA provides them with the tools and the confidence to identify their key concerns and unmet needs, enabling the patient and their family to enter into a partnership with us. Since we have given people more control over what they need after treatment, referrals to our Macmillan information and support centre have increased.

Why do you think the aftercare you provide to head and neck patients is so crucial?
This is a very vulnerable patient group because it’s a very visual cancer and impacts on many very basic day-to-day functions such as speaking and eating. Psychological support promotes timely social reintegration for patients and an important part of aftercare is signposting patients to appropriate support services. Many of these patients come with smoking histories and a number with excessive alcohol intake as well. So a really big part of it is promoting health and well-being, especially post-treatment.

What are the challenges of your role?
Maintaining research activity while doing a busy clinical role. To further progress the ongoing research that informs clinical practice for patient benefit, there need to be more sustained clinical academic posts. There is currently no clear clinical academic pathway for nursing in Northern Ireland.

Another challenge is the same as for anyone working in oncology: the need for downtime. For me, that involves maintaining a work-life balance and taking walks on the beautiful beaches in Northern Ireland.

What are the rewards of your role?
The biggest reward for me is being that frontline member of staff working with cancer patients – making a positive difference.

‘The biggest reward for me is being that frontline member of staff working with cancer patients – making a positive difference.’
Macmillan recognises that people affected by cancer have a rich and valuable insight into the impact of cancer and treatments. User involvement should use that experience to help shape services that we and partner organisations provide.

In 2014 in Scotland, a new approach was developed by the Macmillan involvement coordinators to put people affected by cancer at the heart of user involvement activity. Spearheading the development of a wider Scottish Community of Influence, the Scottish Involvement Group was established to play a key role as partners in helping Macmillan understand what meaningful and sustained user involvement means but also how it is supported, delivered and made accessible for as many people as possible.

The group comprises members from across Scotland, ensuring as many communities are represented as possible. Most have links to support groups and other local community groups. As such, they are in the perfect position to help Macmillan collect, reflect and deliver on local issues.

First-hand experience
Retired GP and group member Rob Lester says this about the group, and the wider Community of Influence we’re aiming to build:

‘The Scottish Involvement Group consists of people with first-hand experience of cancer and can provide a link between the professional administrators who provide the services and those who need them. The Scottish Government is asking for people’s views on how health services should be developed over the next ten years. It is vital that people with experience of cancer make themselves heard as we are the ones who use these services. We know what works well and can see where there is room for improvement.’

Our group is working on a response to this government consultation, which is called ‘Creating a Healthier Scotland’. Creating a spirit of cooperation
Rob perfectly describes our aspiration for the Community of Influence and the Scottish Involvement Group when he says: ‘A new approach to the planning of cancer services is required, so that people affected by cancer are involved at an early stage and their ideas are heard before it is too late to make changes. An ideal situation could exist where cancer services are created in a spirit of cooperation and mutual respect between the users and providers of these services. The Scottish Involvement Group’s role is to work through Macmillan and bring people affected by cancer into the decision-making process.’

There is still work to be done to reach even more people affected by cancer and to bring their voices into the wider Community of Influence, and the Scottish Involvement Group will play a key part in that process.

If you would like to know more about the work of the Scottish Involvement Group or to discuss how it was established and developed, please contact me or the Scottish Macmillan Involvement Coordinator Team by emailing influence@macmillan.org.uk

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‘We don’t talk any more’
This has sometimes been the message between generalists and specialists. But as Lorraine Sloan explains, Macmillan is building bridges.

Effective communication is one of the key challenges faced between health professionals, both in terms of increasing sub-specialisation as well as a lack of opportunity to build personal relationships.

Macmillan has been testing ways to bring together health professionals from across primary and secondary care, to create a shared understanding of different perspectives and address common challenges, including communication across boundaries.

To date, we have held seven events across the country involving over 130 professionals from primary and secondary care, including GPs, cancer leads, consultant oncologists, radiologists, surgeons, junior doctors, and specialists in palliative medicine.

A day in one another’s shoes
Participants of the events have told us it is often the small things that are important and that much can be achieved simply by creating space for conversation. One outcome of the events has been identification of local shadowing opportunities. Macmillan GPs have been linking up with consultant colleagues in their area to spend ‘a day in one another’s shoes’.

Participants have reported that they have valued being able to develop personal relationships and to understand one another’s roles better, resulting in improved communication as well as the potential for effective shared care. Two participants of these shadowing days were Dr Helen Murrie, Macmillan GP cancer lead for Tayside and Dr Caroline Mitchie, an oncology consultant specialising in breast cancer at Ninewells Hospital, Dundee. Both were struck by difference in the time each was able to spend with patients, and the contrast in the depth of knowledge required in secondary care versus breadth of knowledge needed by GPs on many different conditions. This highlighted the importance of clear and succinct communication across sectors.

In particular, Helen identified the importance of oncologists being clear about what they need from GPs: ‘They need to make it obvious to GPs: what’s the plan? What has the patient been told? And what do you want the GP to do? If directions to the GP are hidden in a three-page document they are much less likely to see it.’

The concept of shadowing has also been explored by those undertaking the Macmillan cancer course for practice nurses. Several participants have linked up with local clinical nurse specialists to share knowledge and experiences.

Preparing for the future
With almost 70% of people with cancer now having at least one other long-term condition, it is increasingly important that we create opportunities to share skills and experiences between generalists and specialists. Macmillan is well placed to do this and will be hosting an event in early 2016 to build on this work. If you would like to know more you can register your interest at macdocs@macmillan.org.uk

References
Pancreatic cancer

Three Macmillan professionals discuss pancreatic cancer, their roles, and initiatives they have introduced to improve care.

Philip Whelan on the role of a Macmillan CNS in pancreatic cancer care

Pancreatic cancer is the fifth leading cause of cancer death in the UK. Prognosis remains poor, despite treatment advances, with average five-year survival remaining static at around 3 to 4%. The vague signs and symptoms are difficult to detect.2 Unfortunately, this means only 15% of people diagnosed are suitable for potentially curative surgical resection. Palliative chemotherapy is the mainstay of patients with advanced disease.3

Communicating diagnosis and prognosis

Since 2009, I have worked as a Macmillan clinical nurse specialist in pancreatic cancer at the Royal Liverpool Hospital, a large tertiary referral centre for pancreatic disease. As an autonomous practitioner, my role is diverse and challenging, yet thoroughly enjoyable. I provide physical, psychological and holistic care for people having major pancreatic surgery or palliative chemotherapy. I also support their families. I am privileged to be involved at all stages of people’s cancer journeys. My role includes a particular focus on communicating diagnosis and prognosis.

Nurse-led clinics

Since 2010 I have introduced four nurse-led clinics, which run alongside traditional consultant clinics. This ensures a more efficient use of outpatient reviews and appointments.

In 2013, the nurse-led clinics were evaluated as part of a clinical audit of the CNS role. It showed that over six months, I saw 75% of patients alone and 25% in consultation with a clinician. Of patients I saw alone, 52% required referrals to other services, 59% required medication changes and 71% required further investigations, all of which I instigated and followed up. Most of those seen jointly were new surgical patients, for whom CNS support was vital. In cases of new inoperable cancer or diagnoses of recurrence, the evaluation showed I often take on the role of breaking bad news, a responsibility traditionally perceived to be that of the senior medical clinician.

The results demonstrated the vital role of the Macmillan CNS in the complex management of people diagnosed with pancreatic cancer. It also showed that the CNS will take on increased responsibilities for post-operative surgical patients and those undergoing palliative treatment.

References


Improving pancreatic cancer care Feature

Karen Angel and Penny Kaye on dietary interventions

The average life expectancy for someone diagnosed with locally advanced inoperable pancreatic cancer is 9–12 months. In addition to a poor prognosis, this diagnosis is associated with weight loss and the inability to absorb nutrients. This can result from the pancreas not working properly, or a blockage of digestive enzymes to the bowel. The pancreas produces millions of digestive enzymes each day, which help break down foods into components the body can absorb and use. When this function isn’t working properly, people can suffer side effects such as diarrhoea, steatorrhoea, weight loss, bloating, abdominal pain and wind.

Enzyme replacement therapy

In a 2013 study, patients given pancreatic enzyme replacement therapy (PERT) alongside palliative chemotherapy survived an average of 200 days longer than those treated solely with chemotherapy. It has also been shown that identifying weight loss and providing nutritional intervention are significant factors in influencing overall survival and quality of life for people with pancreatic cancer.

Using this knowledge, we worked with the multidisciplinary team (MDT) to highlight the importance of PERT and developed a dietetic treatment pathway. As part of this pathway, anyone diagnosed with inoperable pancreatic cancer should have access to a specialist oncology dietitian and be started on PERT as soon as possible. Everyone diagnosed with pancreatic cancer is contacted and offered an appointment, with the aim of being seen within 10 working days. Before the appointment they are given a leaflet explaining why they would benefit from seeing a dietitian, a food diary and a dietetic quality of life questionnaire. Patients are reviewed within 2–4 weeks and advised on further dietetic and PERT management as needed. If further symptom management is required the MDT is accessed.

‘A patient told us “It’s such a relief to have support from the dietitian”’

‘I feel normal again’

A patient told us, ‘It’s such a relief to have had great support from the dietitian in helping me feel so much better with my food. I feel “normal” again now. My bowels are back to normal and I can even go out to eat with my family occasionally, which has meant so much to all of us’

Our main aim is to improve quality of life for people with pancreatic cancer. We also want to investigate the impact dietitians can have by providing nutritional therapy and managing PERT. We hope to gather the evidence of this from our dietetic quality of life questionnaires and evaluate the outcomes in the future in order to provide the best possible service locally.

A new edition of Macmillan’s patient information booklet Understanding cancer of the pancreas is available to order from be.macmillan.org.uk

Further information

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Welfare rights

Melvyn Norris, Macmillan Citizens Advice Team Leader in Somerset, calls for your support in referring people to your local benefits advice service.

Just one month after my twenty-second birthday, my father gently told me the cause of months of apparently inexplicable bodily malfunctions. I had experienced a ‘mild’ attack of multiple sclerosis (MS).

‘Mild?’ I thought. I was in hospital, virtually unable to walk, losing control of sight, balance and waterworks, and fatigued even by the effort of getting up in the morning. What would a bad attack do to me?

Little could I know then that, while MS would restrict my physical ability to participate in the world, it would also inspire me towards a career helping others with health problems. Nearly forty years later, I am privileged to lead a team dedicated to helping people with cancer obtain their welfare rights.

Supporting benefit claims

It is no wonder that, among everything else they are coping with, people diagnosed with cancer may not consider financial issues at first. Unfortunately, they may only think of this once debts start to mount. By the time we intervene, they are often struggling to pay bills and afford the extra heating which, for example, chemotherapy or weight loss may demand.

This is a situation Macmillan has sought to address by funding specialist welfare right teams throughout the UK. Ours is dedicated to help people with cancer and their families in South Somerset obtain their welfare rights.

We do so through interviews in a convenient location for the person, be it in their home, in our office, or at a hospital or hospice. We identify benefits they might be missing and help them apply, fill in forms, challenge decisions and go through tribunal hearings if necessary.

A climate of change

We also operate at a time of monumental change. Welfare reform in the UK today might be regarded as the greatest change to the welfare state since its inception some 70 years ago. In England, Scotland and Wales, Disability Living Allowance is being replaced by Personal Independence Payments. A new all-encompassing Universal Credit is with us. These changes are also expected to be introduced in Northern Ireland. The UK government is pressing ahead with £12bn of welfare cuts. It is within this climate that we operate, but we do so knowing that billions of pounds still go unclaimed each year, typically by those who are most ill.
Letting people concentrate on getting well
Our team consists of Macmillan specialists, volunteers and the support of the Citizens Advice in which the service is grounded. Each year we help people access £2.5m in benefits. We are proud of this, for on the one hand it permits people to concentrate on getting well instead of worrying about their bills, and on the other it increases the prosperity of the community in which the money is spent.

Another aspect of our work is to apply for Macmillan Grants to help people with unmet expenses generated by cancer. Each year we help people access £20,000 this way. A typical grant application would be to help with fuel costs or new clothing when body shape is affected. However, support comes in unexpected ways too, such as the cost of gym membership for a person who sought help to fight her way back to fitness.

An email
One student was dealing with cancer while writing her thesis. She wanted an opportunity to convalesce and recharge her batteries. In an email she wrote: ‘Thank you so very much for suggesting me for the Macmillan one-off grant. I was absolutely delighted to receive the full funding from Macmillan for my five night convalescent break. It was such a lift just to feel some support, before even going for the break! The time away was just brilliant and totally what I needed, with time to rest and heal and get stronger with walking on the beach and swimming in the pool every day. It has done me a lot of good.’

How you can help
Our Macmillan Welfare Benefits service, like most others, takes referrals from hospitals, hospice, clients and their bereaved partners. Yet we barely reach half of those affected. The challenge to us and similar projects is to reach everyone affected by cancer. Ultimately, we feel it is the clinical professionals at the front line who hold the key to achieving this. I therefore appeal to you and all Macmillan professionals to refer patients to your local Macmillan Welfare Benefit team or Citizens Advice. People cannot negotiate alone through the benefit maze. They should all have specialist advice.

Eight out of ten people we engage with get benefits or practical support as a result. Those who do not express satisfaction at knowing they are not missing out and that if their circumstances change, they know where to get professional support.

I am a great believer that, on a personal level, we should define ourselves in what we can do rather than what we cannot. MS has given me insight into living with a long-term illness. I feel privileged to be able to apply this to my role and to be part of a team that betters the lives of people affected by cancer.

Four in five people affected by cancer also suffer financially. And when someone is facing cancer, it’s a challenge they should not have to deal with. Our network of cancer care specialists are uniquely placed to provide support on financial issues. People can call Macmillan free on 0808 808 00 00 or visit macmillan.org.uk/financialsupport

Further information
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Reference
Arts for well-being

The organisation Room For You links artists and counsellors to run therapy sessions.

Room for You is a charitable company based in Newcastle upon Tyne, which has existed for 14 years. Our core service is based in the three main hospitals providing cancer treatment in the North East: the Northern Centre for Cancer Care in Newcastle, City Hospital in Sunderland and Queen Elizabeth Hospital in Gateshead. We have also established three ‘Arts for Well-being’ workshops in areas identified by Macmillan as ‘cold spots’ for therapeutic provision in the North East of England. These are in Blyth, Alnwick and Hexham, all in the beautiful county of Northumberland.

We pair a professional artist with a qualified counsellor who acts as a facilitator, meaning sessions are run with a high degree of sensitivity to the experiences and feelings of those having treatment. People can participate however they choose; whether by engaging with an arts activity, or talking with the facilitator, artist or others attending. People value having some time and space to review how cancer is impacting on their life with a non-medical ally. A sister in a cancer unit said, ‘The artists and counsellors from Room for You provide extra time with people that our staff cannot always guarantee. This helps patients and staff, who are able to leave patients engaged in something they enjoy.’

Colourful spaces

We can alter what are sometimes sterile medical spaces by introducing colour, creativity and interest.

At St Bede’s Palliative Care Unit, a ten-bed residential hospice, we have installed an 11-foot wall hanging and three other large artworks. We’ve designed a soft furnishing colour scheme and set up a ‘memory tree’ in the staff room. Each of the individual rooms has a bespoke name plate based on the castles of Northumberland.

6,000 participants each year

The Arts for Well-Being workshops take place over six weeks. Macmillan refers 12–14 patients and carers to us each month.

On average we engage with 550 people a month across our hospital and community-based services in seven sites. This means we engage with over 6,000 people each year.

We use staff observation and experience to record each one-to-one encounter, recording basic information about people and the range of issues they present with. Average percentage improvement across all well-being categories from our workshops over the last ten months is 25%.

With this information we are able to build up an emotional landscape for our stakeholders and NHS trusts, on how people are feeling and coping during treatment.

The workshops are overtly accepted by healthcare professionals, which in turn gives patients and carers confidence in them. This helps their continued success as part of integrated services for people with cancer and carers in the North East of England.
Access to clinical trials information is essential for people with cancer. It helps ensure they are aware of opportunities and supports them in making treatment decisions. Yet access to, and availability of, clinical trials information varies regionally. It can range from general information such as Macmillan’s booklet Understanding cancer research trials, to specific information on trials being conducted locally.

Macmillan information and support centres are a central point of contact for people with cancer seeking information. It is therefore fundamental that they are able to access accurate and reliable clinical trials information, in order to raise awareness of treatment options and to inform decisions. I conducted local research to understand the standard of clinical trial information provided by Macmillan centres and how this information is managed and processed. I focused on centres within hospital trusts covered by the National Institute for Health Research (NIHR) Clinical Research Network: West Midlands (CRN:WM).

How the research was conducted
A survey was sent to Macmillan information centre managers within the hospital trusts. The survey aimed to establish:
• whether Macmillan centres were provided with regular clinical trials information by the network that could be distributed to patients
• the quality of the clinical trials information
• how clinical trials information is processed and managed
• whether centres promoted the network and the service it can provide for patients.

A literature review was also conducted to help us understand the importance of clinical trials information, and how this is (and should be) incorporated within the NHS and the organisations being researched.

Findings
Centres that responded were not provided with regular clinical trials information by the network that could be distributed to people affected by cancer.

There were various sources they used to obtain quality clinical trials information. No streamlined process, supported by the network, was applied across the Macmillan centres to ensure clinical trials information was provided for patients, and the management of clinical trials information varied between hospital trusts. Macmillan centres were not able to promote the network and the service it could provide for patients, as they were not provided with the knowledge or information to support these transactions.

Actions
Based on the results of the project, it was agreed within the CRN:WM that a clinical trials information resource pack would be put together. This has been developed and provided for each Macmillan centre within the Hospital Trusts covered by the network. It includes:
• contact details for the local clinical trials team and a point of contact for the network
• promotional materials, such as leaflets and display posters for Macmillan centre staff and patients
• recruitment reports and portfolio maps, which detail clinical trials recruitment across our area, allowing centres to tell people about these trials.

The resource pack aims to support the process of distributing clinical trials information to patients, to ensure they are aware of their treatment options. It also aims to encourage collaboration and engagement between the CRN:WM and Macmillan centres, to ensure cancer research is promoted effectively and that awareness is raised of the network and the service it provides.

Further information
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In this section

23 Equal access to health information
Abigail Howse, Quality and Improvement Officer, Macmillan Cancer Support

24 Facing cancer as a deaf person
Abigail Howse, Quality and Improvement Officer, Macmillan Cancer Support

26 Supporting patients whose first language is not English
Kathleen MacKenzie, Urology Clinical Nurse Specialist, Raigmore Hospital, Inverness

27 Using videos to reach more people
Abi Delderfield, Quality and Improvement Lead, Macmillan Cancer Support
Equal access to health information

We need to make sure people with particular needs don’t lack information about cancer, Abigail Howse writes.

It’s fair to say there’s no shortage of information about cancer available to people today. There are millions of web pages and countless leaflets and booklets. No shortage at all – unless you happen to speak another language or have a disability.

It is often the most vulnerable patients – those from minority ethnic groups, or those with hearing loss, sight loss or learning disabilities – who suffer the biggest lack of available information.

They don’t necessarily get access to all the background noise about cancer that comes from the TV or media. And while organisations continue to produce more and more printed or online information in written English, the range of information in other languages and formats is increasingly overshadowed.

On our website, we have six new videos exploring the experiences of people with cancer who are deaf, blind or have a learning disability. To hear what it’s like to face cancer with an additional disability, visit tinyurl.com/accessibilityvideos

So what can we do?

There are lots of options available to suit different patients’ needs, whether that’s ordering the audio version of a booklet, or providing a translation in Polish.

Sarah, a Macmillan Colorectal CNS, says, ‘I recently met a lady who was visually impaired and had colon cancer. I contacted Macmillan and they quickly posted us their colon cancer booklet in large print. It was invaluable to the patient. It helped her understand her diagnosis and she could use it for reference during her cancer experience.’

When you provide patients with information in a format that really works for them, it will not only be gratefully received, it will be more effective and have more impact. Macmillan is here to help you provide this.

In England, the NHS has published the Accessible Information Standard to ensure that disabled patients receive information they can understand. To find out more visit england.nhs.uk/accessibleinfo

The table below outlines the range of resources that Macmillan offers. There’s also a selection included with your magazine.

<table>
<thead>
<tr>
<th>Available options</th>
<th>Who might benefit?</th>
<th>Where to find resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Translations in other languages</td>
<td>4.2 million people in the UK speak English as an additional language. Many do not speak English.</td>
<td>macmillan.org.uk/translations</td>
</tr>
<tr>
<td>Audiobooks</td>
<td>Anyone who prefers audio information – may include those with sight loss, those who struggle to read English, those coping with fatigue.</td>
<td>macmillan.org.uk/audio</td>
</tr>
<tr>
<td>Easy read</td>
<td>A format originally developed for people with learning disabilities. Also used by those who are deaf or who struggle to read English.</td>
<td>macmillan.org.uk/easyread</td>
</tr>
<tr>
<td>British Sign Language</td>
<td>People who are deaf.</td>
<td>macmillan.org.uk/BSL</td>
</tr>
<tr>
<td>Braille (on request)</td>
<td>People who are blind and read Braille.</td>
<td>Email cancerinformationteam @macmillan.org.uk</td>
</tr>
<tr>
<td>Large print (on request)</td>
<td>Anyone with impaired vision, may include older people.</td>
<td>Email cancerinformationteam @macmillan.org.uk</td>
</tr>
</tbody>
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Facing cancer as a deaf person

Abigail Howse, Macmillan Quality and Improvement Officer, recently visited the charity DEAFvibe in Staffordshire to find out what it’s like to go through cancer if you are deaf.

I arrived at DEAFvibe on a Saturday afternoon after being invited to their Deaf Café, a monthly social gathering. I was extremely grateful to be invited and was welcomed with open arms and lots of tea! I am especially indebted to the DEAFvibe member (who prefers to remain unnamed) who was willing to share his cancer experience with me.

Experiences of a DEAFvibe member

‘I work for the council. I’ve worked there nine years. I had been there for a year when I got cancer. It was in my stomach. They said it was very serious. I had chemotherapy, then surgery, then radiotherapy. I got really, really ill, but I kept going. Eleven months later I was back at work. I was up and down, and had pains for a long time, but next month it will be eight years since the cancer. So I’m doing okay.

‘I was born hearing and became deaf at 18 months because of chicken pox and measles. I had to stay in hospital for six months. When I came out I was deaf. I’ve been a British Sign Language user all my life. My father was really shocked that I was deaf. It was hard for the family. Mum signed a little bit but I lip-read her. My sister and brother sign, so we used to communicate like that. I went to The Mount, which was a deaf school.

‘I don’t think my experience of cancer was any different to a hearing person’s, because my doctor was fabulous, really good. I don’t think I got treated any differently. I had an interpreter, so it was fine.

‘If it was something really brief, my sister would interpret, but she’s not qualified, so if it was more in-depth or serious then I’d say “I need an interpreter for this”. I knew to ask. If you didn’t have an interpreter, that would be really hard.

‘Some deaf people don’t know much about cancer and don’t understand. Cancer is hard to explain for deaf people. I think as well, cancer can cause panic and fear in the deaf community. Sometimes, information can just go around the community by word of mouth, and it might not even be correct information.

‘To health professionals, I would say make sure you book a qualified interpreter, so the person can communicate. There needs to be an interpreter there if you’re talking about serious medical information.

‘Last Wednesday, I bumped into the surgeon who did the operation! He shook my hand and said “Wow, you’re looking really well.” He couldn’t believe it was eight years this month. He was lovely – super. Both the doctors I dealt with were fabulous, really good, and extremely professional.’

Knowing to ask

Talking to this person about their experience was incredibly uplifting. He had clearly been supported brilliantly by all of his healthcare professionals. It was all hinged on the fact that they booked interpreters. But he also pointed out that he ‘knew to ask’.
Many deaf patients are unaware that they have a legal right to request an interpreter.

An interpreter’s view
After the interview, I spent some time chatting to our interpreter. She explained that while the number of interpreters in the UK is increasing, it’s not always straightforward for deaf people to get access to them. There are various reasons why; one that’s very noticeable at the moment is the financial climate. Another factor is lack of awareness about who should book the interpreter, and how to do this. Sometimes this can lead to stressful and upsetting situations if patients turn up at appointments and there is no interpreter.

The interpreter also told me she knew of occasions where relatives were expected to act as interpreters. This seems like a viable option, but forcing a relative to tell their loved one about their diagnosis and even prognosis puts both in an unfair situation. It also compromises the patient’s privacy and even their safety if important medical information is transmitted incorrectly.

Something very positive that’s happening now, she commented, is that NHS England have introduced the Accessible Information Standard. This talks about providing qualified, registered interpreters for deaf patients. It’s a very positive and welcome step forward in ensuring the safe practice of interpreting in a health setting, and most importantly it protects quality and access for both deaf people and the professionals supporting them.

Speaking with a DEAFvibe trustee and social worker
Next up, we had a brief roundup of the week’s news and politics, relayed to the group in sign language and English (I wondered whether for some, this was the main way they found out the news). I then spoke to a DEAFvibe trustee and a social worker, which was incredibly educational. For me, the main points were these:

• **Deaf awareness training** has had a huge impact in hospitals in recent years. Often, very small adjustments can make the world of difference – for example making sure you face the patient so they can lip-read, or checking the patient has understood what you’ve said. Many hospitals offer deaf awareness training, although sometimes staff aren’t aware of this.

• **Not all deaf people can read well.** This was something I only learnt myself recently. For deaf people, English is a completely different language with a different structure and grammar. Many deaf people can read and write just as well as hearing people, but many can’t. Never assume you can hand a deaf patient some written information. There’s a good chance it will be difficult to understand.

• **Be aware of the Oscar-winning ‘deaf nod’**. Many deaf people, though not all, have grown up in a world where they’ve been excluded from conversations, where people have got frustrated with them, and where communication has always been hard work. Many have therefore learned to sit quietly, nod and say they understand (even if they don’t). They’ve also learnt to stop asking questions. Always check whether a patient has understood what you’ve told them – asking them to feed back the main points is even better.

Macmillan has a range of British Sign Language videos at [macmillan.org.uk/bsl](http://macmillan.org.uk/bsl)

Reference

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It’s important to make sure that any interpreter is NRCPD registered. Inexperienced interpreters are cheaper, but they are not qualified and should not be used for medical appointments.
Supporting patients whose first language is not English

Urology nurse Kathleen MacKenzie on her experiences of using translation services.

My name is Kathleen MacKenzie. I’m a urology clinical nurse specialist based in Raigmore Hospital, Inverness, which is the main acute hospital in the Highlands of Scotland. The urology team consists of five urologists and three specialist nurses, delivering urology services to a population of 320,300. Over the last 10 to 15 years there has been a population increase, with many families from Eastern European countries settling in the Highlands.

Part of my role is to support patients with bladder and renal cancer. I attend clinics with the urologists, so that I can be there when the patient is given information about their diagnosis and treatment. After a patient has spoken to their consultant, I spend time with them, going over their information and giving them the opportunity to ask further questions.

We have Polish-speaking patients who do not speak or understand much English. However, there are ways of overcoming the challenge. I have found some methods to be more effective than others, and it often depends on the situation. Here I’ve described two examples – one very successful and one not so good.

Two examples

A Polish lady in her early 50s had bladder cancer. After being treated for years, her cancer had progressed and she now needed further treatment. She did not speak much English, and although her daughter did, she did not want her to attend appointments, as she knew she was going to get bad news. We arranged for an interpreter to attend the appointment. She was excellent at translating the information and facilitating a conversation between patient and consultant. I then took them both to a separate room to talk more with the help of the interpreter.

I gave her the Macmillan booklet on her condition and told her I would try to get some Polish information. I contacted Macmillan about this and they responded very quickly. Within a fortnight I was sent some translated pages from the booklet. I feel the support we were able to offer this patient was the same as we’d offer to an English-speaking patient.

On another occasion, we had booked an interpreter for a patient but unfortunately they couldn’t make it. Instead, we used our hospital’s telephone interpretation service on speakerphone. This was the method used to tell the patient she had renal cancer and required surgery. The information was delivered effectively, but I was unable to spend much more time with her due to not having access to a speakerphone in another area. I think the telephone interpretation service definitely has its place, as it is far more cost-effective. However in my opinion, it was too impersonal for delivering information about a cancer diagnosis and treatment.

Contacting Macmillan with translation requests

I would certainly encourage other health professionals to contact Macmillan with any translation requests. In my experience, I obtained the translation I needed in a timely fashion.

Macmillan has a large range of translated cancer information in various languages at macmillan.org.uk/translations.

If you can’t find what you need, please contact cancerinformationteam@macmillan.org.uk.
Creating patient information for everyone In focus

Using video to reach more people

Videos are a great way to reach a range of audiences with information, writes Abi Delderfield, Macmillan Quality and Improvement Lead.

New videos this year
This year we’ve produced nine new videos, including:
• Having a colonoscopy: a professional explains the procedure; includes an animation of a person having a colonoscopy
• The late effects of pelvic radiotherapy: three people talk about their late effects of treatment, and a professional offers reassurance and advice
• Talking to your doctor: a guide to help people prepare before they see a doctor; includes animation elements to make it more accessible
• Reaching people with different needs: six videos about people with different needs (sight loss, hearing loss and a learning disability); each area includes a patient talking about their own cancer experience, and an expert professional offering guidance and tips on the best ways to communicate with these patients.

How you can use our videos
You may have already used our videos as a way to engage patients. If not, why not try it? You could suggest a patient watches a video during a chat or consultation, or just signpost generally to our video homepage. You could also show a video at a cancer awareness event, conference or professional event, or perhaps during training.

We’d like to support you to use and share our videos. You can tell us how we can do this better by emailing us (see details below).

Our next steps and how we can help you
By the end of the year, we’re hoping to finish new videos about treatment for thyroid cancer, a guide to reviewing for patient reviewers, tips to keep warm in winter, help with housing costs and an animation about targeted therapies.

We’ll launch another batch of videos in 2016. We’re currently planning these and would love your feedback about ideas for us to consider. Email us at cancerinformationteam@macmillan.org.uk with your thoughts!

Reference

Further information
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Updated

**Understanding testicular cancer**
MAC11642
11th edition
A booklet explaining testicular cancer.
It covers causes and symptoms, diagnosis, staging and grading, treatments and clinical trials. It also talks about emotional, practical and financial issues.

**End of life: a guide**
MAC14313
2nd edition
This booklet explains what happens at the end of life and how to plan for it. It gives information about issues such as choosing where to be looked after, sorting out unfinished business, getting financial help, who can help if you're being cared for at home and what to expect in the last few days of life. It also has information for relatives and friends involved in your care. The booklet is jointly produced with Marie Curie Cancer Care.

**Understanding cancer research trials**
(clinical trials)
MAC11658
12th edition
A guide to clinical trials, answering key questions such as what they are, how they're carried out, and the risks and benefits of taking part in them. It also helps people understand the results, gives you answers to your questions and considers treatment costs and issues of confidentiality.

**Understanding bowel cancer screening**
MAC11687
4th edition
A guide to the risks and benefits of bowel cancer screening programme tests, and what happens after an abnormal result. Also explores feelings that may come up after the test, and lists further sources of information and support.

New

**Malignant spinal cord compression**
MAC15457_card and MAC15457_leaflet
This is a patient alert card that explains the symptoms of malignant spinal cord compression (MSCC). It explains when patients should see a doctor immediately. The card is business-card size so it can easily fit inside a wallet or purse. We have also produced an accompanying leaflet that explains MSCC in more detail.

Order free copies
Visit be.macmillan.org.uk or call 0800 500 800. Some of our resources are also available as audiobooks.

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**Crossword**

Clues across
3 Private instructor
6 Leopard-like animal
7 Big bunny
8 Cap peak which shade the eyes
9 Boil down to reduce the volume
12 Texas farm
14 High-pitched bird sound
15 Jersey or jumper
18 Sales promotion
19 Last meal of the day
20 Filthy living conditions
21 Cavalry weapon

Clues down
1 Of private concern
2 Laundry stiffener
3 Ceremonial chair
4 A column of facts
5 Surprise attacks
6 Conceal information (5,2)
10 Steel emery board (4,4)
11 Ruling sovereign
13 Averse
14 Spring bulb
16 Usual
17 Long-spiked cottage garden plant

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*Answers across: 3 Tutor, 6 Cheek, 7 Rabbit, 8 Cap, 12 Ranch, 14 Chip, 15 Pullover, 18 Offer, 19 Super, 20 Soldier, 21 Lance.*

*Answers down: 1 Personal, 2 Starch, 3 Throne, 4 Table, 5 Beds, 6 Cover, 10 Full Life, 11 Emperor, 12 Aces, 14 Course, 16 Uncle, 17 Japan.*