‘I promised myself that if I got through cancer, I wanted to give something back.’

Mario Barlabá
Macmillan Cancer Support and Information Officer

In focus:
Supporting and developing staff

Sharing good practice:
Supporting Lesbian, Gay, Bisexual and Transgender people affected by cancer
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Celebrating radiographers

A Macmillan Consultant Radiographer has won a prestigious award for her hard work and commitment.

Tracey Ellis, Consultant Radiographer at Lancashire Teaching Hospitals NHS Foundation Trust, was named the North West Radiographer of the Year at the 2016 Society of Radiographers Awards in November. The awards recognise the hard work and commitment of Radiographers across the UK.

Tracey was nominated for the award by a colleague, for her inspirational work in establishing the first role of its kind in the North West.

**Tracey said:** ‘When I first heard that I had won the award for the North West it all felt very surreal and I was overwhelmed. I couldn’t believe that I had won.

‘Now that the news has sunk in a little, I feel extremely proud and grateful for the nomination. I think what makes this award so special is that it is an award nominated by Radiographers for Radiographers.

It is such a privilege to be recognised for your hard work but also to be in a position to raise the profile of the role of the Consultant Radiographer, as well as the profession in general. There is so much amazing work that goes on at our cancer centre at Royal Preston Hospital and it’s great that this has been recognised as there are some really inspirational staff working there.’

There are more than 150 Macmillan professionals working as radiographers or in related specialist radiotherapy roles.

On pages 18 and 19 of this issue of Mac Voice, you can read more about the work of another radiography professional, Rachel Kirby, Macmillan Advanced Practitioner in Thoracic Oncology.

**More information**
You can contact Tracey at tracey.ellis@lthtr.nhs.uk
Mac Voice survey results

Thank you to everyone who completed our online survey about Mac Voice and other communications you receive as a Macmillan professional.

Almost 700 of you responded, representing around 10% of the Macmillan professionals workforce. The findings suggested that:

- 90% of respondents find Mac Voice valuable.
- 51% read every issue.
- 35% read most issues.
- 64% said Mac Voice has a positive impact on the services they provide to people affected by cancer.
- 26% said it has a very positive impact.

Your responses also gave valuable insight into which sections of the magazine you prefer. Sharing Good Practice was named as the most valuable section by 52% of respondents. This was followed by feature articles (25%) and news (16%). The In Focus and Q&A sections ranked lower, so we’ll be thinking about how we can improve on them.

Please email us at macvoice@macmillan.org.uk to share your thoughts about what you would like to read about in Mac Voice.

Congratulations to Rosemary Mack, Macmillan Palliative Care Clinical Nurse Specialist, who won the £50 Marks & Spencer voucher prize draw.

In brief

New Macmillan unit to open in 2017
The new National Gardens Scheme (NGS) Macmillan Unit at Chesterfield Royal Hospital is expected to open very soon. A garden will provide a calm space where patients and carers can spend time during and after treatment. Macmillan’s corporate partner the NGS has donated £1.5 million towards the build. Find out more at macmillanbuilds.co.uk

1 in 5 people face discrimination at work
Research by Macmillan and YouGov shows nearly one fifth of people returning to work after a cancer diagnosis feel discriminated against. Many feel guilty for taking time off or return to work too early, while some stop work altogether. The Macmillan at Work programme offers resources and training to help employers support staff affected by cancer. More information about Macmillan at Work is available at macmillan.org.uk/atwork

You can also turn to page 22 to read an article about supporting staff affected by cancer.

Study highlights bowel cancer emotional support need
The Colorectal Wellbeing (CREW) study, by the University of Southampton and Macmillan, suggests many people with bowel cancer experience a lack of emotional and practical support. Those people are three times more likely to experience clinical depression, according to the findings. Macmillan is calling for wider introduction of holistic needs assessments and care plans.
Are you ready for Carers Week?

From 12–18 June, events to help carers will be happening across the UK.

In 2016, Macmillan revealed that cancer carers across the UK are under more pressure than ever before. The number of cancer carers has soared over the past five years with almost 1.5 million family members and friends supporting a loved one with cancer. They now provide more complex care and face an ever-growing strain which is taking a toll on their health, finances and working lives. Yet more than half are getting no support.

As Macmillan professionals, you may be in touch with these people on a daily basis, so you are ideally placed to identify them as carers and signpost them to support. This could help them to access the support they need and continue in their caring role.

‘It is very emotionally draining. It saps all the joy out of your own life and makes it hard to be positive with others. It doesn’t have to be like that. Proper information and communication from medical, nursing and caring staff, involvement in decisions and inclusion would make all the difference.’ Female carer, 58

Updated Resources

Macmillan has resources to help you support carers. Our guidance booklet for professionals, Identifying cancer carers and signposting them to support has been updated with the latest information about cancer carers in the UK, alongside new legislation and government policy details. The guide is available to order at be.macmillan.org.uk along with sources of information and support that carers can access. You can also view the guide at macmillan.org.uk/supportingcarers

Also new in 2017, is Macmillan’s Rich Picture on Cancer Carers, which brings together all the research to reveal the numbers, needs and experiences of cancer carers in the UK.

Carers Week

Carers Week is brought to life by the individuals, groups and organisations holding events and taking action throughout the UK to build carer-friendly communities. By organising an event to promote your service, you can help us reach more cancer carers than ever before. To download materials and get ideas for your event visit be.macmillan.org.uk

For information resources and posters, visit be.macmillan.org.uk/cancerawareness

April

Bowel Cancer Awareness Month

Depression Awareness Week
17–24 April

May

National Walking Month
Includes ‘walk to work week’ and ‘work to school week’. Visit livingstreets.org.uk

Dying Matters Week
8–14 May

Aims to get people talking about dying and end-of-life planning. Visit dyingmatters.org

Mental Health Awareness Week
8–14 May

Sun Awareness Week
8–14 May

June

Carers Week
12–18 June

carersweek.org
Recognition for young carers service

The Bridge Young Carers Service in County Durham was Highly Commended at the National Children and Young People Now Awards.

The commendation came after Durham County Council nominated the service under the category Supporting Children in a Cancer Caring Role.

Run by the charity Family Action, the service includes specific support for young cancer carers through Belinda Tweed, a Macmillan Family Support Worker (pictured right). Belinda helps young people and families where a child aged between five and eighteen has caring responsibilities for someone with cancer. By December 2016, two years into funding for her post, Belinda and the service had supported 37 young cancer carers.

Belinda says: ‘We identified a gap in support for young carers. Referrals for young cancer carers were not coming into our service. We wanted to explore this and to find out whether there are young carers who aren’t being identified, why this is and how we can work together to give these young people and families better support.

‘Being a young carer can be very emotionally demanding. It affects your home life, relationships, friendships, education, aspirations, ability to look after yourself and your behaviour. Our service works to reduce this impact and provide a support worker who can listen to young carers, understand them and provide a space where they can be young people. This is possible through carers’ breaks and peer support from others in a similar situation.

‘As you can imagine, we were delighted to be recognised at the National Children and Young People Now Awards. We took two young people with us to the ceremony in London. It was all the more special with them there. I hope that we can sustain this project in the new year so that we can continue supporting young carers – in County Durham and beyond.’

More information
You can contact Belinda by email at belinda.tweed@family-action.org.uk
Macmillan has a booklet for young carers and an online video about being a young carer at macmillan.org.uk/youngcarers
A cancer delivery plan for Wales

The Welsh Government has published its updated cancer plan committing to providing the best care and support for people affected by cancer.

The Cancer Delivery Plan commits to offering people with cancer in Wales the Recovery Package, including a holistic needs assessment and a written care plan.

It also commits to routinely offering people information about how to access welfare benefits advice.

The four-year plan aims for cancer services and outcomes that are the best in Europe, but there is some way to go to achieve this ambition, as lung cancer survival rates in Wales are among the worst in Europe.

It pledges a focus on diagnosing cancer earlier with support from the £3.3 million Macmillan Framework for Cancer in Primary Care project.

The project aims to develop a framework of resources for GPs to diagnose cancer earlier as well as tools for providing better primary care support when cancer treatment has ended.

Another positive aspect of the plan is a commitment to running further cancer patient experience surveys.

Macmillan Wales is pleased that the plan focuses on meeting the needs of every person with cancer.

The Wales team’s focus will now include monitoring how the plan is being implemented and holding the Welsh Government and others to account where improvements are needed.

More information
Contact Kerry-Lynne Pyke, Communications Manager for Wales, at kpyke@macmillan.org.uk
Flying the banner for community nursing

Congratulations to Lesley Nixon, Macmillan Community CNS in Palliative Care, on being named a Queen’s Nurse.

The title is awarded to community nurses who have demonstrated a high level of commitment to patient care and nursing practice. Applicants must have the support of their manager and testimonies from two patients, as well as submitting five written accounts of their work.

Lesley received her Queen’s Nurse badge at a ceremony in November. She works in Lincolnshire alongside Lyn Wilkinson, Senior Macmillan Palliative Care CNS, who appeared on the cover of Mac Voice last autumn, having also been awarded the title.

‘Our awards are a recognition for community nursing,’ says Lesley. ‘The number of District Nurses has decreased in recent years, but despite this we maintain a high-quality service, caring for patients at home and preventing the need for hospital admissions. We are always trying to improve standards for the people we care for and for our colleagues, regardless of how busy we are with everyday work.

‘I’ve been nursing for more than 38 years and am very proud to become a Queen’s Nurse. Patients see the badge and ask what it means – it can provide some extra reassurance that they will receive a good standard of care.

‘Being a Macmillan nurse is already such a respected title in itself. I have always been very proud about being part of Macmillan. I am passionate about my job and my role in the community.’

More information
Visit qni.org.uk to find out more about Queen’s Nurses and the application process.
Making new connections

‘Start it, own it, grow it’ – Debbie Smith, pictured above, explains why and how Macmillan Connections in Manchester is spreading this message.

Macmillan Connections encourages people to take back control after a cancer diagnosis, through organised activities and informal interactions. A cross between a network and a community, it’s a blend of planned beginnings and organic growth.

Identifying a need
After completing treatment, people can struggle to find the ‘new normal’. Treatment is generally accompanied by extensive support, but afterwards people can feel like they come to a full stop. Many experience a loss of confidence or motivation. They may feel isolated or lonely.

To help combat this, patients told us they were keen to resume previous interests and activities, or develop new ones. They wanted to do this in the company of people who understood what it was like rebuilding a social life after a life-threatening
illness and living with ongoing effects. In Manchester, we have been running HOPE (Help Overcome Problems Effectively) courses for the past five years. Developed by Coventry University and Macmillan, HOPE is a six-week long, interactive, group-based, self-management support course. The courses have been extremely successful but at the end we were always asked the same question – what next?

Developing a solution
Initially, we developed a leisure and social directory – a comprehensive guide to local activities, social groups and organisations. However, we realised we needed to listen to people rather than make assumptions, so we held a series of listening events. We learned that people wanted to:
• be with others in similar circumstances
• carry on with or start a new interest or hobby, but without the restrictions of a course
• drop in and out as they pleased or as their health determined
• participate in local activities with a social or ‘wellness’ aspect, without being told what to do or what was good for them.

Macmillan Connections was the solution. The focus is on social interaction and support, rather than the activity. Our aim is to build an individual and group sense of wellbeing, not just physically but psychologically.

Start it, grow it, own it
We started by offering patients the opportunity to join walking groups, organised in collaboration with Macmillan’s Walking for Health. These became our first ‘Start It’ groups – entry points for all participants in Macmillan Connections. It became clear that people valued the companionship and supportive interactions, but they also wanted other activities. Now thanks to specialist volunteers, our yoga and mindfulness groups have also become Start It activities, as well as our Macmillan Make-up Days, Massage & Relaxation and Chat & Craft groups.

The Start It groups take responsibility for organising and sustaining activities. Our role is a combination of sponsor and facilitator as we help to contact venues and organisations that could host activities and introduce new members.

Start It activities are the entry point but the ‘Grow it, own it’ activities that evolve subsequently are initiated, run and owned by participants.

Examples have included aquafit, theatre trips and a charity run. If someone has an idea for a social event, he or she will contact potential participants and organise it. Members keep in touch between events, including through social media, which provides a valuable network of informal support. No-one is under any obligation to participate in any activities or social media interaction. However, if someone does not attend an activity for a while, another member of the group will discreetly make contact to find out how they are.

Details of Start It activities and members are kept securely on a database, which we use to put new members in touch with groups. The database also includes details of Macmillan Connections locations and Providers – these are friendly venues and organisations that have expressed a willingness to offer support or facilities.

We asked Macmillan to help us brand the initiative and develop it with publicity and promotion materials, including the ‘Start it, grow it, own it’ strapline. We wanted a structure that could be replicated anywhere, so the branding is generic and transferable and can incorporate other organisations’ logos and messages.

Measuring success
We measure success in three ways: we look at the growth of the groups, feedback from participants and the growing number and variety of providers willing to support our groups.

The next phase is a formal evaluation of the impact on mental wellbeing. Feedback so far tells us the groups meet a need that other groups and relationships may not. Some have described Macmillan Connections as their ‘other family’. They tell us they feel more comfortable and relaxed around people that have an intuitive understanding of what it is like to live with cancer, and the physical and emotional effects that can continue long after treatment has ended.

More information
Contact Debbie Smith, Macmillan Cancer Information and Support Manager at debbie.smith2@uhsm.nhs.uk
What are the aims of your role?

My role is about giving information and support to people affected by cancer here at County Hospital, and connecting them with services that can help. Like other Macmillan Cancer Information and Support Centres we provide a drop-in service, so we meet a diverse range of people. Some are upset, while some are cheerful because they’ve been given good news. I find it interesting because every day is different.

We support people with whatever they need at that time – it might be information or emotional support. We also work with the clinical team at the hospital, liaising with consultants, nurses and other cancer specialists.

One of the biggest concerns after a cancer diagnosis can be your finances. I can connect people with our benefits advisers, who can find out more about their money worries and help them fill in application forms or apply for a Macmillan grant.
How did you come to work for Macmillan?
I began volunteering for Macmillan in 2009 at the support centre at Queen’s Hospital in Burton. I wanted to help because of the support I’d had from a Macmillan nurse when I was going through cancer three years before. I promised myself that if I got through cancer, I wanted to give something back.

At first, I volunteered one day a week. Then my manager became poorly and I took it upon myself to keep the centre open five days a week. I was thrown in at the deep end but it was also brilliant for me as I gained a lot of knowledge.

Volunteering gave me confidence and helped me to get back out there, because for three years prior to that all I knew was consultants, hospitals and treatment.

I began thinking about working for Macmillan when I was awarded the Vicky Clement-Jones Macmillan award in 2012 for my volunteering work. The award showed me that the organisation thought I was worth something. I believed in the ethos and values behind Macmillan and decided that if the possibility came up, I would like to work for them.

The opportunity came when New Cross hospital was looking for an Information and Support Assistant. I worked in that role from March 2013 until November 2015, before taking this role in Stafford.

How did Macmillan support you on your own cancer journey?
When I was diagnosed with Non-Hodgkin Lymphoma in 2006 my Macmillan nurse, Pat Holland, was always there. In one of my meetings with Pat, I broke down in front of her. I had just found out that my insurance company were not going to cover me.

On my next visit to the hospital, Pat presented me with a Macmillan grant in the form of two cheques. The money helped me buy a carpet and a cooker for the council flat I had been given. Before that I had been evicted from my home as I was unable to work and had no income.

Whenever I needed someone to talk to, Pat was always there. She never waited until the next day to get back to me. I didn’t have anyone else to turn to because my kids were young and my family was split between Italy and Bermuda.

I didn’t have access to the same level of support that is available to people today. In hindsight, I realise how amazing everything Pat did for me was.

How important is access to initial information and support?
It’s very important. If all of the services available now were available back then, my journey would have been so much easier.

When I was evicted from my home I could have gone to the advocacy support service that we now have for help and support. I got railroaded out of my house – I had just finished my treatment and was very vulnerable. I just allowed it to happen because I couldn’t be bothered with the fight and struggle.

When I had cancer there weren’t as many benefit advisers available, so I went for the first 12 months without the benefits that I was entitled to. If it were today, I could have gone to the benefits advisers and they would have helped me straight away. It would have made a massive difference.

That’s my motivation – I don’t want anyone to go through what I went through.

Has your cancer journey helped your role as a Macmillan professional?
I use it as a kind of ‘trick up my sleeve’. I don’t always have to, because a lot of people are forthcoming in talking about their cancer. But as soon as some patients find out that I’ve been through it myself, it seems to take that shield away from them and they let their guard down. Although there are many different types of cancer, the broader concerns that people have are often shared; for example finances, making decisions about treatment options and ‘will I still be around in six months’?

What are the greatest rewards and challenges of your job?
One of the challenges of my job has been adapting to how the NHS works and working in a white-collar environment. I used to own a restaurant. I’ve always been a labourer and never worked in an office. There is a lot that I’m getting used to but since being in paid employment for Macmillan, things have gone from strength to strength.

I love what I do. I get a lot of satisfaction out of that and being able to help people. It’s not a job, it’s something that I have a real passion for.
A new advanced breast cancer pathway

Advanced breast cancer pathways are in focus as part of the Macmillan Cancer Improvement Partnership in Manchester.

People with advanced breast cancer are treated with non-curative (palliative) intent. They have complex needs, are managed mainly within the community, and may need to be referred across organisations and between teams. Many will have a prognosis at diagnosis of advanced disease that may be estimated in years.

The improvement of pathways for advanced breast cancer patients is recognised as having fallen behind the work on primary breast pathways. In part, this is due to the complexities involved in supporting this smaller group of patients.

Addressing this inequity is one of several goals of the Macmillan Cancer Improvement Partnership (MCIP) in Manchester. MCIP is a partnership between Macmillan and the city’s hospitals, clinical commissioning groups, patients and carers, as well as Manchester City Council and St Ann’s Hospice.

In 2015, MCIP set up a small group of patients and professionals from Pennine Acute Hospitals NHS Trust and The Christie to review support and care for advanced breast cancer. The group agreed on how gaps and weaknesses in existing services could be addressed. Issues identified included:

- an unclear pathway of support and care for some patients
- large numbers of professionals being involved as needs change, resulting in patients being unclear of their key contact at a given time
- communication between professionals sometimes being ineffective.

Key aims were therefore:

- to clarify roles, responsibilities and interfaces between professionals
- to establish clear communication and uniform access to coordinated support and care.

The group has produced a patient-centred pathway – characterised by consistent key worker coordination and guided self-management – and is now working towards implementing the key elements of the pathway:

- A ‘Support for You’ card is given to patients, describing the support and care they can expect. The card includes personalised key worker contact details and information about access to wider support.
- A holistic needs assessment and care plan are now offered and updated at different points of the pathway.
- Best practice tools such as a ‘hand-held record’ are offered, with additional self-management information and support.
- Appropriate correspondence to GPs, community teams and other professionals is sent at progression and when best supportive care becomes the focus.
- An annual networking event has been introduced to share best practice and promote collaboration.

There is a city-wide commitment to the ideal pathway. This is enabling information-sharing and development of services where people feel cared for and in control. To watch our video about the pathway, visit tinyurl.com/mcip-video

Further Information
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With acknowledgement of everyone involved in this team effort, including Dr Anne Armstrong, Tracey Coleby and Berenice Cowan.
Transforming care after breast cancer treatment

A new approach to supporting people after cancer treatment led to significant improvements in patient experience, and a 50% reduction in demand for follow-up consultant appointments.

Our pilot project at Stobhill Hospital, Glasgow, gave 150 women who had finished treatment for breast cancer a new personalised model of medical follow-up. This ran alongside increased emotional, financial and practical support based on a detailed assessment of their individual needs.

The project is part of the Scotland-wide Transforming Care After Treatment programme (TCAT) – a partnership between NHS Scotland, Macmillan and local authorities.

How the project worked
Prior to the pilot, women who finished breast cancer treatment attended a yearly appointment with a consultant and mammogram.

The women involved in the pilot still attended the yearly mammogram, but were also offered a holistic needs assessment (HNA).

A Clinical Nurse Specialist (CNS) reviewed the HNAs and called each woman to discuss their responses. The CNS then created a care plan for each woman and helped them access the most appropriate support services for them.

What was the impact of the new approach?
This personalised approach to aftercare resulted in only 50% of the women being referred onto a consultant for follow-up – a 50% drop.

It also led to an increase in referrals to emotional, financial and practical support services, and to NHS clinics for help managing side effects.

Surveys of 34 women who received care before the new approach, and 46 women who took part in the pilot, found the new approach led to significant improvements in patient ratings of their care after treatment. Women in the pilot rated their support after treatment at 8.9 out of ten, compared to an average of 6.5 from the pre-TCAT project women.

A highly encouraging 66% (29 women) in the pilot said their needs were completely met when managing the consequences of treatment. This is compared to just 24% (8 women) of those who received the traditional model of follow-up care.

What now?
This pilot adds to a growing body of evidence from across the UK, showing that when people are offered care after treatment built around an individual assessment of their needs, it results in a better patient experience.

The reduction in consultant appointments also indicates that this approach leads to better use of NHS resources.

This new model of care is now being rolled out to everyone who has finished treatment for breast cancer in Stobhill and is being embedded into everyday practice.

A review of the clinical histories of the women in the pilot found far fewer than the 50% who saw a consultant after treatment ended had a clinical reason to do so. It is hoped the roll-out will reduce demand for consultant appointments by at least 70% at Stobhill Hospital. This will free up consultant time to spend with new patients those with complex needs.

Decision-makers across the NHS in Scotland are being urged to look at the project and consider how its lessons can be used to improve care after treatment across Scotland.

Further information
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Macmillan Cancer Support TCAT Project Manager
Glasgow
anna.morton@ggc.scot.nhs.uk
LGBT support in Staffordshire

Macmillan has joined forces with Stoke-based charity Disability Solutions to support Lesbian, Gay, Bisexual and Transgender (LGBT) people in Staffordshire. Jo Coulson explains.

The gay scene here in Staffordshire is somewhat fragmented. LGBT people can often feel isolated. When our project was launched in 2016, we looked at the LGBT Foundation in Manchester and Birmingham LGBT and realised we had a lot to aspire to.

I have worked for Macmillan for four years, since my own experience of cancer, in which I came to realise there wasn’t a level playing field for everyone and I would need to become my own advocate.

Angie Bunn, our Engagement Officer, has led several successful projects at Disability Solutions including LGBT Disability.

As a result, Angie and I are both passionate and optimistic about this project, which is funded by Macmillan and run by Disability Solutions.

Objectives

In engaging with the LGBT community, we aimed to answer these important questions:

• Why do LGBT people often report worse cancer experiences than mainstream patients?
• Why is cancer awareness and screening uptake often lower?

• What LGBT needs are being overlooked?
• What are the barriers and where are the gaps in services?
• How can we make cancer care more inclusive?

Entrenched inequality

We’ve found that, as a marginalised community, LGBT people are more likely to present later and with more advanced symptoms of cancer. Lifestyle factors account for some of this. LGBT people are more likely to smoke, drink and take drugs (25.3% people who describe themselves as gay or lesbian smoke, compared with 18.4% who describe themselves as heterosexual). This is compounded in Staffordshire where, in its most deprived areas, smoking rates can be as high as 34%.

Lower engagement with services is also a contributing factor due to experiences of discrimination, heteronormativity and a lack of information and/or staff knowledge. Some people have reported that their same sex partner wasn’t acknowledged or caused a shocked reaction in staff.

Mainstream cancer literature also tends to assume everyone is straight. Sexual function after prostate
cancer, for example, can affect gay and bisexual men very differently. Radiotherapy can cause rectal bleeding and soreness and men should be advised to abstain from anal sex for the duration of the treatment. This isn’t covered in mainstream literature and how many doctors would think to mention it if the patient hadn’t had the courage to come out to them first?

Transgender communities
Transgender men and women encounter additional risks, most significantly from their use of hormones. We know that oestrogen influences the development of certain cancers for trans women, and that trans men are more likely to be diagnosed with cervical, ovarian and uterine cancers.

There is no consensus on the exact risks as more research is needed. We should also bear in mind that trans people have a poor uptake of screening. Trans men may be unaware that if they still have a cervix, they need to have smear tests. They may be ‘falling off’ the national screening list, or a receptionist may see a man’s name on the list and assume it’s a mistake. Similarly, trans women are still at risk of prostate cancer, which leads to questions around the sensitive treatment of a female patient with an exclusively male cancer. Trans people also tell us that surgeries and clinics don’t always feel like welcoming and safe spaces for them.

Increasing awareness
Not a week goes by when we aren’t out and about with our banners and leaflets, talking to the community. We’ve popped up everywhere from hospital foyers and hospices to libraries, trans events and Stoke Pride. We’ve amassed a large following on social media and helped start a LGBT staff network at our local hospital. Our talks around LGBT awareness have included a conference in September where we spoke to over 100 healthcare and Macmillan professionals about the barriers LGBT patients face.

Throughout all this, we have collected a range of individual patient stories that sharply illustrate some of the issues at hand, as well as over a hundred survey responses with detailed views.

A little training goes a long way
A common recommendation is to provide LGBT awareness training to healthcare providers. Staff may not be sure what terminology or pronoun to use for a trans person or they may feel afraid of offending somebody by mentioning sexuality. Yet the evidence we’re hearing is that LGBT people wouldn’t feel embarrassed by the question and would prefer to be asked. In fact, it’s important to monitor sexual orientation and gender status of patients to make sure we’re doing the best we can for people, as well as meeting the obligations set out in the 2010 Equality Act.

High hopes
Our second year will be more of the same; engagement, investigation and research. There will also be an event for Dying Matters Week, looking specifically at end-of-life care issues for LGBT people, and a summer conference on sex, sexuality and body image for people affected by cancer.

At the end of the two-year project, we’ll make recommendations that we hope will help bridge the gaps and reduce the inequalities we’ve found. I would like us joining the ranks of Manchester, Birmingham and beyond with a centralised LGBT ‘hub’ or meeting space with support for everybody under one roof. It’s ambitious, but we have high hopes for this project and where it will lead.

See the Sharing good practice pull-out for more information about the specific issues faced by LGBT people affected by cancer, and best practice tips on providing care.

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After working in clinical radiotherapy in both the UK and Canada, I began a newly created Macmillan Advanced Practitioner post at Addenbrooke’s Hospital, Cambridge, in July 2015. The post is a joint funding venture between Macmillan and Cambridge University Hospitals NHS Foundation Trust (CUH) and is aimed at improving the experience of lung and oesophageal cancer patients. Single and multi-modality treatments are helping to improve lung and oesophageal cancer outcomes, albeit modestly, but they are commonly associated with significant morbidities. Unfortunately many patients continue to face a very limited life expectancy.

What does the role involve?
This multi-faceted role has been initially modelled on existing advanced practice radiographers within the department. The provision of holistic information and support to patients and carers throughout treatment and beyond is central to the role. Chemo-radiation regimens are complex. Therefore continuity and having a single point of contact are not only valued by patients but also the wider multidisciplinary team, to ensure the patient journey is seamless and efficient.

Radiographer-led radiotherapy review and follow-up clinics have provided an excellent forum to assess patients and ensure that their toxicities are optimally managed. This has been facilitated by embedding elements of the Recovery Package: a series of interventions developed by Macmillan and the National Cancer Survivorship initiative for patient assessment and the documentation of all aspects of management (macmillan.org.uk/recoverypackage).

Non-patient-facing responsibilities are equally important to ensure that the service is safe, adheres to government waiting time targets and remains at the forefront of oncology and radiotherapy practice. CUH actively partakes in local, national and international clinical trials in both medical and radiation oncology.

Two-week post radiotherapy follow-up clinic
The immediate post-radiotherapy window is a period where patients are at increased risk of losing physical, conditional and emotional strength. In addition to respiratory symptoms and fatigue, patients receiving high-dose radiotherapy to centrally located tumours invariably experience dysphagia, oesophagitis and an increase in secretions. These acute toxicities typically present in the final weeks of treatment. However, they persist and often worsen, peaking around ten days after treatment has finished. During this time, patients are more likely to access GPs and acute hospital services such as the cancer assessment unit and the emergency department. In addition to addressing physical and functional morbidities, the clinic

‘Continuity and having a single point of contact are not only valued by patients, but also the wider multidisciplinary team’
provides an ideal opportunity to listen and offer support to patients and carers to help them cope with the psychological, social and financial consequences of their situation. This is a crucial time to inject support as patients make the transition from active treatment into follow-up.

The creation of a resource folder that is structured around the electronic holistic needs assessment (eHNA) has facilitated consistent and effective signposting to further information, charity-based support and activities, and community-based services. A care plan and treatment summary are shared with the patient and GP for future reference.

Ultimately the aim is to educate and empower patients to actively manage their symptoms, develop coping skills and get the most out of life as they move forwards, regardless of their prognosis.

The future of cancer services

The pressures on cancer services to cope with current demand and secure a sustainable future are now very real. The Macmillan Integrated Cancer Care Project (MICCP) is a Macmillan funded initiative at CUH, which aims to improve and develop stratified patient pathways and implement the Recovery Package.

Nurse-led and Allied Health Professional-led clinics represent a sustainable way of coping with increased workloads, while continuing to offer a high-quality service based on existing expertise within the cancer division. Changes to legislation in April 2016 mean that registered therapeutic radiographers are able to train as independent prescribers, which will facilitate further improvements in patient care and efficiency.

CUH has actively embraced the Allied Health Professional four-tier structure and currently supports six site specialist advanced practice or consultant therapy radiographers within oncology alone.

My role represents a key link between Macmillan, the MICCP and thoracic teams, and the radiotherapy staff. Communicating progress to the radiographers and others to raise awareness and encourage participation is crucial to the success of the MICCP, which affects many staff groups and departments within and external to the cancer division. It is hoped that the thoracic pathway will provide a valuable model for other advanced practice radiographers as the MICCP rolls out across all tumour sites.

What are the rewards?
The Macmillan ethos is synonymous with the values that underpin CUH and I hope that these are reflected in my practice. I feel incredibly privileged to work with Macmillan, CUH, the cohesive thoracic team and a fantastic patient group. The resilience and determination of our patients never ceases to amaze and perpetually drives me to make a positive difference to their journey, however small that difference might be. Additionally, the gratitude expressed by patients regardless of their outlook is deeply humbling. I would like to express my thanks to everyone who helped to secure this post and for the support and encouragement I have received since.

‘The resilience and determination of our patients never ceases to amaze’

Further information
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Keeping cancer on the agenda in Northern Ireland

Heather Monteverde, Head of Macmillan Services for Northern Ireland, on how Macmillan continues to influence government despite recent upheaval.

More people in Northern Ireland are living with cancer than ever before. This number continues to rise and is expected to reach 74,000 by 2020. Macmillan invested more than £6 million in the development and delivery of cancer services in Northern Ireland during 2016.

Political instability returned to Northern Ireland at the beginning of this year, resulting in the collapse of devolved government and a snap election in March. As a result, no budget has been agreed for departments to deliver vital services throughout the year. Without committed political leadership, the important ongoing reforms in health and social care could be disrupted.

Responsibility for health and social care is entirely devolved, meaning that the NI Assembly must take key decisions. People facing a cancer diagnosis need parties to work together at Stormont, ensuring the best possible use of resources to meet the growing demand in a sustainable way.

That’s why we worked hard after the previous election in May 2016 to keep cancer care firmly on the agenda, by:

• writing to every new Member of the Legislative Assembly (MLA) to provide an overview of our work.
• meeting with MLAs on the Health Committee, who speak for their parties on healthcare issues.
• attending party conferences to get our message across to more representatives.
• sending briefings to make sure MLAs were aware of key issues ahead of an Assembly debate on cancer services.
• welcoming the Health Minister’s publication of the Expert Panel Report and ‘Health and Wellbeing 2026: Delivering Together’ and offering our continued support to improve care.
• launching our ‘Time to Deliver’ campaign to call on the Health Minister and the Committee for Health to work towards a new dedicated cancer strategy.
• responding to the draft Programme for Government to detail why a cancer strategy is needed and to outline steps for achieving high-quality care.
• holding an event at Stormont to celebrate Macmillan nurses and promote their invaluable work.

We want to see a strategic approach to ensuring that everyone diagnosed with cancer receives the right care at each stage of the cancer journey.

We will continue to keep a close eye on developments and take all opportunities to bring the voice of people affected cancer to all who were elected in March.

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Meeting the needs of staff affected by cancer

Macmillan Lead Cancer Nurse, Dawn Miller, explains how a focus group in Wirral led to a wider project to improve experiences for healthcare staff coping with cancer.

Wirral University Teaching Hospital NHS Foundation Trust (WUTH) is one of the largest and busiest acute trusts in the North West of England, serving a population of around 400,000. With a 5,500 strong workforce, we are also the biggest employer for the local area.

As the newly appointed Macmillan Lead Cancer Nurse, one of the challenges I considered was how we could support our own staff when they are affected by cancer.

Understanding staff experiences
In March 2016, a small focus group was brought together and facilitated by the Macmillan Involvement Coordinator. The aim was to explore staff experiences of being affected by cancer while working at WUTH, and determine what could have improved these experiences. The group included two members of staff who had been recent patients and three who had cared for a close family member, one of whom had been bereaved.

Some members of the group reported an overall positive experience, while for others it was less so. There was a lack of consistency about how managers handled staff taking time off. Those who were carers and not patients did not always feel their needs were recognised to the same degree.

Making improvements
The following potential improvements were identified:

• Managers should maintain contact with staff during sick leave, and not just to chase up a sick note.
• The standard letter sent from WUTH lacked sensitivity and was distressing to some staff who were off due to a serious illness. The standard letter should be reconsidered in certain instances.
• Staff would have found it helpful to have a return to work interview before coming back, to consider if any adjustments should be made to their role or workplace.
• Some people felt they could have returned to work earlier if a more flexible approach had been applied.
• Staff would have appreciated the opportunity to talk to someone else in a similar situation.
• Most staff were unaware that they could self-refer to occupational health for support.
• Signposting to services or information, for example about support for staff’s children, would have been helpful.

After the initial meeting, the group expanded. It was joined by others including staff from Human Resources, Occupational Health, Chaplaincy and our Macmillan Cancer Information Centre. It was established that this would now be a steering group to address the needs of staff members affected by cancer at WUTH.

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Progress to date
Macmillan produces information
for both employees and employers affected by cancer. This includes *The essential work and cancer toolkit*. Included in the toolkit are Macmillan’s 10 top tips for line managers; these have now been adopted as best practice by HR staff and are used for training and advice.

The tips, which are expanded upon in the toolkit, are:

1. Communication is key
2. Be sensitive to your employee’s needs
3. Respect your employee’s right to privacy
4. Be prepared to make adjustments
5. Check guidelines and policies
6. Find out about financial support
7. Respect carers’ rights at work
8. Discuss a return-to-work plan
9. Recognise the impact on your team
10. Macmillan is here to help

In addition to promoting Macmillan’s work information to staff, we are piloting cards to help staff who have been diagnosed with cancer to communicate with colleagues or managers. The card can help if they find it difficult to put their emotions or preferences into words. It tells their colleagues what they are experiencing and what would help. A questionnaire is being given out with the cards to help us evaluate its impact.

In addition to these steps:
- Staff affected by cancer are invited to patient health and wellbeing events, and a stall is present at the events for staff.
- ‘Cancer in the workplace’ training sessions (educational events for employers and employees) are being promoted among WUTH staff as a means of further training. Relevant training is available through the Macmillan at Work programme and the charity Maggie’s.

There remains enthusiasm within the group to influence change and as new members join fresh ideas will emerge. It is vital that the needs of staff are paramount within the organisation to promote staff retention and staff satisfaction this in turn will have a positive impact upon sickness.

The steering group is working closely with the HR department to look at the staff sickness policy and adopting a sensitive approach when staff are off sick as a result of a cancer diagnosis.

In addition Occupational Health is now closely linking with the Macmillan Cancer Information and Support Centre and promote the use of the centre for staff and families.

A confidential email address has been promoted via our communication department so that staff can access the centre without being in view of the hospital.

The Information and Support Manager and I are now members of the Trust’s Health and Wellbeing board and able to support the wider agenda for a healthy workforce. Details of the information and support centre are displayed on the health and wellbeing staff web page.

More information
To find out more about work and cancer resources available from Macmillan, visit macmillan.org.uk/work
The Macmillan Allied Health Professions Competence Framework

Guidance will soon be available to support AHP recruitment, workforce planning and development.

The Macmillan Allied Health Professions Competence Framework (MAHPCF) will be the first of its kind for Allied Health Professionals in the UK working with people affected by cancer.

This MAHPCF is being designed for use by and with registered Allied Health Professionals (AHPs) including:
- arts therapists
- dietitians
- drama therapists
- music therapists
- occupational therapists
- orthoptists
- paramedics
- physiotherapists
- podiatrists
- radiographers (therapeutic and diagnostic)
- speech and language therapists.

The competencies were developed through an extensive engagement process with more than 200 Allied Health Professionals, other health professionals and academics. The first working draft was the result of a thematic analysis of competences outlined in ‘A Competence Framework for Nurses’ produced by Macmillan followed by consultation both online and face-to-face in workshops. A pilot of the framework was completed in February 2017, resulting in positive constructive feedback to refine the framework.

Supporting teams and individuals
The primary intention of the MAHPCF is to support managers, teams and individuals by identifying appropriate competencies in a number of specific areas that apply to the majority of AHPs working with people affected by cancer. The framework should help individuals and organisations by supporting recruitment, role design, career progression and workforce planning and development. It should also help them to consider both individual and team needs to ensure that people affected are being effectively supported.

It is hoped that the MAHPCF will be widely adopted and help educate the workforce by informing academic curricula and professional development programmes as well as highlighting the skills required to provide safe, effective, high-quality and accountable care for people affected by cancer.

Benefits for AHPs
For an AHP, the MAHCF can:
- enable care and information to be shared across different health settings
- help standardise care
- motivate staff by setting challenging objectives and providing positive feedback.
- support continuing personal and professional development as part of the requirements of the Health and Care Professions Council registration requirements.
- help inform and direct AHPs to move from one level of competence to another.

The MAHPCF is due to be completed and available to Macmillan and non-Macmillan Allied Health Professionals this spring. Look out for more details in the next edition of Mac Voice.

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‘Grow your own’: supporting future nurse specialists

How a forum is helping Cancer Support Sisters work towards becoming Clinical Nurse Specialists.

Access to a Clinical Nurse Specialist (CNS) has been shown to play a vital role in delivering high-quality, patient-centred care and treatment. Patients allocated a CNS have reported a more positive outcome regarding experience of their care.1 However, access to CNSs varies both geographically and by tumour site, leading to inequalities in patient experience.2

At South Tees NHS Foundation Trust, it has become increasingly difficult to recruit into band 7 cancer CNS posts, due to lack of suitably experienced applicants. An additional concern has been that 60% of the current cancer CNS workforce may potentially retire in eight years, leaving a huge void in the cancer CNS workforce, with little succession planning in place.

While we were discussing these concerns, a number of band 6 Cancer Support Sisters approached Nicky Hand, Lead Cancer Nurse for the Trust, requesting support and professional development to help prepare them in progressing to band 7 CNS posts.

It occurred to Nicky that there might be a way to address both issues by setting up a professional development and support forum for Cancer Support Sisters. Simultaneously, this would provide an additional opportunity for cancer CNSs within the Trust to develop their leadership roles by chairing and supporting the forum.

The inaugural meeting took place in November 2015 with the forum focusing on two key areas:

- Professional development to support and facilitate band 6 Cancer Support Sisters in developing the necessary knowledge, skills and behaviours needed to progress to a band 7 cancer CNS role.
- Peer support and clinical supervision opportunities to help sustain a healthy workforce.

To date the forum has met every three months, with 13 out of 15 Cancer Support Sisters attending regularly. There have been a variety of discussions and presentations, covering areas such as:

- the benefits of clinical supervision
- findings from an MA dissertation exploring the leadership role of cancer CNSs
- a practical session on library skills
- discussions around the key role differences between the Cancer Support Sister and the CNS.

The meetings have also included a 30-minute slot for peer supervision and an opportunity for individual support sisters to showcase innovative practice development.

The forum members have also developed their own terms of reference and will take over chairing and managing the forum in the coming year. The highlight of 2016 was an ‘away day’ for the Cancer Support Sisters, funded by a Macmillan Educational grant. It focused on understanding and preventing professional burnout, negotiation and assertiveness, managing difficult conversations and developing personal resilience.

As one of the CNSs involved in chairing and supporting the forum, I would whole-heartedly recommend the experience of being involved in such a project.

Further information
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References
2. NCAT Cancer. CNS Survey 2011.
Succession Planning

When she decided to retire, Karen Mackinnon took steps to ensure her skin cancer service would continue.

Having made the decision to retire, I was driven to succession plan following the sudden realisation my entire service would be at least temporarily suspended. I was determined my actions would not affect the skin cancer patients’ pathway. Nationally there are a limited number of nurses with specialised experience. Alongside this, we have an ageing workforce, increasing workload and lack of funded student nurse places. Consequently, a business case was completed focusing on capacity, demand and resources for succession planning.

Innovative solution
I met with Rachel Pedder, our Macmillan Cancer Support Partnership Quality Lead, who felt a training post was a positive step. We managed to secure funding for a band 6 Skin Cancer Support Nurse. This would be for one year and the candidate would be eligible to apply for the band 7 post when it became vacant.

The Role
When I first started as a Skin Cancer Clinical Nurse Specialist (CNS), the idea a nurse could run a clinic to inform patients of their cancer diagnosis was novel. I wrote protocols then gained feedback from clinicians and users about the service and my vision for the future. At the time of launch, this was the first nurse-led skin cancer diagnosis clinic of its kind in the country.

Suspected skin cancer patients have an appointment for their results in the nurse-led clinic. The diagnosis is discussed, a full history taken and clinical examination performed. Information on self-examination and sun protection is given and a follow-up programme is arranged with the CNS. In the Annual National Cancer Patient Satisfaction Survey, our service consistently receives a 100% score for the question ‘Did you receive your cancer diagnosis sensitively?’ We continually strive to maintain this and seek ways to improve the service.

The process
Kim was chosen for her enthusiasm and ‘can do attitude’ as well as her skills. A tailored orientation programme was developed as she had no previous dermatology experience. A schedule was completed to address Kim’s learning needs. This post allowed for concentrated one-to-one training. Kim secured a place on the advanced communication and psychological assessment skills courses – essential for a CNS multidisciplinary team core member. She registered for the skin cancer care e-learning module at Birmingham University and will continue her MSc next year.

Following weeks of observation in new and follow-up clinics, Kim undertook her own consultations with supervision. This has been the perfect environment for her to complete the skin cancer competencies which are an integral part of the module. Kim has researched the current systemic therapies for skin cancer during self-directed learning and has successfully presented to other healthcare professionals. Throughout the entire process, there have been opportunities to discuss progress and development needs with regular appraisals and one-to-one meetings.
Kim says …

‘I felt this role would be an amazing opportunity to specialise and for career progression. I was lucky enough to be offered the position and eight months in there is definitely no turning back. To be able to train one-to-one with a Macmillan professional who has created an irreplaceable nurse-led service for skin cancer patients has been incredible and indispensable. Due to the specialist nature of the job, I have had the time to study and attend courses to ensure I develop the appropriate skills and gain the relevant knowledge. Hopefully it will allow the service to continue in a seamless manner’

Karen says …

‘I feel very privileged to have been able to develop such a successful nurse-led service. I am confident Kim has the qualities needed to take forward this role and now feel optimistic regarding the future of the service for our skin cancer patients’

Potential pitfalls and solutions
We were acutely aware that there was the possibility that the candidate may not have settled into the role resulting in a waste of time, resources and opportunity. It is worth considering the possibility of candidate signing a contract to commit to training and if successful remaining in post for a set amount of time.

We were mindful of the fact the current post-holder’s circumstances could change during the training period. This was recognised by the trust who requested the post-holder confirm the intention to retire prior to the new appointment in writing.

Lastly, the trainee may not have been successful in obtaining the band 7 post. It’s important to have a rigorous initial interview process to establish a suitable candidate. Regular updates and testing of competencies can ensure the candidate is achieving milestones.

Conclusion
The project has nurtured individual development, with supervision, appraisal and measurement of competencies, while allowing a smooth transition for local people with skin cancer. We are extremely grateful to Macmillan who have enabled us to maintain a high-quality, nurse-led service for the future.

Further information
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Cancer and complimentary therapies
MAC11645
8th edition
A realistic and balanced guide to the complementary therapies used by people living with cancer. These include mind therapies, physical therapies, acupuncture, complementary medicines, alternative therapies and psychological and self-help therapies. Also includes a list of relevant organisations and resources.

Your feelings after cancer treatment
MAC12517
4th edition
A booklet looking at your feelings after cancer treatment. It talks about the emotions you may experience and suggests ways of dealing with these. This new edition includes a tool for people affected by cancer to write down their feelings.

Understanding rectal cancer
MAC12475
4th edition
This booklet explains rectal cancer, covering causes and symptoms, diagnosis, staging and grading, treatments, clinical trials and how to cope with it.

Understanding anal cancer
MAC14811
2nd edition
This booklet explains how anal cancer is diagnosed and treated, and looks at feelings you may have.

Understanding colon cancer
MAC12474
4th edition
This booklet explains colon cancer, covering causes and symptoms, diagnosis, staging and grading, treatments, clinical trials and how to cope with it.

Cancer and pregnancy
MAC16128
This booklet is for women who have been diagnosed with cancer during pregnancy. Jointly developed by Macmillan Cancer Support and Mummy’s Star, it contains information about the emotional and practical issues you may experience in this situation. It also talks about the treatment and support available to you.

Crossword

Clues across
3 Criminal deception
6 Large ape
7 Requiring immediate attention
8 Underage person
9 The inside
12 Foreigner
14 Something well worth having
15 Water tortoise
18 Spiny shrub with yellow flowers
19 Ingenious device
20 Dried bean used in stews
21 Very tiny

Clues down
1 The border of a country
2 Old British coin worth two bob
3 Defective or imperfect
4 Wrath
5 Wild Australian dog
6 Athlete
10 To teach how to do tasks
11 Withdraw into seclusion
13 A complete lack of interest
14 Silky-haired breed of rabbit
16 Correct in every detail
17 Rascal