Peter Armstrong
Macmillan Palliative Care Service
Improvement Pharmacist

In focus
Teenagers and young adults

Sharing good practice
Primary care
Welcome

Welcome to the Winter 2018 edition of Mac Voice.

Firstly, congratulations to all our Macmillan Professionals Excellence Award winners, who were revealed at the Macmillan Professionals Conference in November. You can read more about the inspiring and innovative ways our winners are supporting people affected by cancer on page 8.

On page 12, Macmillan Palliative Care Service Improvement Pharmacist Peter Armstrong talks about his work in Northern Ireland to improve access to palliative medicines for people with cancer at the end of life. And in our In focus section, Macmillan professionals describe how they are working to address the physical, social and emotional needs of teenagers and young adults living with and after cancer.

Sharing good practice provides an update on the work that Macmillan is doing to support professionals to improve cancer care within primary care. As the number of people affected by cancer in the UK continues to grow, GP practices have a key role in supporting patients, from testing and diagnosis, to helping to improve quality of life for people living beyond cancer.

As we start planning for the new year, we want to hear your opinions about Mac Voice, and some of the other ways that we communicate with Macmillan professionals. What do you find most useful or interesting? What could we do better? If you would like to have a say in how we develop Mac Voice for the future, please complete our five-minute survey by going to surveymonkey.co.uk/r/MacVoice, with the chance to win one of two fantastic prizes.

Lastly, I would like to thank two of our editorial board members, Debbie Proven and Maxine Astley-Pepper, who are now stepping down. We are very grateful for all their ideas, comments and contributions over several years.

Rachel Hunter
Managing Editor
News

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Building the future together

Macmillan Workforce Advisor Nikki Cannon on the next steps in Macmillan’s new five-year strategy.

More people are living with cancer than ever before, and more than half of people diagnosed in the UK now survive cancer. Macmillan believes everyone should have access to the support that’s right for them, but this is not the reality for the 2.5 million people living with cancer today.

We know that cancer affects so much more than a person’s health. And we already help thousands of people with the emotional, practical and financial impact of cancer on their lives. But many more people need our support.

Over the past few years we have built a better understanding of when people need us most and why they need us. But we know too many people are missing out on our help because they don’t know who we are or don’t feel that we are relevant to them. Our new strategy sets out what we will do over the next five years to work towards our aim of helping everyone with cancer live life as fully as they can.

Support from diagnosis

Many people don’t know that Macmillan can help them when they are first diagnosed, and throughout the whole cancer pathway. This means people are missing out on vital information and support when they find out they have cancer. To raise awareness of the support that Macmillan can offer from the point of diagnosis, we will:

- extend the opening hours of our Support Line to 8am-8pm, seven days a week
- work with health professionals so that they understand how Macmillan can help the people they are caring for
- improve how we engage with and support Macmillan professionals, including developing new resources
- use advertising and marketing campaigns to reach more people diagnosed with cancer
- invest in technology to provide a greater variety of ways to contact us.

Addressing vital needs

Beyond the healthcare support in hospital, thousands of people have no one to talk to about their needs and don’t know who can help. We want everyone to have a conversation about all their needs and concerns, and to have these met by high quality services. To support this, we will:

- fund more than 1,500 new roles in hospitals and local communities
- bring together the different types of financial support we provide so that people can get this help seamlessly
- demonstrate excellent end of life support through 13 high standard services and spread best practice across the UK
- develop new services for people’s practical and emotional needs, working with experts in mental health and social care.

Living longer with cancer

Improvements in treatment mean more and more people are living with cancer that is not curable. These people face uncertainty every day and have a range of needs which can change from scan to scan. We want to help them get support that’s right for them by:

- supporting professionals to have more conversations about someone’s ongoing and changing needs, including how to live and die well
- build our understanding of what people with treatable but not curable cancer experience and use this to influence governments and the NHS
- develop services that help people identify and talk about their needs while living with incurable cancer.

You can watch a video of Macmillan’s Executive Strategy Team talking about our future direction at this year’s Professionals Conference at macmillan.org.uk/professionalsconference
Macmillan research shows ticking time bomb for Wales cancer nursing workforce.

Macmillan Wales has warned that high vacancy rates, combined with an older average age workforce, means the Welsh cancer nursing workforce is in danger of becoming unsustainable. This is especially worrying against a backdrop of growing numbers of people living with cancer, with more than 19,000 people being diagnosed in Wales every year.

The Cancer Workforce in Wales census reveals that the number of whole time equivalent posts for breast cancer nursing have dropped by 14% since 2014. Vacancy rates among specialist cancer nurses also appear to have increased since the previous census in 2014.

Richard Pugh, Macmillan Head of Services in Wales, said, ‘Our census highlights real areas of concern including varied numbers of specialty cancer nurses per new cancer diagnosis, high vacancy rates and the fact that 4 in 10 of our specialist cancer nurses are aged 50 or over, and so many could retire in the next decade.

‘However, it is pleasing that the number of specialist cancer nursing posts has increased by more than a third since 2014, as we know from the previous Wales Cancer Patient Experience Surveys that having a clinical nurse specialist has a significantly positive impact on patient experience.

‘We want the Welsh Government, health boards and Velindre NHS Trust, and the newly-formed Health Education and Improvement Wales, to analyse the census results to inform their plans and address the clear challenges it highlights urgently. That way we can ensure Wales has a skilled, sustainable cancer care workforce to support our growing number of people living with cancer and their often-complex needs.’

The census was completed by all lead cancer nurses working in Wales’s health boards and Velindre NHS Trust to describe the workforce on 9 October last year. It included a wider range of roles compared to the previous census, covering cancer support workers, specialist chemotherapy nurses and specialist palliative care nurses working in cancer.

To read the full results of the census, visit macmillan.org.uk/wales-census
What’s coming up?

January
Dry January
[alcoholconcern.org.uk](http://alcoholconcern.org.uk)

Cervical Cancer Prevention Week
21-27 January
[jostrust.org.uk](http://jostrust.org.uk)

February
World Cancer Day
4 February
[worldcancerday.org](http://worldcancerday.org)

Cancer Research UK Early Diagnosis Research Conference
12-13 February
[cancerresearchuk.org](http://cancerresearchuk.org)

March
Ovarian Cancer Awareness Month
[targetovariancancer.org.uk](http://targetovariancancer.org.uk)

Prostate Cancer Awareness Month
[prostatecanceruk.org](http://prostatecanceruk.org)

Radiotherapy gets 360° treatment

A new immersive video marks a first for Macmillan.

A new video produced by Macmillan in partnership with Fujitsu and Mount Vernon Cancer Centre features Jerry, a person living with mouth cancer. Jerry visits Mount Vernon Cancer Centre and walks through what happens during radiotherapy treatment for head and neck cancer.

In the video, Jerry talks about his own cancer experience and narrates as the viewer watches the mask moulding, CT scan and radiotherapy treatment processes in a 360° format.

With 360° videos, a view in every direction is recorded at the same time using specialist cameras. This innovative technology is helping Macmillan to meet the information and support needs of people with head and neck cancer in a new way.

The viewer has control of the viewing direction, and the immersive experience allows people to explore a treatment environment from the comfort of their own home. The video can be viewed on a smartphone or laptop (using Chrome), or using a specialist virtual reality headset.

The video was created with guidance from subject matter experts and people affected by cancer. Radiotherapy treatment was chosen as its immersive nature lends itself to the 360° format.

For many undergoing radiotherapy treatment, this is an especially difficult time. This video shows the radiotherapy process to help reassure and prepare people for the treatment.

You can watch the full video at [bit.ly/2OxgJl](http://bit.ly/2OxgJl)
Implementing guidelines in Northern Ireland

The latest advice to support rehabilitation for people with metastatic spinal cord compression.

An education programme has been rolled out across Northern Ireland to introduce community practitioners to new guidelines for the rehabilitation of patients with metastatic spinal cord compression (MSCC).

The guidelines, published in May 2017, provide the best available evidence-based practice for occupational therapists and physiotherapists in the assessment, treatment and rehabilitation of patients living with MSCC in the community. MSCC occurs in approximately 5% of patients with advanced cancer. It is due to metastatic spread or direct extension of malignancy causing compression of the spinal cord or cauda equina by direct pressure and/or vertebral instability or collapse, and so threatening or causing neurological disability. The guidance aims to raise awareness among practitioners of patients who may be at risk of developing MSCC, and also to:

• Provide clarity on ‘red flag’ signs and symptoms requiring urgent medical management

• Provide guidance on a pathway to access urgent medical assessment and investigation

• Promote clinical vigilance as early identification of suspected MSCC is crucial in minimising disability and optimising quality of life (QOL)

• Educate the wider multidisciplinary team in referral, diagnosis, assessment, treatment, clinical vigilance and rehabilitation of this patient group.

The document highlights the importance of managing the expectations of the patient and their family throughout the assessment and treatment process, given the impact of this life-limiting diagnosis and subsequent levels of disability.

Practitioners are encouraged to communicate with the person and their family in an open and sensitive manner. It is essential that there is co-ordinated team work with all community staff involved in the person’s care. Occupational therapists and physiotherapists should work as part of a multidisciplinary team, delivering interventions and optimising physical and psychological functioning, while supporting patients and their families as they cope with the effects of advancing disease.

When end of life has been recognised and is approaching, the person’s needs should be reviewed, and goals of intervention modified appropriately. It may not be feasible to continue active rehabilitation and comfort will be the overriding and acceptable goal.

It is important to acknowledge the role of, and need for, peer support, as well as the benefits of reflective practice for those staff working with this particular patient group.

The guidelines and evidence table are available via the Regulation and Quality Improvement Authority’s website at rqia.org.uk.

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Further information
The Macmillan Professionals Excellence Awards 2018

The Macmillan Professionals Excellence Awards provides an opportunity to recognise and thank teams and individuals who are delivering the highest standards of care for people living with cancer. Whether they are demonstrating innovation, collaborative working or improving standards, our winners were all nominated by their colleagues, and selected after presenting their work to our specialist awards panel.

The winners were announced on 8 November at an awards ceremony hosted by multi-award-winning journalist and broadcaster Victoria Derbyshire.

To find out more about their work, visit macmillan.org.uk/professionalsawards

Innovation Excellence Award winners
Innovators who are driving new initiatives, products and services to help shape the future of cancer care.

Macmillan Cancer Care Development Project
South West Ambulance Service NHS Foundation Trust

The South West Ambulance Service NHS Foundation Trust and Macmillan have come together to promote best practice in cancer, palliative and end of life care for patients who access emergency care by calling 999. The team have developed systems and protocols to provide ambulance clinicians with specialist advice while on scene. This ensures people with cancer receive the right care in the right place at the right time.

Macmillan Geriatric Oncology Liaison Development Team (GOLD)
Guys and St Thomas’ NHS Foundation Trust

The Macmillan GOLD service was created to optimise older patients’ health before and during treatment. By combining care of the elderly and oncology services, the team is supporting oncologists to significantly improve outcomes for older patients. Before, during or after treatment, older patients visit the GOLD clinic for a comprehensive health screening with an advanced nurse practitioner and full medical assessment with a geriatrician.

Macmillan GI Specialist Nursing and Dietetics Team
Northern Health and Social Care Trust, Northern Ireland

The GI Specialist Nursing and Dietetics Team was established to fill a huge gap in the provision of care for people with GI cancers. The multidisciplinary team has dramatically enhanced the level of person-centred support available and includes specialist nurses and dietitians who work collaboratively to prevent dramatic pre-operative weight loss, boost post-operative outcomes and support self-management. The team offers a pre-diagnosis advice and support service, and completes a screening holistic needs assessment at diagnosis, as well as providing bespoke dietetic support.

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Tracey Ellis
Macmillan Consultant Radiographer
Lancashire Teaching Hospitals

In Lancashire and South Cumbria, a shortage of consultant oncologists meant many people with prostate cancer were opting for surgery without waiting to discuss radiotherapy. To re-introduce real choice for patients, Tracey took on the new post of Macmillan Consultant Radiographer. As a highly-experienced radiographer, Tracey can see patients more quickly and offer support through evening clinics, holistic needs assessments and individualised care plans. She has created a truly patient-centred service.

Tracey also been selected as a Macmillan Fellow for her outstanding achievements. As a Fellow, Tracey can access a grant of up to £10,000 to continue improving services.

Integration Excellence Award winners
Developers of integrated services that have greatly improved patient experiences and outcomes.

Bolton Macmillan Cancer Information and Support Service
Bolton Hospice

In 2014, the Bolton People Affected by Cancer user involvement group teamed up with Macmillan, Bolton Hospice and NHS Bolton Clinical Commissioning Group to co-develop the Bolton Macmillan Cancer Information and Support Service. This exemplary patient-centred service now operates from three beautiful centres in prime locations across the town and provides life-changing practical, emotional and financial support. Anyone in Bolton can now access a comprehensive array of the very best cancer support, from benefits advice to walking groups.

Clinical Psychology Cancer Service
Sherwood Forest Hospitals NHS Foundation Trust and Nottinghamshire Healthcare NHS Foundation Trust

The Clinical Psychology Cancer Service has integrated excellent psychological support across all cancer teams at King’s Mill Hospital in Nottinghamshire. The service model emphasises the importance of healthcare staff routinely screening patients for symptoms of psychological distress, and building strong working relationships with multidisciplinary cancer teams and local commissioners to successfully embed psychological provision. The team have developed some innovative psychological support initiatives, including a text support relapse prevention package called ‘Flo’ to help patients monitor and self-manage emotional difficulties outside of service hours.

Macmillan Advanced Communication Team
Western Health and Social Care Trust, Northern Ireland

Sensitive, effective communications skills are particularly important for professionals who deliver significant news to patients. The Macmillan Advanced Communication Team have integrated specialist training courses across Northern Ireland for healthcare staff to develop these critical skills. The training is highly experiential and takes place in small groups, where participants can practice difficult conversations through role play with actors.
As the only primary care nurse facilitator in Cornwall, Judy has enabled more joined-up working between primary and secondary care colleagues to support people with cancer. She has made a palpable difference to the patient experience through numerous impressive initiatives using her influence to shape strategy at high levels and effect change.

Lesley set out to transform head and neck cancer outpatient services in Tayside, which were being delivered through a medical-led model of care that did not take full account of peoples’ holistic needs. Working with the University of Dundee, she led a co-design project, which resulted in the implementation of holistic needs assessments, treatment summaries and a health and wellbeing clinic. Patients are now able to alternate medical-led outpatient clinics with a patient-led follow-up clinic.

People with hepatobiliary and pancreatic cancer often suffer from significant weight and muscle loss at diagnosis. These issues can lead to high complication rates and poor outcomes after surgery. The Macmillan Prehabilitation Team have implemented a prehabilitation programme to help make patients fitter, and better prepared for surgery and post-surgical treatment. The team empowers patients to take responsibility for their own care by providing tailored diet and exercise plans, rapid access to their clinic, telephone support and the opportunity to attend a gym.

To better meet the needs of people with gliomas, the Surgical Neuro-Oncology Team at Addenbrooke’s Hospital have reconfigured their service so that peoples with favourable long-term prognoses are now followed up in a nurse-led telephone clinic. This has freed-up more slots in the consultant-led outpatient clinic for high grade glioma patients and those with secondary brain tumours. The telephone clinic has negated the need for hospital appointments, reduced waiting times in the consultant-led clinic, and dramatically improved the patient experience.
The Christie Macmillan Secondary Breast Care Nursing Team
The Christie Hospital, Manchester

Unlike patients with primary breast cancer, those with metastatic disease may have a limited support structure. The Macmillan Secondary Breast Care Nursing Team recognised this disparity, and have established a clear pathway of support for people with secondary breast cancer. This includes a holistic needs assessment for newly-diagnosed patients with bespoke information and support, follow-up care through telephone clinics and health and wellbeing events and immediate re-access to the service when needed. Face-to-face support is available for people with complex physical or psychological needs.

Lifetime Achievement Award winner
This prestigious award recognises one individual's tireless and inventive contribution to the development of cancer care over the course of their career.

Lorraine McDonald
Macmillan Partnership Manager, North Yorkshire

As a Macmillan partnership manager since 2004, Lorraine has been responsible for an extraordinary range of developments during her time in post, including 294 new posts and 160 new services. She has appointed 408 new professionals and overseen the investment of a staggering £11.85 million. With a passion for improving the lives of people with cancer that was cemented during her 15 years as a Macmillan nurse, she is a remarkable ambassador for our organisation. With plans to retire next year, Lorraine will be sorely missed, but her exceptional legacy will be felt for generations to come.

For more information about all our winners, plus how to nominate a Macmillan professional for next year, visit [macmillan.org.uk/professionalsawards](http://macmillan.org.uk/professionalsawards)
Q&A: Peter Armstrong

Job title
Macmillan Palliative Care Service Improvement Pharmacist

Location
Mater Hospital, Belfast

In post
Since 2016

Contact
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How did your professional background lead to this role?
My background is in hospital pharmacy. I studied in Manchester and stayed on in the city working in Central Manchester Healthcare Trust. Before returning to Northern Ireland, I worked as a locum pharmacist in a few rural locations in Australia. Prior to my role now, I was the specialist palliative care pharmacist at the Marie Curie Hospice, Belfast and in Belfast City Hospital. As a palliative care pharmacist, I focus on people with any life-limiting illness for example heart failure, motor-neurone and Parkinson’s disease, as well as cancer. Seeing first-hand the benefits that good palliative care provides for patients and their families has given me the skills and confidence to take forward into my current role.
How did your role come about?
As part of a Northern Ireland-wide programme called Transforming Your Palliative and End of Life Care, pharmacy was identified as an area to be developed under the initiative. Macmillan is funding and providing ongoing support for a Pharmacy Service Improvement project. I lead a team of pharmacists in each of the five locality areas in Northern Ireland. Together we work on the project’s four main objectives, which are improving access to palliative medicines, facilitating hospital discharges to ensure continuity of care, promoting anticipatory prescribing at the end of life and education and training.

What does your day-to-day job entail?
I could be out providing training, promoting the project and the role of the pharmacist in palliative care or linking in with the team on our various work streams. Currently we are developing a palliative care resource pack for community and GP practice-based pharmacists, which will include guidance on all aspects of palliative care medication, tips on dealing with palliative prescriptions and signposting patients to other services, such as the Macmillan services. We are also running a series of training roadshows for pharmacists across Northern Ireland to promote good palliative and end of life care.

Another work stream is a pilot of ‘Just in Case’ boxes, which are designed to hold medicines that might be needed at the end of life, and are placed in the person’s home ahead of this time. We hope that they will reduce delays in prescribing and accessing medication.

How would you like to see the role of pharmacy develop within cancer care?
The goal is for all community and hospital pharmacists to have a good working knowledge of general palliative care that gives them the confidence to deal effectively with people who have palliative care needs, and the complex medication that can be involved. I would like to see greater links between community pharmacy and the wider healthcare team, especially after people have been discharged from hospital. Greater numbers of people with increasingly complex palliative care needs are being treated in their own homes, and often community pharmacists lack basic information about medication changes, plans for treatment or who to contact for any medication queries.

By promoting the ways that pharmacists can contribute to the health and wellbeing of people with palliative care needs, I hope to see pharmacists become core members of the palliative care team in all settings.

What is your biggest challenge?
With over 500 community pharmacies across Northern Ireland it has been a challenge to engage with them all, and unfortunately many community pharmacists don’t get the protected training time that other professionals do to access appropriate training, resources and advice around palliative care. To combat this, we are using the innovative Project ECHO. This videoconferencing model connects palliative care specialists in Belfast with a network of community pharmacists all around Northern Ireland, providing a forum for learning.

What is your proudest achievement?
I think seeing everything the team has worked for over the past 18 months start to come together. The guidance on symptom control at the end of life and information on how to access palliative medicines in the community is one of the best things to come out of the project. It is very rewarding to help people get the best care possible in their own homes at the end of life.

What does being a Macmillan professional mean to you?
It is a real privilege to be a Macmillan professional and have access to all the training resources and guidance. Macmillan Learning and Development grants have enabled me to attend conferences and promote our work through poster and oral presentations, and the support, guidance and mentorship from the Macmillan team in Northern Ireland has been crucial to the success of the project.

For pharmaceutical guidance on palliative and end of life care, visit bit.ly/2PDZczy

It is very rewarding to help people get the best care possible

macmillan.org.uk/macvoice
Supporting health and wellbeing in local schools

Cornwall Council’s School Workforce Health and Wellbeing Coordinator Karen Keast describes a growing project to promote health and wellbeing in schools.

The School Workforce Health and Wellbeing Project (SWHW) was commissioned in 2014 to promote employee health and wellbeing in schools across Cornwall.

We provide support, resources and training to help anyone in the school community affected by cancer. This might be supporting a member of staff directly, helping staff have difficult conversations or enabling staff to feel more confident to support children affected by cancer and their families.

The SWHW project works with schools to introduce an employee wellbeing programme. This engagement begins with training a health and wellbeing champion, who voluntarily supports health awareness campaigns and introduces wellbeing initiatives for their peers, using support, training and resources provided by the project.

As part of the training, all champions undertake the Royal Society of Public Health Level 2 exam in Understanding Health Improvement, which adds to their continuing professional development and boosts their knowledge in wider health improvement. A total of 231 health and wellbeing champions have been trained to date, with a further 20 schools due to get training in the new academic year 2018-19.

These champions are able to provide Macmillan Difficult Conversations training to staff, and can introduce Macmillan’s Work and Cancer toolkit and Teaching Toolkits. They have also provided a range of wellbeing events, including spa days, mindfulness and relaxation sessions and team building events to boost morale in what can be a highly stressful career.
SWHW has had its funding extended by Macmillan, Cornwall Council and Public Health England until 2019, and now has 146 engaged schools.

In 2017, we set out to engage specifically with staff working in Special Schools and Alternative Provision Academies (APAs), who support children and young people with very complex needs. All Special Schools and APAs in the county have engaged with the project, with 25 champions trained between them.

Project plans are set annually to ensure we continue to provide the right levels of support and identify new opportunities in the wider community to engage employees in their own health and wellbeing. In 2018, we developed bespoke training for multi-academy trusts (MATs), which are single organisations with overarching responsibility for the governance of a group of schools. This approach enables more schools to access support based on one training session. As a result, eight MATs, comprising 81 schools, have joined the project. Another three MATs comprising 23 schools await training in 2019.

Dedicated support
The SWHW project has a dedicated website providing information, advice, help and signposting to numerous wellbeing support services. This has had over 16,000 unique visitors and over 371,000 page views since it was launched in 2014.

The most frequently accessed online support includes an events calendar with links to national health campaigns and resources to support them, dedicated sections such as support for headteachers and mangers, women’s and men’s health, healthy eating, physical activity, dementia awareness, mental wellbeing, cancer support and volunteering opportunities.

An annual Health and Wellbeing Conference is also provided for all champions. In the past two years the conference has enabled more than 160 champions to expand their awareness and complete more training and workshops to support employees with a range of health and wellbeing issues.

Macmillan referrals
A unique element of the project has been the ability to make referrals for specific cancer support for children and their families. When the Cove Macmillan Support Centre opened in Truro, we made sure that the team were familiar with the project and now keep in regular contact.

We developed a referral system that allows the Cove team to refer to the SWHW project if the person they are supporting has concerns about their children while at school. We can then ensure that the school their children attend has all the support and resources they need to be able to support them well, and are aware of the ongoing stresses the children may be under. We also offer dedicated support for staff to make sure they feel confident to have a difficult conversation with young children.

The SWHW project continues to go from strength to strength and is looking to expand the support offered from local schools into the local council and other public service teams. We have recently trained more than 70 champions within Cornwall Council and are currently developing the programme for Cornwall Fire and Rescue Service. Our aim is to ensure the local working community are happy and healthy at work, and able to support peers and families with confidence.

Further information

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macmillan.org.uk/macvoice
Talking about death and dying with children

Macmillan Palliative Care Nurse Consultant Dawn Orr on raising awareness of Dying Matters with local school children.

Following Dying Matters Week in May, the Queen Elizabeth Hospital in Gateshead has forged new links with a local secondary school to help break the taboo of talking about death and dying with children.

The initiative aims to encourage young people to talk about death and support each other when their family members, teachers or school friends are faced with a terminal illness.

Macmillan nurses from the Queen Elizabeth Hospital and St Bede’s In-Patient Palliative Care Unit initially met with staff at Cardinal Hume Catholic School to look at how we can support and raise awareness with pupils and staff about the Dying Matters project.

The project is all about getting young people to talk more openly about death and dying, which is a very challenging thing for anyone to face, let alone a young person.

We decided to run a special Macmillan day at the school, with the help of Michelle Henderson, Macmillan End of Life Care Facilitator, and Liz Lough, Ward Manager of the St Bede’s Unit. The idea was to provide an opportunity for pupils and staff to speak to the staff and ask questions, and a market place stall was set up with information to read and leaflets to take away.

We hoped to raise awareness of the importance of talking and sharing with others. All the pupils were made aware of the nurses being in school through their teachers, and as a result the stall was overrun with pupils wanting to speak to Michelle and Liz, putting a question bubble on their board and taking away Macmillan pens and other gifts to give to people in their families.

‘The responses were overwhelming and showed that children do want to be involved in these conversations’

Michelle Henderson
Macmillan End of Life Care Facilitator

Jo Proctor, Lay Chaplain at Cardinal Hume Catholic School says, ‘I admit I was a little apprehensive as to how this would be received by our pupils. But thanks to the amazing work and personalities of the team, I was blown away by the stall’s success. We are very grateful that Michelle and Liz gave up their time to come into our school and help us with such a difficult challenge.

‘I feel that this is only the beginning of our links with the Queen Elizabeth Hospital and I am very excited about how we can all work together in the future. As a result of this event, we now have some of our sixth form pupils volunteering in the hospital as they are looking towards a career in

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medicine or care. This is just a small way that our pupils can support and give back to our local community and we will very much continue to encourage this in years to come.

The Specialist Palliative Care Team at St Bede’s In-Patient Palliative Care Unit are keen to encourage young volunteers. Although it is often thought that young volunteers are too immature to work in such environments, recent studies have shown that both students and the very ill can benefit greatly from this collaboration.

We hope that another myth, that we should not talk to children regarding death, dying and bereavement, has been addressed by this project. It has helped to change the way that teachers and children think and actively encouraged young volunteers to apply to the Queen Elizabeth Hospital for volunteering and work experience placements.

During the Macmillan day, our nurses asked what the children thought about three important questions:

1. Should children be involved in discussions about death, dying and bereavement?
2. What would you say or do for someone who had just lost somebody?
3. What would you want somebody to say or do for you if you had just lost somebody?

Macmillan End of Life Care Facilitator Michelle Henderson says, ‘What a fantastic day the Specialist Palliative Care Team had at Cardinal Hume Catholic School. It was such a privilege to speak to the children and get their views. The responses were overwhelming and showed that children do want to be involved in these conversations and need to be.’

Further information

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Supporting people to find a ‘new normal’

Macmillan Health & Wellbeing Programme Manager Janet O’Brien reports on the outcomes of a two-year health and wellbeing pilot programme.

The National Cancer Survivorship Initiative has acknowledged that the traditional clinician-led, out-patient-based model of follow-up care is not the best way to help recovery following cancer treatment. It is recognised that when treatment stops, support to return to a ‘new normal’ needs to be improved.

In response to this, Macmillan funded a two-year pilot in February 2016 for a health and wellbeing programme at Harrogate and District NHS Foundation Trust. The programme offered an alternative model of follow-up care that was patient-led and focused on recovery and health and wellbeing, both physical and psychological. It was based on individual patient needs and preferences with the appropriate clinical assessment, support and treatment.

During the two years, the programme delivered events to more than 500 people. Initially it was offered to people who had received treatment for breast or colorectal cancer. It was then extended to other cancer sites including skin, prostate and gynaecology. A programme was also developed to provide support to patients with a palliative diagnosis. Engaging all members of the multidisciplinary teams is essential when embarking on such change.

The content of the programme covered topics such as the cancer journey, managing the consequences of treatment and raising awareness of symptoms for the future. Healthy lifestyle tips, welfare, benefits and travel insurance information were provided as well as signposting to community services. Patients were also given free access to a Pilates-based exercise programme, focusing on the physical side effects of treatment.

Participation was encouraged, sharing knowledge and experiences within a welcoming and safe environment. This informal setting was shown to have positive benefits, with many people reporting that they felt reassured they were not alone. Time was available at the end of the event for people who had individual concerns to speak privately with the programme manager. Where necessary, referrals to supportive services such as complementary therapy or clinical psychology were also arranged.

Half of the people who attended the programme were able to follow a self-management pathway instead of traditional clinician follow-up. For breast cancer patients, a ‘risk stratified pathway’ based on the Nottingham Prognostic Index was used to determine future follow-up. Working with the radiology department, we created a more efficient block booking system for future mammograms. This change will save more than 1,500 clinic appointments over five years.

A telephone audit of patients was conducted a year after attending the programme. All were aware of the route back to services if needed. People gave positive accounts of the impact of attending, including lifestyle changes they had made and sustained, such as increased physical activity and better weight management.

A copy of the full report is available on request.
Taking part in a health and wellbeing event

Senior Radiographer Michelle Shirto on attending a workshop run by the Macmillan Next Steps Cancer Rehabilitation team in Gloucestershire.

For more than two years, the Macmillan Next Steps Cancer Rehabilitation team in Gloucestershire has delivered free, three-hour group health and wellbeing events two to three times a month at various community venues throughout the county.

Their Take Control Health and Wellbeing Clinics are run by a group of cancer specialists comprising a therapeutic radiographer, dietitian, physiotherapists and healthy lifestyle specialists.

Earlier this year, I attended a workshop run by a dietitian who facilitates eating, exercise and relaxation workshops, and one of the healthy lifestyle specialists who run sessions for people experiencing depression and anxiety. I was keen to gain a better understanding of the impact that living with and beyond cancer has on people's lives. Being a radiotherapist, I only see people on a one-to-one basis. So to hear people talking together about their experiences was so enlightening.

The group I was with was very small and friendly. There were five people there and I was the sixth, but initially they didn't know I was there as an observer. To begin with we all sat down and enjoyed healthy snacks together. We had apples and oat cakes, which made a change from chocolate biscuits and was a good way of breaking the ice.

Then everybody took it in turns to introduce themselves. They could say as much or as little about themselves as they felt comfortable with, but everybody did open up and talk about their cancer diagnosis and what stage they were at. I think that because it was such a small group, everybody felt quite safe to do this.

At this point I did explain who I was and asked if they minded me being there. They all said 'no'. I asked them how it felt to meet people outside of a waiting room, and the overriding response from the group was that they found it reassuring to know they were not on their own and could share experiences quite openly.

The Take Control sessions are small, friendly groups where people living with and beyond cancer are equipped with the tools and coping strategies they need to enhance and maintain their health and wellbeing.

This particular workshop was the initial session that patients go to after their treatment. It dealt with everything a person might be experiencing, such as problems with sleep, anxiety and fears for the future. We talked about coping strategies for fatigue and the importance of maintaining a healthy diet and active lifestyle. It was also an opportunity to signpost people to individual follow-up sessions where clinical specialists can use their expertise to help with their particular issues.

As a professional it was helpful to gain an insight into this bridge between the hospital and the community, and to find out more about where I can signpost people who need this continued care.

Further information

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Developing a new service for metastatic prostate cancer

Macmillan Metastatic Prostate Clinical Nurse Specialist Rebecca Peak marks two years since setting up a new service.

Metastatic prostate cancer is increasingly seen as a chronic disease. Extended life expectancy and greater use of hormonal treatments are resulting in increased demands for supportive therapies and help with managing side effects as part of a holistic approach to continuing care.

The oncology department at St Luke’s Cancer Centre works closely with the urology department at Royal Surrey County Hospital, especially in the area of prostate cancer. I was recruited as the centre’s only metastatic prostate clinical nurse specialist (CNS) in 2016, following recognition of a growing need for a dedicated keyworker for this patient group.

Part of my role was to develop a pathway to co-ordinate service provision and support for people who need follow-up care after treatment, as well as support for patients and families from the time of referral. This included co-ordinating appointments and treatment plans. The pathway has led to reduced consultant clinic list numbers, and improved patient satisfaction and waiting times.

Working with five consultants at St Luke’s department, we have seen increasing numbers of newly-diagnosed metastatic prostate patients referred into the service.

During the past two years I have worked hard to establish two CNS-led clinics, as well as a telephone service, for patients on Abiraterone, Enzalutamide, upfront Docetaxel systemic therapy and Radium 223. Holistic needs assessments are completed with a care plan and referrals to palliative care.

Patients with metastatic prostate cancer have a variety of needs. Most are over the age of 50, but the majority are over 70. Many of these patients have a number of co-morbidities that need to be considered alongside the prostate cancer.

The number of patients surviving for more than 10 years is increasing on a yearly basis, and with significant treatment advances in the past 5 years from the STAMPEDE trial, there are many new treatment options available and more in the pipeline. Whilst this is exciting, it also places a huge demand upon the oncology service.

Challenges

There have been many challenges along the way. As a new member of the team, it was important to shadow and build a trusting rapport with the multidisciplinary team, and with the pharmacy team. This included setting up joint management guidelines to adopt a robust and clear pathway.

Finding clinic space was difficult, while negotiating with other practitioners took its toll. Informatics required a template for assessing new appointment time slots and follow-up time slots, while medical records and a template name for my clinic needed to be agreed. Over time the medical records team were able to pull medical notes for me, ready for clinic.

I also needed to raise awareness with patients about CNS follow up, which had not been available before, and build their confidence in me to help support them through their treatment.

Further information

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References
1. www.stampedetrial.org/
Our service is helping the Trust to meet existing contractual obligations, comply with national guidelines on patient care, contribute to improved one and five-year survival rates in metastatic prostate cancer, and potentially improve the Trust’s results in the national cancer patient experience surveys.

In the past year we have achieved our aims, and continue to evaluate the service on an ongoing basis. We introduced a Living With and Beyond Wellness Day for this patient group in September 2017 and I hope to repeat this on a yearly basis.

As the service continues to grow, it is a privilege to work within this very rewarding and satisfying role. I have also completed my V300 non-medical prescribing course and this has been instrumental in complementing my clinical practice.

Our Trust, alongside local charity The Prostate Project, has funded a new urology centre, which is due to open before the end of the year. This state-of-the-art building will not only provide much-needed additional outpatient clinic rooms, but will also create four dedicated urology treatment rooms.

St Luke’s Cancer Centre has been through a pharmacy refurbishment and new signage has been placed throughout the unit to help patients find their way around. The clinical space and waiting areas are also being improved.

In the future I hope to be able to appoint a care-coordinator and another nurse to help embed and provide quality nursing care and development of the service.

My sincere thanks go to the St Luke’s Oncology Team, Vicki Mumford DHoN and Denine Williams, Outpatient Manager. Not to forget, the overwhelming thanks to my patients.
Helping patients in a different way

Macmillan Survivorship Lead Morven Angus talks about the benefits of being a professional reviewer for Macmillan.

Macmillan’s Cancer Information Development team produces 170 booklets and leaflets and more than 200 cancer drug fact sheets for people affected by cancer. To ensure that the information is accurate and up-to-date, each piece of information is reviewed by a wide range of professional advisers, from surgical oncologists and cancer nurse specialists, to counsellors and benefits advisors.

Macmillan asks professionals to review information tailored to their own specialisms – both clinical and non-clinical. In my recent post as a lead breast clinical nurse specialist, I mainly looked at information about treatment for breast cancer, including breast reconstruction, emotional effects and body image. If I’m asked to review very specific information that is slightly out of my remit, I’ll pass on the details of another colleague who might be able to help.

Reviewing information for Macmillan is a voluntary opportunity, and it can be a challenge to fit into a busy schedule. But I manage to find the time by doing it in chunks, and looking at how much time I have got. There are times where I have had to say no to a review because I have had too much on, but that doesn’t happen often. And when I do agree to review something, I really enjoy it.

How it helps me

Macmillan’s information is all up-to-date and evidence-based. As a professional, I want to know that any information I am giving to patients reflects what is currently happening in practice. Being able to review information for Macmillan helps me to keep my finger on the pulse of what information is out there for my patients, so I can relay that back to my team. Macmillan helps to inform us about what is happening elsewhere, and the cross-working definitely helps. Reviewing patient information sometimes challenges your own ways of thinking about your practice as well, which is good. You might look at information that is quite new and perhaps not something everyone is doing yet, and that sparks conversations with your team.

For revalidation with the Nursing and Midwifery Council, reviewing information evidences that I am doing something additional to support patients, other than my day to day clinical work and job description. I have also talked about my reviewing work in job applications and on my CV as well. It is useful because when talking about the scope of your practice and what you do, you are able to say that you have been involved with organisations outside the NHS and that you support Macmillan. You can add a string to your bow by talking about what you do to help people with cancer in a different way.

Can you help?

We are currently looking for more professional reviewers to contribute to our award-winning information. If you are interested, please email professionalreviewing@macmillan.org.uk

Our professional reviewers are integral to maintaining the accuracy of our information, and are recognised with thanks in our information booklets.

Further information

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In focus: Teenagers and young adults (TYA)

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Making our cancer information age-appropriate

Adolescence is a critical time in a young person's development, from gaining confidence in independent decision-making to taking more responsibility for their own lives.

Young people are also using this time to form their own perceptions of themselves, the people around them and the wider world. They may challenge the boundaries set by adults. Significant personal exploration occurs within this phase, including forging new relationships, discovering sexual awareness and exploring sexual activity.

Being diagnosed with cancer as a young person adds intense stress to this already unique, and sometimes challenging, period of personal development.

Over 2,600 young people are newly diagnosed with cancer each year in the UK, and the number of cases in 15 to 24-year-olds has increased by more than a quarter since the early 1990s. Although the total number accounts for less than 1% of all cancer diagnoses in the UK, it is important to acknowledge that these young people have different and distinct needs.

Information needs

While adult cancers have well known aetiologies and contributing factors, such as environmental causes, cancers that are diagnosed in people below the age of 30 appear to be spontaneous, and are often unrelated to either carcinogens in the environment or any predisposing genetic traits.

For example, carcinogens in the environment (such as tobacco or sunlight) and poor diet can be linked to certain cancers, such as smoking and lung cancer. However, younger people have had less exposure to these factors. Therefore, it is not surprising that these cancers are less common within this age group.

When it comes to making decisions about health and wellbeing, we all want good quality information. This is especially vital for young people, for whom a cancer diagnosis may be much more difficult to understand and the impact harder to comprehend.

Providing a young person with age-appropriate information can help to ensure that their cancer journey is as informed as possible.

At Macmillan, we think this information should be accessible and accurate, but also sensitive to a young person’s feelings of vulnerability at this scary time. That is why our information development team provides separate, tailored information for young people that is:

• written in a way they can understand
• appropriate for their age and maturity
• accessible to them
• considerate of their views and involves them as much as possible in their own health decisions.

Information for young people should also signpost to resources that are appropriate for them.

One of the challenges of editing our information for teenagers and young adults is trying to retain the Macmillan ‘tone of voice’, while making the information accessible and appropriate. The information is aimed at young people aged 16 to 24 years.
This is a wide age span, including school children, people of university age and those already working. Making the content easy to understand and accurate, without being patronising, can be difficult.

One of the ways we try to create a softer tone is through using contractions, for example ‘I’m’ rather than ‘I am’. We avoid contractions in our general information for people affected by cancer, as they can sound vague, and may be difficult to understand if English is not your first language.

Using them appropriately in our information for teenagers and young adults can help to reflect the kind of information that most young people are used to accessing, making the content more inviting, and less intimidating.

We also try to stick to the key information, and signpost out to more detail in our wider information. We don’t want to overwhelm young people, particularly when talking about sensitive and possibly frightening topics.

We also use videos and animations within the content to try and make it more appealing to people in this age group.

‘If Macmillan’s leaflets and online information hadn’t been there, I wouldn’t have known what to expect.’

Amrik, diagnosed with Hodgkin’s lymphoma.

Where to find it
Macmillan’s information for teenagers and young adults is on the Macmillan website, and sits in a separate part of the website under ‘How can we help you today?’. We also signpost to it from other relevant sections of the main website, which is often a starting point for young people looking for information.

The TYA section includes pages that are similar to our general content, but have been specially amended. This includes information on the most common cancer types, tests and scans, treatments, sex and fertility and life after cancer. We also have videos available on our YouTube channel that are aimed at a younger audience, including animations that explain PICC and central line procedures.

Young people who are affected by cancer can also join Macmillan’s Online Community to share their experiences with other young people and find support. Visit community.macmillan.org.uk.

Further information

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Amrik found Macmillan’s information helpful after being diagnosed with cancer.
I was appointed in March 2015 to develop Macmillan's East Midlands cancer survivorship service for teenage and young adult (TYA) patients aged 18-25. The service covers one principle treatment centre across two trusts, Nottingham City Hospital and Leicester Royal Infirmary, with an additional five designated hospitals in the region.

Our initial focus was to address how, when and why young people were going to be supported. We set up survivorship pathways to ensure all patients were referred to the service on completion of treatment – around 75 young people each year.

They are supported by our survivorship clinics that we have established in each site, as well as telephone clinics for those treated by the designated hospitals. Young people are supported for the duration of their medical follow up, often five years, depending on their needs.

The main objective of my role was to deliver the three elements of the Macmillan recovery package, holistic needs assessments (HNAs), wellbeing events and treatment summaries. All support through the clinics is based on completion of an HNA. Currently patients are assessed using both the Macmillan HNA and the more age-specific integrated assessment map (IAM)1.

Delivering treatment summaries for young people with different tumour types has been challenging. However, feedback from young people who have received a treatment summary have found the document very useful, both in understanding the potential of late effects and how to look after themselves in the future. It has also been helpful in circumstances such as employment, travelling and opening up conversations with their GP.

Young people often don’t engage with events that cater for the general adult population, so I have delivered a number of different wellbeing groups/events that are age-specific and aim to engage, educate and support young people to self-manage in the future. Young people can also attend wellbeing events delivered annually by the Teenage Cancer Trust.

Prospect, a group for young adults working in collaboration with Nottingham Youth Service, was delivered in 2016-2017 each month for a year, to address topics of interest to young people.

And in 2018, we delivered the Macmillan HOPE course, adapted to suit the young adult population, with a strong focus on anxiety and depression. Lessons learnt from these activities are helping to shape what we will deliver in the future.

Our focus now is to meet the needs highlighted by young people themselves through HNA data collection. What has become evident are the gaps in community services to meet the needs of this population. In order to address this, we have been developing new services and projects with the support of third sector organisations.

For example, a key issue reported frequently by young people is loneliness, which often begins during treatment when normal life and relationships are affected. To support this, the Macmillan One2One Support Project was established in
In 2016, working in partnership with Macmillan, De Montfort University and Self Help UK. The service provides young volunteers who can give emotional peer-to-peer support and companionship, as well as practical support for young people living in Nottinghamshire and Leicester who have disabilities as a result of their diagnosis and treatment. For patients living outside of these counties, the Virtual One2One Support Service is available via telephone.

In 2017, we established Boost, a service to support young people to get back into work or education. This was originally set up in partnership with Leicester College, where patients are supported by the careers team with vocational and educational needs.

Boost Leicester has had 34 referrals and outcomes, including course or university enrolment and supporting young people onto new career paths in line with their post-treatment abilities. Following this success, Boost Nottingham has now been established in partnership with Nottingham College.

We also have a close partnership with the Move charity, which provides bespoke exercise and nutrition support to young people with cancer. In 2018 we facilitated a four-month self-management course to support young people experiencing cancer-related fatigue, with a focus on increasing motivation, exercise, improving sleep hygiene and supporting anxiety and depression using cognitive behavioural therapy and mindfulness.

Through repeated assessments of patients, anecdotal evidence is showing us that delivering a biopsychosocial model can improve clinical outcomes for young people, increase quality of life and independence and therefore reduce the long-term burden on the NHS.

Challenges and rewards
To date, our service has supported 165 patients, but while demand is growing, our capacity to take on new referrals is becoming stretched. Ensuring sustainability has therefore become a priority, alongside addressing other challenges such as lone working and developing a service that meets patients’ needs across a large region.

This year I was awarded second place for the British Journal of Nursing Oncology Nurse of the Year Award, and our work was shortlisted for the 2018 Nursing Times Awards.
An ever-evolving service

Macmillan Clinical Psychologist Emily Betts on providing joined-up support for teenagers and young people across multiple locations.

I have been qualified as a clinical psychologist for four years and a Macmillan professional for two and a half years. As part of my training I did a year-long placement in an adult oncology service, and then my dad was diagnosed with cancer. Being a professional in the field while also being a family member of someone with cancer was a challenge, but also gave me an insight into the particular rewards, and challenges, of working in cancer care.

Working with young people living with cancer has its own specific highlights and difficulties. As part of the Teenage and Young Adults with Cancer team in Oxford, I work with a dedicated multidisciplinary team with input from three charities, Macmillan, Clic Sargent and Teenage Cancer Trust. We provide physical, emotional, psychological, practical and social support to young people aged 16-25 years during any stage of the cancer pathway. We comprise a range of professionals including nurses, a social worker, a youth support co-ordinator, clinical psychologists and a community support worker.

We have dedicated physical spaces for our patients across two hospitals and also provide out-reach support to those visiting our shared care hospitals.

The team strongly believes in offering support and guidance that is appropriate to young people’s needs, which are sometimes different to the needs of children or adults with cancer. We have around 70 newly-diagnosed patients a year, so numbers are small but we get to know our patients and their families really well. While this means we can develop care on a more individual basis, it can be hard as we are a not a 24/7 service. This is particularly difficult if someone receives bad news or we hear a young person has died.

As a Macmillan clinical psychologist, I offer psychological input to patients, families, carers, or anyone affected by the young person’s diagnosis. The TYA team has skills in emotional support but refer patients to me who they feel need additional strategies or techniques to manage how they are coping with the cancer, or anything that may contribute to psychological difficulties while they are in our care.

Some young people may have pre-existing mental health difficulties, so I may liaise with other services to provide them with support. Others just find the adjustment to a serious illness overwhelming and need someone to talk to. Ultimately I see my role as being an additional person who they can share their thoughts, feelings and fears with, and find ways to get through such a life-changing event.

In addition to my clinical work, I have been involved in service development, research, social events, supervision and support of other professionals, and developing TYA psychology services on a national level. I might be on a trip to Alton Towers with a group of patients one day and then be offering psychological therapy the next, because our work is about engaging with these young people and understanding their world. Sometimes that means riding a rollercoaster with them!

As a team we offer a range of social events where they can meet other young people with similar experiences, for example Look Good Feel Better pamper sessions, boys’ nights, bowling etc. I also co-facilitate

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our Patient Panel, which lets our young people help influence service development plans.

Since April 2018, I have piloted an end of treatment psychosocial clinic, which I run jointly with one of our nurses. We recognised that the end of treatment is a pivotal transition in the cancer experience, and felt it was necessary to offer a space for young people to come and discuss any concerns they have.

We offer signposting, information and a follow-up plan, using the Macmillan Holistic Needs Assessment as a discussion tool. So far this has been well received and I will evaluate the clinic in 2019. I am helping to develop a memorial day to remember young people who have died with their families. I am also helping to develop a transition pathway for young people moving between paediatric and adult services, as this is also highlighted as an important stage.

I am very proud to be a part of this service. We are the only principal treatment centre in the country without a designated TYA unit, so we see young people across lots of different hospitals. This can make it difficult to provide joined-up care, and we must be creative to help patients meet other young people.

The various charities involved all have different ways of working and negotiation is often required to ensure we work in the best interests of each patient. Teenagers and young people keep us on our toes, making for some interesting work days and the need to evolve the service all the time to meet their needs.

“Our work is about engaging with young people and understanding their world.”

Dr Emily Betts
Supporting holistic health

Macmillan TYA Counsellor and Wellbeing Specialist Merry Gibbons on supporting young people to thrive, with and after cancer.

As the Teenage and Young Adult (TYA) Counsellor and Wellbeing Specialist at the Royal Surrey County Hospital (RSCH), I work for the TYA Macmillan cancer team running a psychological and holistic wellbeing support service for 18-29-year-olds living with or after cancer.

The Cancer Strategy for England (2015-2020)¹ states that holistic support, including psychological support, should be made available from diagnosis onwards. This is because there is increasing evidence that psychological difficulties experienced by young people are a very significant part of their cancer journey, often impacting their ability to thrive.

Teenagers and young people are at a disadvantage psychologically as their brains are still developing, meaning cognitive functioning is not fully matured. This reduces their coping mechanisms and processing capabilities. Consequently, they are three times more vulnerable than adults to experience psychological distress.

Providing support from the point of diagnosis onwards means the service can play a more preventative role in reducing the risk of early psychological distress such as anxiety or early depression, which can develop into more serious mental health issues later on.

Cancer can disempower a young person very quickly. Therefore, the service aims to support a young person's autonomy by empowering them to better manage their holistic wellbeing independently of their healthcare team or hospital. This way they can regain some control at a time when all can feel out of control.

We offer counselling, including cognitive behavioural therapy, which can support a young person's ability to be more self-compassionate. Counselling provides a safe space for young people to process difficult or traumatic experiences and recognise, explore and understand any difficult beliefs, thoughts or feelings inhibiting their ability to get on with living their life.

It also introduces the different choices available to them in caring for their holistic health, such as sleep hygiene, physical activity, pain management, self-care, complementary therapies and helpful attitudes. This hopefully enables them to go on creating positive changes in their overall wellbeing.

A practical approach

As well as counselling, the service offers more practical tools and techniques to try, such as mindfulness, breath work, relaxation, guided imagery to help reduce symptoms such as anxiety or pain and stress management.

We also signpost to further resources, such as audiobooks, apps and TED talks, to help them build a bespoke toolkit of skills and techniques personal to their needs. Then if they experience a difficult moment like a panic attack, anxious or intrusive thoughts, or symptoms that are distressing for them, they can draw on these tools to better manage that moment or symptom. Young people say that knowing they have this toolkit helps them feel more confident, safer and more in control.

Early next year I will run my first six-week TYA ‘Kindfulness’ course. This approach aims to support young
people to bring mindfulness into their cancer journey, but with a focus on kindness. They learn to cultivate a more compassionate, kind and friendly attitude towards themselves, ultimately learning to be their own best friend.

Many young people I work with initially believe they are responsible for getting cancer, bringing about guilt and shame. Helping young people cultivate an attitude of kindness helps them feel less judgemental and more forgiving towards both themselves and their body.

This year I also wanted to make therapy more accessible to young people who do not wish to use the service. We achieved this by taking therapy out of the therapy room and into the outdoors with a ‘Reboot your confidence’ outdoor pursuits weekend. The feedback was great with many young people leaving their comfort zones and discovering in themselves qualities they didn’t know they had. They described feeling they had achieved something.

I also facilitate relaxation, mindfulness and wellbeing workshops for other hospitals, and try to meet with other TYA counsellors as I believe it’s important to maintain an ongoing exchange of ideas to support developing TYA cancer services throughout the UK.

Macmillan has provided funding for our service for three years, and this stops in March 2019. We hope to continue the service and are working hard to find funding.

Having Macmillan’s support to help establish the service has enabled me to develop it beyond a service that offers psychological support to one that also provides wellbeing support for overall holistic health.

Our young people have so much spirit, creativity, drive, humour, big hearts and so much potential! To honour this means not just providing services to help young people with cancer to survive, but also supporting their ability to thrive with or after cancer. This age group is a real privilege to work with and we couldn’t have done it without Macmillan’s support.

‘Our young people have so much spirit, creativity, drive, humour, big hearts and so much potential!’

Merry Gibbons
Updated

Cancer genetics
MAC11673 (Edition 6)
This booklet is for anyone who is worried, or has been advised, that cancer may run in their family. It explains what we know about this subject, including information about genetic counselling and testing through the NHS, plus advice on living with and reducing a high risk of cancer.

Are you worried about bowel cancer?
MAC12151 (Edition 7)
This leaflet discusses how a person’s genes and family history can affect their risk of developing bowel cancer.

Are you worried about cancer?
MAC12150 (Edition 7)
This leaflet discusses how a person’s genes and family history can affect their risk of developing cancer.

Are you worried about ovarian cancer?
MAC12152 (Edition 7)
This leaflet discusses how a person’s genes and family history can affect their risk of developing ovarian cancer.

Are you worried about breast cancer?
MAC12153 (Edition 7)
This leaflet discusses how a person’s genes and family history can affect their risk of developing breast cancer.

Are you worried about prostate cancer?
MAC12154 (Edition 7)
This leaflet discusses how a person’s genes and family history can affect their risk of developing prostate cancer.

You can order these booklets and leaflets, plus many more, at be.macmillan.org.uk, or call 0800 500 800. To find out more about our full range of information, including audiobooks and easy read, visit macmillan.org.uk

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2 Gobbledygook
3 Illuminations
4 Apathy
5 Outpatient treatment centre
6 Group of musicians
11 Critical examination
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