'Our service means people with sarcomas are being diagnosed earlier'

Johanne Vass
Macmillan Sarcoma Advanced Nurse Practitioner

In focus:
Working as one team
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Home and garden support

An innovative partnership between Macmillan, Volunteer Cornwall and Cornwall Council is improving lives.

The partnership was launched in 2013 with a simple premise:

1. People affected by cancer are referred to Volunteer Cornwall by healthcare professionals, Citizens Advice and other local services.
2. Volunteer Cornwall liaise with Cornwall Council, which arranges for staff to spend a day helping with gardening, simple DIY or other useful tasks around the home.

In 2015, Cornwall Council was named Macmillan’s Corporate Volunteer of the Year for its role in the partnership. Since then the project has continued to grow, with 58 people affected by cancer helped and counting.

One of these people is Pamela. After receiving support she said, ‘It’s been a wonderful day. With thanks to Candy, my Macmillan nurse, people were sent to clear my garden, which had completely overgrown while I was in hospital. I had tackled a bit, but having broken my pelvis I can’t do a lot each day and I was getting quite despondent about it. I do love my garden. A lovely bunch of people came along, all cheery and worked like mad, and they have cut back the brambles, cleared the bushes and done everything I can’t do myself. I’m absolutely delighted.’

Jacqui Hodge, Macmillan Partnership Manager for Devon, Cornwall and the Isles of Scilly, said the partnership is ‘a great project showing innovation and collaboration between a charity, a statutory organisation and a volunteering organisation that leads the work.’

Colum Taylor, Corporate Volunteering Officer at Volunteer Cornwall, believes the work has benefits for everyone involved. Colum said, ‘By engaging in the project, an employer invests in its staff by allowing them out to volunteer and supports Macmillan at the same time. A day of practical help and support to get things more manageable has a big impact on the wellbeing of both volunteers and patients.’

More information
Contact Amanda Nadin, Macmillan Partnership Quality Lead for Devon, Cornwall and the Isles of Scilly at anadin@macmillan.org.uk
In brief

Cancer workforce report
‘Thinking Differently: Macmillan’s vision for the future cancer workforce in England’ is a new policy report. It focuses on issues faced by the NHS in England and outlines five ways in which the cancer workforce could be strengthened. This includes improving career pathways to specialist cancer roles, and enhancing the skills, confidence, and communication of existing staff. Read the report at macmillan.org.uk/documents/policy/thinking-differently.pdf

How does Macmillan produce cancer information?
Have you ever picked up a Macmillan patient information booklet or read our online information and wondered how it is produced? In a new video, members of the Cancer Information Development team explain the processes involved, and volunteer Julia talks about how the information helped her in her cancer journey. To watch the video, visit tinyurl.com/cid-team-video

Join our review panel
We regularly look for opinions from professionals on a range of topics – from the direction of our advertising campaigns to developing tools and resources to support your work. You’re the experts, so we want to know what you think to help us shape our work. If you’re interested in giving input as part of our review panel, please email Denise Etherington at detherington@macmillan.org.uk Participation is optional and you can accept or decline opportunities as you wish. Most reviews are done online and feedback collected through questionnaires.

Safeguarding at Macmillan

Our Safeguarding Team is here for you, Macmillan staff, volunteers and people affected by cancer.

Safeguarding is about protecting children, young people and vulnerable adults from abuse or neglect; either from other people or from themselves. A vulnerable adult is defined as: ‘any individual who may be in a vulnerable circumstance or require additional care and support’.

It is worth remembering that any adult can be vulnerable, or have vulnerable moments. For example, an adult who has led a fully independent life might find that their cancer diagnosis means they can no longer work, and so they find themselves financially vulnerable.

What can the Safeguarding Team offer Macmillan Professionals?
The quick answer is support. Look a little deeper and we start to see the various types of support available. Unlike most staff working directly for Macmillan, you may already have access to safeguarding support through the NHS or your local health body. The Safeguarding Team can take that support the extra mile. With two emergency safeguarding phone numbers, we offer advice, support, and a listening ear from 8am to 8pm, seven days a week and at times when you may not be able to access your usual support. We are happy to talk through the issues and offer advice and reassurance on how to proceed.

Safeguarding and you
Everyone connected to Macmillan has a responsibility for safeguarding. Whether you manage a project or a team, deliver services or have direct contact with volunteers or service users, it is your responsibility to ensure you’re working to best practice and within the law.

Do you work with volunteers? If you have a volunteer network who supports and enhances what you do, what safeguarding training is available to them? We can offer dedicated training specific to their needs, ensuring that their volunteer experience is as happy and as safe as possible without the ‘what if’s’ that can occur.

We all know that looking after ourselves and being prepared in the workplace makes for a healthier, happier working life. If you, or colleagues, are part of networks which would benefit from safeguarding refresher training, please do get in touch. We are happy to come to you to deliver training best suited to your situation.

Come and visit us at the Macmillan Professionals conference in November, where we will be running a stand.

Who are we?
• Neil Morter, Safeguarding & Inclusion Manager
• Christine Riddoch, Deputy Safeguarding & Inclusion Manager
• Al Chester, Safeguarding & Inclusion Officer

More information
Contact us in an emergency on 07595 002 022 or 07793 579 375, seven days a week, 8am to 8pm.
You can also email safeguarding@macmillan.org.uk or follow us on Twitter at @MacmillanSG

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News

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

July
Ethnic Minority Cancer Awareness Month

August
Douglas Macmillan’s birthday
10 August
Find out more about Macmillan’s founder and our history at macmillan.org.uk/about-us/who-we-are

September
Childhood cancer awareness month
Highlighting the vital work of charities such as CLIC Sargent.
Visit clicsargent.org.uk

Lymphatic cancer awareness week
11–17 September
Visit lymphomas.org.uk

World’s Biggest Coffee Morning
29 September
Visit macmillan.org.uk/coffee

Making money one less worry

Have you seen the pocket cards included with this issue of Mac Voice?

As you’ll know, nearly everyone with a cancer will be financially worse off as a direct result of their diagnosis and many will benefit from knowing where to go for support at some stage of their cancer experience.

In this issue of Mac Voice, we’ve included a sample pack of information cards focusing on Macmillan’s financial services. The cards are pocket-size so can be easily be carried around, referred to or shared with your non-Macmillan colleagues.

The cards include information about Macmillan professionals who provide a range of financial services, from energy advice to financial guidance and help accessing welfare and benefits support. They also include quotes from patients who have been supported through financial difficulties.

Related news: new digital service for ‘special rules’ benefits
A new online process will help health professionals support benefit applications for people who are terminally ill.

The Department for Work and Pensions (DWP) is now piloting the service in England, as an alternative to the paper form known as a DS1500. Health professionals have previously needed to sign this form on behalf of someone who wants to claim benefits under the ‘special rules’. These rules apply to certain disability-related benefits and mean that claims of people who are expected to for only live six months or less can be fast-tracked, and paid at a higher rate. Benefits for which these rules apply include Personal Independence Payment and Attendance Allowance, which are for people with care or mobility needs.

The online DS1500 has been designed to complement the current paper version, as an alternative for professionals who may find it quicker to submit the form online. DS1500 forms will still be available in the paper format.

More information
You can order more pocket cards to share with your colleagues at be.macmillan.org.uk
To find out more about the digital DS1500, email Margaret Roffe, Macmillan Financial Support Partnerships Manager, at mroffe@macmillan.org.uk
Supporting outstanding practice

Improvements in cancer services have helped University Hospitals Bristol achieve the top rating from the Care Quality Commission (CQC).

The CQC recently rated University Hospitals Bristol NHS Foundation Trust as ‘Outstanding’. The achievement is even more remarkable because the Trust advanced from ‘Requires Improvement’ to ‘Outstanding’ between two annual inspections – making it the first Trust in the country to achieve such a leap.

Cancer services played an important role in this achievement, including implementation of a Cancer Support Worker role as part of the Macmillan One-to-One Support Programme pilot. Introduction of this role undoubtedly impacted the Trust’s rating for the question, ‘are services at the Trust caring?’

The report highlighted that, ‘staff went out of their way to meet the emotional and physical needs of patients’. The CQC rated the effectiveness of services as ‘outstanding’, commenting that ‘patients had comprehensive assessments of their needs’.

Support from Macmillan has enabled the wider implementation of the Recovery Package, ensuring routine use of holistic needs assessments and regular health and wellbeing events.

Services for young people

While inspectors identified several areas of outstanding practice, work by the Teenager and Young Adult (TYA) cancer service, for 16 to 24-year-olds, was singled out for attention.

Macmillan supported the service by funding two projects: On Target and the IAM Portal.

On Target was funded by Macmillan over four years, and explored the early introduction of strategies to allow young people to transition from cancer patient to survivor. The idea was to help them achieve ‘a life as it would have been lived without the intrusion of cancer, or as the young person decides to recreate it’.

Central was the concept of co-designing solutions with young people themselves and an emphasis on self management. Outcomes included the creation of the ‘Help!’ website (tyahelp.co.uk) which offers emotional support, wellbeing sessions and a work mentoring programme linking to the local Macmillan direct volunteering service.

Work on a TYA-specific holistic needs assessment (the ‘IAM’ or Integrated Assessment Map) led to the IAM Portal Project, which was also funded by Macmillan for two years from May 2015. The portal (tyaiam.co.uk) links the IAM to the resources of the Help! website, to match relevant information to a young person’s own assessment of their needs. A co-design approach enhanced the design and functionality of the IAM, making it available as an app for tablets and smart phones.

After development and evaluation in the South West, the IAM Portal was piloted by the TYA cancer team in the East Midlands. Teenage Cancer Trust, in partnership with Macmillan, will now take it forward for national dissemination.

More information

Contact Professor Mike Stevens, Director, TYA IAM Portal Project at m.stevens@bristol.ac.uk
A space for young people to meet

The East Surrey Macmillan Cancer Support Centre is developing its services for families, in partnership with local charity Jigsaw (South East).

The East Surrey Macmillan Cancer Support Centre was opened last year through a partnership between Macmillan and Surrey and Sussex Healthcare NHS Trust. The modern centre offers a wide range of services and support. Recently it has been working with the charity Jigsaw.

Jigsaw supports children and young people who have a family member with a serious, life-limiting condition. It also provides grief support through local support groups. The charity has partnered with Macmillan since 2012 and can help children affected by cancer at school or at home – offering information, advice and signposting to local professionals and services.

Six young people supported by Jigsaw, aged 10 to 16, met with the manager of the East Surrey Macmillan Cancer Support Centre, Shelagh Sheldrick to find out more about the support the centre offers. You can read their interview with Shelagh in the panel on the next page.
New support groups for young people
As part of their conversation with Shelagh, the young people also discussed the possibility of creating informal support groups at the centre. With thanks to their influence, this has now become a reality, and in March 2017 Jigsaw launched its monthly groups for young people at the centre. The groups take place between 5.30pm and 7.30pm on the last Thursday of every month. They aim to provide:

• an opportunity to meet other young people who have a family member with a life-threatening condition
• a chance to share stories, explore feelings, coping mechanisms, relaxation techniques and more.

To join a session, young people and their parents or carers must be registered with Jigsaw beforehand.

Drop-in sessions for parents and carers
The new support groups complement drop-in sessions the charity has been running for parents and carers at the centre since September 2016. These monthly sessions take place on the first Tuesday of every month from 12.30pm to 2.30pm and aim to provide:

• support to parents or carers facing the loss of a loved one
• advice about managing difficult conversations or making plans for the future and identifying coping strategies
• a chance to meet other parents in an informal, comfortable environment with the option of booking a private appointment with a fully trained member of staff.

Parents and carers do not need to be registered and can just turn up.

More information
Contact the East Surrey Macmillan Cancer Support Centre by calling 01737 304 176 or email informationcentre.sash@nhs.net

Jigsaw supports children and young people across Surrey and parts of West Sussex with a family member who has a life-threatening illness (prognosis up to one year). Call 01342 313 895, email info@jigsaw southeast.org.uk or visit jigsaw southeast.org.uk

What kind of support does the centre offer?
Shelagh: ‘We offer emotional and practical support to the patient, their family and carers and anyone affected by cancer. We can help with practical matters such as finances, travel insurance and work related issues. We also offer complementary therapies at the centre to support wellbeing and relaxation, such as acupuncture, massage and reflexology, as well as group activities such as art, yoga, walking groups and make up sessions. We will support people for as long as is needed. People can just drop in or are referred by their healthcare professional.’

When do most people come here for support?
‘When someone has first been diagnosed, they are relieved to find they can come here and talk to somebody in a safe environment, be themselves and know there is always someone here for them to come back to for support. People come here at all different stages of their cancer journey. Some people don’t come in until they have finished their treatment – that is a common time for people to come to the centre as they often find that is when they need additional support as the structures of treatments are not there anymore and have lots of time to reflect.’

Is the centre aimed at a certain age group?
‘Most services at the centre are for adults (aged 18 years plus), but we are able to welcome young people who are being supported by Jigsaw here. It is a very worrying time for everyone when a parent has a cancer diagnosis so we are thrilled to be able to offer this additional support to young people in partnership with Jigsaw and look forward to welcoming them to the centre.’
How does the rapid access clinic work?
Sarcoma is a rare cancer, diagnosis can be difficult and patients often experience delays in referral to specialist services. There are several reasons for this, including of a lack of knowledge of the disease amongst healthcare professionals and the public. To help improve outcomes, NICE guidelines and the Welsh Sarcoma Standards suggest specialist rapid access, one-stop diagnostic clinics, provided by a specialist MDT (multidisciplinary team) member. Historically and where in place, these clinics have been run by consultant surgeons and radiologists but workload can be high and resources are under pressure. In south west Wales, we felt that the workforce could be utilised differently and that an appropriately trained nurse with the right knowledge, clinical experience and academic background would be able to set up and run the clinic.

In 2011, I piloted a weekly clinic in one health board. This was then rolled it out to a second health board.
board in 2012. GPs refer patients who offered an appointment within the two-week urgent suspected cancer time-frame. At this appointment the patient is clinically assessed by me. If the soft tissue lump is considered suspicious the patient will have an ultrasound and, if indicated, a biopsy with a sarcoma radiology consultant, at the same appointment. This means patients are being referred into specialist services at an early stage and are receiving appropriate investigations and treatment with appropriate clinicians. People are hopefully getting a quicker diagnosis, and they have early, pre-diagnosis information and support from our service.

What led you to pursue this project?
I worked for several years in the Welsh Centre for Burns and Plastic Surgery, on the ward and in a nurse-led pre-assessment clinic, so had experience of nursing patients with sarcoma. When the MDT agreed that a nurse was needed to fulfil the key worker role and to set up the diagnostic clinic, I was keen to be involved.

What were the biggest challenges?
There were expected challenges associated with resources and workload but here in Wales, geography can pose a problem. It is a huge geographical area, some areas are more densely populated than others – there are six counties, eight acute hospitals and many GP practices. To get the message across about the new service and to provide equity for all is challenging. However, probably the biggest challenge at set-up was acceptance. Having a new nurse-led service in a traditionally medical role led to some difficult times with colleagues both nearby and in the wider area. But, with determination, persistence and time to prove the value of the clinic, that has changed.

What has been most rewarding about the clinic?
Knowing that we’ve improved the patient pathway is rewarding. Based on clinical data and patient responses in surveys, we know that experience is better because of the clinic. It’s still early days, our population is small and sarcoma is rare so it takes time to obtain useful clinical data. However, it appears that compared with other studies carried out in the UK, on average, tumours are smaller on presentation when patients come to the diagnostic clinic, suggesting earlier diagnosis. That’s a very positive outcome.

How did it feel to win the Macmillan Innovation Excellence Award?
I was delighted. You think you may be doing a good job but it’s so nice when it is formally recognised. I think sometimes, when you come from a place with a small population and work with a relatively small group of patients, there’s a tendency to imagine your work isn’t valid in the wider context. The award gives some credibility to your work and allows dissemination on a large scale. It’s really good to hear that people elsewhere are interested in replicating your work.

What’s next?
Ultimately, we want to roll this service out to the whole of South Wales, but it takes quite a lot of planning and resources. I will soon have a permanent colleague which is great. We will be developing the nurse service and I will provide in-house training so that the nurse can also work in the diagnostic clinics. We’ll need more resources to provide clinics across Wales and I’m sure the award will help support the case for this. We’ve got plans underway, looking at supportive care programs for people affected by sarcoma in South Wales. It will be done via co-production with us, the university, patients and their carer’s. They will have the opportunity to tell us what they want and need and we will design something based on what they tell us.

What advice would you give to people considering starting a similar project?
You need somebody behind you who believes that it is the right thing to do and that you are capable. If you believe it will improve services and that it is better than the way in which people have been working previously, then I think that can push you on to ensure success.
Cancer during pregnancy

Christine Akilade, Macmillan Expert Information Development Nurse, writes about this difficult and complex situation – and a new booklet to help women facing it.

A diagnosis of cancer during pregnancy is uncommon but as more women have children later in life the incidence is increasing. The most common cancers diagnosed during pregnancy are breast cancer, melanoma, cervical cancer, lymphoma and acute leukaemia.

Delays in diagnosing cancer in pregnancy sometimes occur. Symptoms caused by the cancer may be confused with common changes that can happen to a woman’s body during pregnancy. And, health professionals may be less suspicious of certain symptoms in pregnancy. It is important that pregnant women have their symptoms investigated in the same way as non-pregnant women and according to NICE referral guidelines for suspected cancer (2015).

Making decisions

Pregnancy and cancer are major life-changing events. Women experiencing both of these at the same time deal with distressing and complex factors. They have the anxiety of making decisions about the best treatment for their own health and maintaining the health of their unborn baby. They may also have other children to consider.

Women need to be fully informed of the potential risks to their own health and to the baby’s before making decisions. Their decisions will be unique to them and not only based on the information they are given but also their own beliefs and needs.

It is not usually necessary to end a pregnancy unless a woman makes this choice for herself or her specialist advises her to consider it carefully. This could be, for example, during early pregnancy when a woman has a fast-growing haematological cancer that needs urgent treatment. These are particularly distressing decisions for women to have to make.
Pregnancy Feature

Treatment

There is currently not enough evidence to guide the management of pregnant women with cancer. But the general principle is whenever possible, they should be treated in the same way as non-pregnant women. Treatment decisions depend on the type and stage of cancer and how many weeks pregnant a woman is.

The multidisciplinary team should include an obstetrician, neonatologist and midwife as well as the cancer team. The woman should be fully involved in decision-making with support from her partner or family.

Diagnostic and staging tests should, as far as possible, be carried out as they are in non-pregnant women. It is important to limit the developing baby’s exposure to radiation but this should be balanced with the mother’s well-being. Computed tomography (CT), nuclear bone scans, and positron emission tomography (PET) scans should be avoided through pregnancy.

It may be possible to monitor certain early, slow-growing cancers during pregnancy and delay treatment until after the birth.

Chemotherapy is the most common treatment given in pregnancy. It is avoided in the first trimester but can usually be given safely from the second trimester (14 weeks) onwards.

Women can be reassured that research doesn’t show any more long-term complications in babies born to women who have had chemotherapy than babies whose mothers didn’t have chemotherapy.

Surgery can be carried out anytime, but there is a slightly higher risk of miscarriage during the first trimester so it may be delayed until the second trimester. Surgery with a local anaesthetic can usually be done anytime.

Radiotherapy is usually delayed until after the birth, as it can result in growth problems and birth defects. But, it may be given in an emergency when the site is far from the womb and using lead shielding to protect the baby.

The use of hormonal therapies and most targeted therapy drugs are avoided during pregnancy. Hormonal therapies have a high risk of birth defects and there is limited information about the effect of targeted therapy drugs during pregnancy. Women will see their midwives and obstetricians regularly for pregnancy monitoring. Their midwife will assist them with their birth plan and tell them what to expect if an early delivery is advised. Most women go to full term with their pregnancy and have a normal birth.

Emotional support

During pregnancy, women may experience loss at not having the pregnancy they had anticipated or hoped for. They may feel too much focus is given to treating the cancer and not on them as a pregnant woman. They may also feel anxious about finding time or energy during treatment to bond with their unborn baby.

Specialist nurses and midwives can provide support and expert advice during the pregnancy. Support from other women who have been through a similar experience can be invaluable in helping women feel less alone. Women can also benefit from psychological support from counsellors or a psychologist.

Our new booklet with Mummy’s Star

Macmillan, in partnership with Mummy’s Star, has produced a booklet for women with cancer during pregnancy to provide support and information to help women in this difficult and complex situation. Mummy’s Star is a charity that offers support to women diagnosed with cancer during pregnancy or within a year after the birth. It also supports partners and families. Visit their website mummystar.org for more information.

The booklet features Polly’s story through quotes and photographs of her and her family. Polly was diagnosed with breast cancer when she was about 12 weeks pregnant and had surgery and chemotherapy.

Looking back, she now says, ‘I can’t believe Alfie is nearly four and I will be celebrating my 40th next month. One thing I have learnt along my journey is be grateful for the simple things in life.’

You and the people you support can order copies of Cancer during pregnancy from be.macmillan.org.uk People affected by cancer can also order from the Macmillan Support Line on 0808 808 00 00.
Connecting haematology and oncology for older people

A liaison team is tailoring care for older people with blood cancers.

Dr Pamela McKay, a Consultant Haematologist for Greater Glasgow and Clyde, recognised the need for specialist geriatric input as her patient population aged. Simultaneously, the Macmillan report ‘Cancer Services Coming of Age’ acknowledged that the needs of older cancer patients are not being met, and our service was born.

The team consists of a Haemato-Oncology Nurse with a special interest in frailty and two Consultant Geriatricians. Working with the haematology team at the Beatson West of Scotland Cancer Centre, we aim to help older people with haematological malignancies live as independently as possible and with optimal quality of life, while accessing the treatment most suitable for their needs.

Comprehensive geriatric assessments
The team delivers comprehensive geriatric assessment to the over-65 population. This is an evidence-based approach which has been proven to increase the likelihood of an older person being alive and in their own home at one year. It has also been shown to reduce chemotherapy toxicity and increase tolerance of treatment. It is a multidisciplinary approach to meeting patients’ physical, mental and social needs, by looking at mobility, co-morbidities, polypharmacy and cognition.

In the first year, 148 patients were assessed, with 535 patient contacts. Four patients received 77 contacts between them. All patients are screened for frailty and cognitive impairment including delirium. They have a face-to-face assessment by the Haemato-Oncology Nurse, at which point they are given appropriate written advice or onward referral to other services to meet their needs. This can include falls advice booklets and financial guidance. They are all given an advice leaflet about our service, which includes a number for the Haemato-Oncology Nurse, who can address issues and concerns as they arise.

Patients requiring a more detailed comprehensive geriatric assessment will be seen by one of our geriatricians in the ward or outpatient setting, or our newly-set up haemato-oncology older persons’ clinic. Joint assessments with haematologists are also provided when patients are newly diagnosed, to optimise management of co-morbidities and function prior to treatment, and to aid treatment decisions.

‘Ready to listen’
The service has been met with universally positive feedback from patients:
• ‘The service is very helpful for an older person like myself.’
• ‘I would like to thank the nurse for the assistance I have received in having me supplied with aids to help me in the house.’
• ‘I found the staff to be friendly and helpful, always ready to listen.’

We are in no doubt that our service benefits the patient group. We look forward to expanding in the future, including developing our own blood transfusion service and support group. We will leave the last word to one of our haematology colleagues: ‘I now have the confidence to start or stop treatment, knowing that the needs of patients will be appropriately managed regardless of the haematological treatment plan.’

Further information
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NHS Greater Glasgow and Clyde
Partnering with Age UK in Wakefield

A small Macmillan team of four people is making a big impact on the lives of older people living with cancer in the Wakefield district.

Our bespoke service provides home visits and telephone support for people aged over 50 who are living with cancer. Team members originate from a diverse variety of previous roles and bring years of experience to the service, all sharing a passion for people while endorsing the values and visions of Macmillan and Age UK Wakefield.

The partnership involves older people, their carers, families and professional teams from across the health economy to support people through their cancer journey. We also have a team of volunteers offering various support and feedback back to us on a regular basis, enabling us to monitor changes in a client’s situation.

Issues facing older people with cancer

No matter what age you are, going through a cancer journey brings fear, uncertainty and worry. It can often rock the foundations that a person’s life was built upon. We support older people and the following concerns are often reported:

- Isolation and loneliness.
- Multiple health conditions and poor mobility.
- Fear, confusion and uncertainty.
- Lack of support.
- Access to care and funding and knowing where to turn.
- Financial worry.

Our aim is to untangle those concerns and join up the dots, to enable the person to feel more prepared and supported. The overall emphasis is one of empowering older people to feel confident and involved every decision that affects them.

How is the service helping?

**Emotional support:** Home visits allow people the time to talk about their concerns with the same key worker.

**Practical support:** Connections are in place with other Age UK Wakefield services such as advocacy, bereavement support, home support and social contact and befriending. Onward referrals are made to local hospices, palliative care teams, district nurses, GPs and local authorities.

**Financial support:** We make referrals for benefits and Macmillan grants. In a 16 month period we enabled clients to claim £408,896 in benefits. In a four month period of we enabled clients to claim more than £5,000 in Macmillan grants.

We respond to referrals within 48 hours and visit within seven days. Our timely interventions also enable clinical professionals to focus on their roles. The streamlined referral pathway from clinical nurse specialists straight to us within a short time frame is vital.

Making a difference

The service has recently been independently evaluated and client feedback so far has been unanimously positive. Clients articulated the genuine and heartfelt appreciation of the processes and ethos within the team, describing it as ‘gold standard’ and ‘dependable’. One person who had been supported said: ‘They’ve made such a substantial difference to my life. It was the best thing I ever did to get in touch with them.’

Further information

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Enhancing upper GI cancer services

A two-year project at Mid-Cheshire Hospitals NHS Foundation Trust has led to tangible benefits for people with upper gastrointestinal (GI) cancers.

After 10 years in post, Vicky Woodall, Upper GI Clinical Nurse Specialist (CNS), had a clear idea of how upper GI cancer services could develop to meet patient’s care needs. The required outcomes of a project to improve pathways were agreed and outlined in a funding bid, which was approved by Macmillan.

Caroline Firth, Macmillan Upper GI CNS, joined the team at the same time as Eleanor Fountain, Project Manager, allowing Vicky to devote two days a week to the project for its two-year duration (May 2015 to May 2017).

The main objectives of the project were as follows:
• Improve survival and quality of life for patients.
• Implement the recovery package including HNA (Holistic Needs Assessment), end of treatment summary and cancer care review.
• Streamline the patient pathway, from referral to treatment.
• Improve the overall patient care experience.
• Establish a pancreatic cancer patient support group.
• Raise awareness of upper GI cancer.
• Diagnose people at an earlier stage of cancer.

A steering group and work streams were set up to ensure accountability. The work streams were diagnostics, data and performance, and survivorship and awareness. The project has been led by clinicians, nursing staff and managers, with input throughout from patient representatives and patient support groups.

Diagnostics
A new administration-led triage has been introduced, for patients with suspected upper GI cancer who had been referred on a two-week wait. The experienced Upper GI secretarial team triage the referral in place of a consultant, using a standardised, symptoms-based process documents.

Since implementation of the protocol, the proportion of patients seen in under seven and fourteen days has increased.

<table>
<thead>
<tr>
<th>Percentage of patients seen</th>
<th>January 2016</th>
<th>January 2017</th>
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<tbody>
<tr>
<td>Seven days</td>
<td>38%</td>
<td>74%</td>
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<tr>
<td>Fourteen days</td>
<td>88%</td>
<td>93%</td>
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All suspect upper GI cancer patients are reviewed at the upper GI cancer multidisciplinary team (MDT) meeting. At the point of diagnosis, they are given the option of meeting the Upper GI Clinical Nurse Specialist. They are also offered information leaflets and a HNA.

Patients attending an initial endoscopy for suspected cancer leave the department with a scheduled CT appointment that will take place within 72 hours, and a first consultant clinic appointment. Previously, the wait for an appointment after endoscopy for suspected cancer was fourteen days. This has now decreased to seven days for most people.

All patients are offered a HNA clinic at point of diagnosis, and an end-of-treatment clinic appointment within six weeks of completing treatment. If this is not convenient, an alternative date (not necessarily within six weeks) will be offered.

Data and Performance
Before the start of the project, a survey was completed to establish patient views of the service. Suggestions that arose included more clinical trials for patients to opt into; more options for care at home; more disease-specific information; and information about services outside the hospital. These recommendations fed into an action plan, which was implemented.

Staging data for patients diagnosed with upper GI cancer is routinely recorded, and records are more comprehensive. This will enable audits and a review of staging data to see if patients with upper GI cancer are being diagnosed earlier.

Survivorship and Awareness
The Trust website now features pages for the public about upper GI cancer, including stories, hints and tips from patients and a ‘meet the team’ section about healthcare staff. The web pages have had positive feedback from patients and carers, GPs, hospital staff and a cancer charity.

Two patient support groups are available: one for people living with oesophageal and gastric cancer, and another for those with pancreatic cancer. Carers are also welcomed.

Communication to medical staff has been improved. Quarterly upper GI newsletters are sent to staff on the Trust intranet, and emailed to the local Clinical Commissioning Group (CCG) and GP practices.

Presentation slides have been produced to display on the screens in waiting areas at the Macmillan Unit and local GP practices, and for use in the training of local cancer champions. The Macmillan Unit was lit up purple for Pancreatic Cancer Awareness month.

There is access back into the system for people living with cancer. If their condition changes, a cancer review will take place and the necessary action will be taken.

Lessons learned
It is fair to say that the project has been a success and the blueprint for the work carried out could be rolled out to other tumour groups.

This type of project would suit clinical areas that do not see a great deal of funding, investment or coverage because they are not as common as other cancer types or illnesses.

A lot of small changes have made a big difference. There has been strong commitment from work stream and steering group members. Having a dedicated project manager has meant the work can be done alongside clinicians, who can lead the direction of the project without having to take time away from patient-facing duties.
End of life care

The challenge of delivering consistently good experiences and outcomes for palliative and end of life care patients, and their families and carers, is growing. Around 480,000 people die in England each year – two thirds of whom are aged over 75. By 2035, this figure is predicted to rise to 550,000.

Ambulance services play a crucial role in delivering care for these patients when they are in crisis. They are a first point of contact for anyone needing urgent and emergency care, taking millions of calls every year. They provide planned transfers between settings; emergency transfer to hospital; transfers away from hospital, to enable people to spend their last days in the place of their choice; verification of death; and immediate support to the bereaved.

How the collaboration began

North East Ambulance Service (NEAS) recognised, within their Clinical Strategy 2016–2020, the need for expert clinical support and education to support their Integrated Urgent Care Alliance (IUCA) Clinical Hub. Following engagement with The Queen Elizabeth Hospital in Gateshead, I undertook a secondment role one day per week in August 2016 as a nurse advisor and clinical expert.

Recognising that ambulance services could support more people

Ambulance services and end of life care

Dawn Orr was seconded to provide expert advice to the North East Ambulance Service and to help improve palliative and end of life care.
to achieve a good death and reduce unnecessary or unwanted hospital admissions and treatment, my role has had a two-pronged approach:

• Providing clinical expertise, through education, training and coaching for all staff.
• Developing policies and guidelines to shape and improve services.

A pre-service audit of clinical staff showed a thirst for improved knowledge regarding palliative and end of life care and an appetite to change services for the better.

I initially commenced a two-week placement across two sites within NEAS. I was fortunate to shadow staff within the clinical hub and the various ambulance crews on the road, including shadowing the first responder paramedic and the Health Service Journal-nominated end of life transport service. Within the clinical hub, I listened to calls taken by a variety of call handlers and clinicians operating the 111 and 999 services, gaining understanding of the processes and pathways in place.

Enabling change
To enable ambulance services to provide high-quality care, a unique set of challenges and barriers need to be addressed and overcome. Ambulance clinicians often find themselves responding to those at the end of life with very limited information of the person’s history, condition, preferences and wishes. They may have to make very difficult and time-critical decisions, often in isolation. Integrating existing services and establishing links with colleagues in palliative and end of life care are imperative.

To do this, we began future-modelling for service improvement, in line with the national agenda for palliative and end of life care. A work plan was developed based on ‘The route to success in end of life care – achieving quality in ambulance services’ (2008). The plan had six work streams, which are briefly summarised below:

• **Strategy**: Develop a three-year overall strategy for 2016 to 2020.
• **Systems**: Map service provision and match with the Directory of Services.
• **Education**: Develop an education strategy including mandatory training and induction; work with academic centres to have education accredited and publish findings.
• **End of life transport**: Understand demand profile and current provision, aligning services with gaps; develop a model for out-of-hours demand.
• **Governance and reporting**: Develop metrics aligned to quality markers, demonstrating safety, clinical effectiveness and efficiency.
• **Communications**: Develop a network with regular communications updates; create a video showcasing work and an intranet site.

Each of these work streams are vitally important to developing and improving services. Our Specialist Palliative Care colleagues, including the Northern England Strategic Clinical Networks, have been integral to the success of this project to date.

Since August, we have held eight educational sessions for 67 staff, including call handlers, paramedics and clinicians. Those who have accessed the training have evaluated it as good or excellent. From the evaluations, we have now developed an education strategy that is mandatory for all staff and will continue to update and coach staff in the future. Early performance data shows the Integrated Urgent Care Alliance Clinical Hub, which was launched in December, is achieving around 80% diversion away from Emergency Departments and signposting to other services for all patients.

NEAS will continue working in partnership with The Queen Elizabeth Hospital and Macmillan to improve the services for people with palliative and end of life care needs. The service has recently invited users to take part in a focus group, to elicit views on how they can improve services in line with the ambitions for palliative care and the national agenda. There are future ambitions to employ a team of dedicated palliative and end of life care professionals within the Integrated Urgent Care Alliance (IUCA) Clinical Hub. This will support NEAS in their quest to improve services and further develop the early successes of this project.
One year of the Accessible Information Standard

The Accessible Information Standard has been live for almost a year. It works alongside the Information Standard as a way to govern health and care information.

NHS England is reviewing the Accessible Information Standard to assess its impact for organisations and users. Results are expected to be published by the time this issue reaches you. Visit england.nhs.uk/ourwork/accessibleinfo to find out more.

Here we recap on what the Accessible Information Standard is and how it differs from the Information Standard. We ask for feedback about your experiences meeting the information needs of patients, and we also tell you about our range of accessible information.

What is the Accessible Information Standard?
The Accessible Information Standard aims to make sure that people who have a disability or sensory loss get the information they need in a way that they can access and understand. This also includes support to enable effective communication with health or social care professionals. In England, adherence to this standard has been a legal requirement for all organisations that provide NHS care or adult social care since August 2016.

How is it different to the Information Standard?
The Information Standard ensures the quality and accuracy of health and care information. The logo enables you and those you support to recognise information that has been produced using the best evidence available, is reviewed regularly, and adheres to strict quality-control guidelines. This is a voluntary scheme run by NHS England for health and care information producers. Macmillan is a certified member of the Information Standard and you will see the logo on the back of our cancer information. The idea is that both Standards work together to ensure that everyone can access good quality health information in the way that works for them.

Does this just apply in England?
While adhering to the Accessible Information Standard is only a requirement in England, it’s also best practice in other UK countries. Policy across the UK also supports the same principles:
- **Wales**: All Wales Standards for communication and information for people with sensory loss.
- **Scotland**: NHS Health Scotland has an Accessible Information Policy.
- **Northern Ireland**: The Disability Discrimination Acts (DDA) includes special provisions around the rights of disabled people to access to health and social care.

**Tell us how you meet the information needs of your patients**
We want to know how you are meeting the accessible information needs of your patients. Do you see fabulous practice at your hospital? Have you faced challenges following the Accessible Information Standard? Please let us know – see the contact details at the end of this article.

**Cancer information in accessible formats**
We can support you to meet the information needs of your patients with our cancer information in different formats, including:
- Audio (CDs and online)
- Easy read booklets
- British Sign Language (BSL) videos
- Braille
- Large Print

Order or download accessible information from be.macmillan or get in touch with us through the email address below.

**Further information**
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cancerinformationteam@macmillan.org.uk
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Macmillan Financial Help Service in Northern Ireland

The Macmillan Financial Help team speak to us about the integrated service that has been created across Northern Ireland’s five Health & Social Care Trusts.

Over a decade ago, Macmillan developed partnerships with Citizens Advice Belfast and North West Independent Advice Centre to provide much-needed advice on financial issues to patients in a hospital setting. The multi-organisational team now provides one central telephone number for on-the-spot financial advice or face-to-face appointments across all five Health & Social Care Trusts in Northern Ireland.

We spoke to Barry McVeigh, Macmillan Services Programme Manager, and the following team members about the collaboration:

• Liz Kennedy, Welfare Rights Adviser, Citizens Advice Ards & North Down
• Nuala Harraghy, Triage Supervisor, Citizens Advice Belfast
• Linda Williamson, Director Citizens Advice Belfast

Why was the financial support service redesigned?

Barry: Ten years ago we had a Macmillan-funded service at Altnagelvin Hospital in the west of Northern Ireland and the Northern Ireland Cancer Centre at Belfast City Hospital. These were seen as opportunities to test the idea of providing financial advice to people with cancer in a hospital setting.

Back then, financial issues were often overlooked, forcing people into financial difficulties because of a cancer diagnosis. Health and social care professionals began to realise our service was essential for people with cancer and it quickly became overwhelmed. As we couldn’t see everyone face-to-face, we needed to look at how we could streamline and prioritise people to address the gap elsewhere in Northern Ireland.

Liz: With the old system, when we had a person who had travelled far to a different hospital, it was very difficult to transfer them to their local service. Communication between services wasn’t very good and the patients were being passed between different people and having to repeatedly tell their story. If we were on leave, it created a huge backlog of people waiting a long time for financial advice.

How does the new system work?

Barry: We decided to offer the service to people who were most in need, at three key stages: at diagnosis, during treatment, and at the end of life. We would signpost other people affected by cancer, for example, anyone who had received treatment a number of years ago, to the Macmillan Support Line or a local advice centre.

Nuala: We have a central telephone number which anyone can call and speak to a triage adviser to get the
advice they need there and then. Triage advisers can also make appointments for face-to-face sessions in hospitals or at their local site. Our electronic referral process and single database guarantees a seamless service for people who contact different advisers. **Linda:** At Citizens Advice we work across five sites. We developed the single database at Citizens Advice Belfast and gradually brought the other sites onto it. If a person travelled between hospitals, their information and their background was always available to the adviser.

**What kind of feedback are you getting from people now the service is fully integrated?**

**Liz:** Some healthcare professionals were a little bit resistant to the change to start with, but now they absolutely love it. They know their patient can talk to someone immediately on the phone, or get a face-to-face appointment on the wards. It’s all about offering them the support they need in a way that suits them.

**What do you find the most rewarding part of your role?**

**Liz:** It’s great to be able to identify the areas we’re not covering. If there are not many referrals from a certain area, we need to promote the service better there.

**Linda:** For me it’s about continuity of service. Patients can talk to the same person no matter where they live or move to in Northern Ireland. People with cancer list financial concerns as the second most worrying thing after their cancer diagnosis. To know we have developed a service that is positively impacting on people’s lives makes it all worthwhile.

**Barry:** I think, from Macmillan’s point of view, it’s great to see individual partner organisations work together as a team to enhance the patient experience. They bounce things off each other and learn as a team.

We’ve also been working closely with our Macmillan colleagues in Shipley to become more integrated with that service. The service is really engaged with the local information and support centres too. The benefits advisers link up people who have information needs, physical activity needs or complementary therapy needs to give them a holistic experience. And the people in the information and support service will refer people to our service. We’re creating one huge team across health and social care that doesn’t just look after people’s health, but their wellbeing.

**Nuala:** For me the most rewarding thing is that we really were five separate services, but we shared the same goal to form one consistent and accessible service to all our clients. It wasn’t easy, but going forward we are working as one team.

The team won the 2016 Macmillan Professionals Excellence Award for Integration Excellence.

**Further information**

Email Barry McVeigh, Macmillan Services Programme Manager, at bmcveigh@macmillan.org.uk

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L-R: Fiona McDonald, Liz Kennedy, Nuala Harraghy, Mairead Johnson and Jean Murray
Radiotherapy Late Effects Service

Emma Hallam, Macmillan Radiotherapy Information and Support Radiographer, told us about how the Radiotherapy Late Effects service at Nottingham University Hospital has tapped into existing expertise to plug a service gap.

The Radiotherapy Late Effects (RTLE) team includes myself and Liz Stones – both Macmillan Radiotherapy Information and Support Radiographers – and Dr Judy Christian, Consultant Clinical Oncologist.

The team was established after a gap was acknowledged in services for people who had received radiotherapy. For many of these people, cancer was being treated successfully, but they were returning later with problems. Some services for people with late effects of treatment were there, but people were not always aware of this or how to access them.

Now, when a patient has finished treatment, we ensure that they know about the late effects they may potentially experience and inform them about our service. The late effects service is for any patient who is experiencing a physical or emotional impact as a consequence of their treatment at any point from six months onwards. Patients and any other health professionals can refer to the service either by telephone or email. Any patient attending the clinic is offered an initial assessment and a follow-up appointment, along with referrals to other services if needed.

Promoting the service has involved presenting at support groups, conferences, attending MDT meetings, GP study days and teaching sessions.

Team-working
Liz Stones and I are both therapeutic radiographers with a number of years of experience in delivering radiotherapy treatment and in information and support roles. We have a dedicated helpline that anyone can call if they have a question about radiotherapy or its side effects, or needs additional support. Liz and I have an excellent working relationship and provide support for each other, especially when dealing with this complex group of patients.

Developing relationships and networking was crucial to the initial success of the project. A lot of it came down to giving up our own time to go out and speak to people. For the first year of the service, we went knocking on doors asking people to help our patients. Many departments told us they could not take any more patients on, but they would be happy to train us to support them and be there in the background if we needed any more help. So that’s what we did. As a result, our skills have been enhanced to include pain management, simple lymphatic drainage massage and psychological support to name but a few.

Challenges
There were some challenges around raising awareness among clinical colleagues about the purpose of the RTLE service. As part of this, we needed to demonstrate that there was a gap in service provision. It was also important to be sensitive to other services and to not encroach on the good work being done by other specialists. In some cases, we helped colleagues to learn more about the late effects of radiotherapy.

Over time, we have increasingly been able to demonstrate the difference the service is making and raise our profile. Barriers have been broken down and referrals have increased significantly since the service was introduced.
Understanding
People say they really like coming to see us and get a sense of reassurance because they feel we understand radiotherapy. We can talk to them about the dose they have had and discuss exactly why they have certain side effects. We can’t always get rid of the side effects – and sometimes we can’t even make them any easier – but just that contact with us and providing a listening ear can make all the difference. Patients have told us that we’ve provided them with the motivation to carry on. It’s humbling and rewarding to hear that kind of feedback, because this role can take a lot out of us. We spend a lot of time with each patient – often one or two hours – and conversations can be difficult.

It’s great when you see the positive impact you can have on patients. We get amazing emails from people who keep us posted on their progress, and knowing that we are able to give them the tools to improve their quality of life is very rewarding.

The RTLE team won a 2016 Macmillan Professionals Excellence Award for Innovation Excellence.

Further information
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Jennie Mealor, Macmillan Specialist Breast Care Nurse, tells us how the Wirral Clatterbridge Breast Unit Team worked collaboratively to pilot the unique physical activity course Taking Back Control.

I have been a Macmillan Breast Cancer Nurse Specialist for six years. Over this time, I have seen that evidence of physical activity improving the chances of surviving breast cancer and reducing recurrence is so strong, and we knew we needed to do something for our patients. The Taking Back Control course we created gave women with breast cancer the opportunity to take part in a variety of physical activities and receive vital cancer information in a friendly environment.

Seven-week programme
Each session incorporated an informal component. For example, I would take the lead on talking to the women about menopausal symptoms. Then we’d have a coffee break, and a physical activity session run by our Live Well trainers – a community team that put on free physical activity programmes. Our Consultant Oncoplastic Breast Surgeon Maria Callaghan and I would join in with this. In the evaluation report afterwards, the participants said seeing us take part really spurred them on.

We did a lot of chair-based exercise, mini circuits, and a health walk around the park. The trainer, Cathy Quinn, who was part of the Live Well team, was great at knowing how to pitch the exercise. Some of those attending already did regular exercise, while for others it was less part of their routine. People also ranged in age.
Collaborative Approach
In order to meet the physical, emotional and social needs of the patients, we tapped into our contacts and arranged for a representative from the Wirral Holistic Centre to speak about the benefits of holistic treatments. And a person from a support group talked about how it can be worrying and isolating when you finish your treatment, but that their group can support them through it. Participants were really happy to know there was a network out there for them.

I’m very lucky because I work as part of a cohesive and effective team. This includes three nursing colleagues, and four consultants, with Miss Maria Callaghan, Consultant Oncoplastic Breast Surgeon, leading on this project. I was only able to deliver every session because my colleagues supported me and picked up my work. Miss Callaghan has been so supportive and this wouldn’t have happened without her. At the start of every course, Miss Callaghan gave a talk called ‘Exercise: The Wonder Drug’ and it was so interesting to see how powerful the participants found it.

The enthusiasm, passion, commitment and drive of the team have been the key to the success of the pilot.

Positive Feedback
We’ve had some excellent feedback. People told us they’d never thought about doing any physical activity until they saw me and Miss Callaghan doing it. Another benefit was the support group aspect of the sessions – people became very good friends and are still in contact now.

I think what set us apart was the fact that we were the only Trust at the time that was attempting to meet both exercise and information needs. The participants said that once they’d been diagnosed and had their treatments, subsequently coming on the course made them reflect on the things that they hadn’t really focused on at the time of diagnosis.

Cuts
Sadly, the Live Well community team was decommissioned as a result of cuts. This has since put the course on hold. It’s been frustrating because we worked so hard to create Taking Back Control and its benefits were enormous. But we haven’t given up. The team has had to go back to the drawing board and look at different ways of incorporating aspects of the course into what we’re doing at the moment. We’ve recently received funding to set up a portal for our patients and we’re hoping to use a lot of the information from the course as a part of that. We’re also planning on doing some education days where we will deliver the information from the course to patients.

Next Steps
We haven’t lost sight of Taking Back Control and want to see what else we can do to make things better for our patients. We need to ensure our patients are getting the best information because physical activity is hugely important and reduces the risk of cancer occurrence.

I am so proud of this team and what they’ve done. I think the fact that we haven’t given up shows we’re an innovative team.

The Wirral Clatterbridge Breast Unit team won a 2016 Macmillan Professionals Excellence Award for Innovation Excellence.
Crossword

Clues across
1  Blubbery mammal of northern seas
4  Very bad
7  Raspberry-blackberry hybrid
8  A musical piece for two
9  Back tooth
11  Hot dog condiment
13  To ruin
15  Jeans fabric
17  Small cut
18  A let-down
20  Efts
21  A knotted mass of hair

Clues down
1  One of four double back teeth
2  Underground part of a plant
3  Gull or albatross
4  A book for photos
5  In favour of
6  Stratum
7  Portion of scripture read in church
10  The upper windpipe
12  Tooth doctor
14  Hurrah!
15  Waste channel
16  Ridicules
17  Cut, as wood is
19  To pull with a rope

Resources

Updated

Help with the cost of cancer
MAC4026
15th edition
Now includes Northern Ireland as well as other UK countries. A booklet that helps people affected by cancer understand what benefits and financial support may be available to them. Updated for April 2017 to April 2018.

Looking after someone with cancer
MAC5767
6th edition
This booklet, created with support from carers themselves, includes useful information to help people who are caring for someone with cancer. It also includes practical tips about caring for someone with advanced cancer.

Travel and cancer
MAC11667
6th edition
Now includes detailed information about travel insurance. This booklet advises on a range of travel issues, from vaccines and preparing to travel, to avoid health problems and taking medicines abroad.

How are you feeling?
MAC11593
4th edition
This booklet offers advice and guidance to anyone affected by cancer who may feel lonely or isolated. The booklet discusses how you may be feeling, and provides information about further sources of support.

Signs and symptoms z-card
MAC15200
8th edition
This ‘z-card’ gives the signs and symptoms of the main cancers for men and women and advice on cancer prevention for anyone worried about their cancer risk.

New

Diabetes and cancer
MAC16127
This booklet is for anyone who has been diagnosed with cancer and also has diabetes. People may also want to read it if they have been told they have an increased risk of developing diabetes because of cancer treatment. It includes tips for coping with side effects.