

Issue 54 autumn 2010

Macmillan **VOICE**

for Macmillan professionals

In this issue

Dr Isabel White

Remedi/Macmillan Clinical Research Fellow
in Cancer Rehabilitation

Focus on long-term and late effects

Sharing good practice

Business planning in cancer care

**WE ARE
MACMILLAN.
CANCER SUPPORT**

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We welcome feedback!

Let us know your views on *Macmillan Voice*.
Email macvoice@macmillan.org.uk

Writers and news wanted

Macmillan Voice is for you. It's where Macmillan professionals can share news about their work, activities and successes, so please tell us what you've been doing.

We're also looking for new writers to contribute articles. You can write about the issues that matter to you and share your knowledge with other Macmillan professionals. You don't need to be an experienced writer to get involved in *Macmillan Voice*. We can help you turn your idea into a news item or feature. All you have to do is get in touch with our Managing Editor Rosie Cotter at rcotter@macmillan.org.uk or call her on **020 7091 2219**.

Maximum word counts: news stories up to 300 words; features up to 500 words. Please also send us photographs if possible, using the highest resolution on your camera.

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The launch of our combined phone service last October was a big success. But something's been missing...a name.

To come up with a suitable name we asked people affected by cancer what they thought. **Macmillan Support Line** came out as the favourite because it clearly explains what people get when they call.

The Macmillan Support Line offers help and support for people affected by cancer, adding to the vital work you do. The new name should also make it a lot easier for you to refer people to our phone support service.

The line is staffed by a team of specialists from the former CancerLine, Benefits helpline and cancer information nurse helpline. They can provide information on topics from breast reconstruction to radiotherapy, how to get in touch with local support groups, and practical advice about

benefits or employer relations. The information can also be interpreted into over 200 languages.

Recently, health and social care professionals have been using the phone service to assist them in the work they do. This service is available to all and we're happy to provide any information that we can to help.

If you haven't already, head to be.macmillan.co.uk to order your free Macmillan Support Line publicity materials. We need your help to get the new name out there so please keep recommending and using the service.

The Macmillan Support Line on **0808 808 00 00** is open Monday to Friday, 9am–8pm. Calls are free, including all mobiles. For the hard of hearing, a textphone service is available on 0808 808 0121, or the Text Relay system.

Transforming services

UK-wide Macmillan professionals event

Now in its fourth year, the Macmillan professionals event has gone from strength to strength.

Almost a year ago, we gathered over 300 Macmillan professionals in London to focus on innovation and improvement in services.

We hope that this year will be even better. The focus of this year's event will be **'Transforming services: meeting the quality and productivity challenge.'**

We've invited keynote speakers to address the theme and to present lots of food for thought.

Throughout the event there will be opportunities for networking, sharing good practice with fellow professionals, and to hear about what is going on across Macmillan. We'll also provide you with tools that you can take away to help you in your work.

You should have received your invitation by now and, if you haven't already looked at the programme and registered for the event, then go to macmillan.org.uk/learnzone to find out more.

The event is one of many ways that we aim to support Macmillan

professionals, so be sure you check out what else is available on the Learn Zone.

4–5 November 2010

Macmillan professionals event

Renaissance Hotel,
Heathrow

Caring for carers



Carers often miss out on things most of us take for granted, like going on holiday, a meal out, or even just relaxing for an evening without responsibilities or worries.

As part of this year's Carers Week (14–20 June), themed 'a life of my own', Dawn Casey, Macmillan Learning and Development Manager for Wales, organised a free event at a leisure centre in Swansea. Carers were able to talk to organisations and charities about the local support available, as well as enjoy some holistic therapies.

'The Macmillan Information Day offered a wide range of help and support from partner agencies such as Network 50+, Care Aware, the Old Mill Foundation, local self-help and support groups, and the Princess Royal Trust for Carers,' says Dawn.

'Everyone who attended told us they were able to access support they didn't know existed and found the event very beneficial. It also provided a good opportunity for local groups to network and look at future partnerships to help carers in south west Wales.'

Macmillan will be supporting this year's Carers Rights Day on 3 December. For more information, contact Charlotte Argyle at cargyle@macmillan.org.uk

Guidance on treatment and care towards the end of life

New guidance on advance care planning, responding to a patient's advance requests for treatment, and decisions involving infants and children is available from the General Medical Council (GMC).

The guidance is available to professionals to help make complex decisions for patients at the end of life. In publishing the new guidance, the GMC seeks to improve end-of-life treatment and care for all. The guidance was developed over two years and involved an extensive consultation with doctors, patients and their carers, family members and healthcare teams.

The GMC is encouraging doctors, other health professionals, patients and their family and carers to read the guidance and supporting resources. They are available to download at gmc-uk.org/end_of_life_care

Researching cancer survivorship abroad

Macmillan professional Charlie Ewer-Smith has been awarded the Winston Churchill Fellowship to research approaches to cancer survivorship overseas.

Charlie, a Macmillan Occupational Therapist at the Bristol Oncology Centre, will be travelling to Canada, the USA, Australia and New Zealand this month to carry out her research.

The award gives British citizens the opportunity to take sabbaticals and visit activities and projects overseas related to their profession, craft or personal interest. Beneficiaries return with unique experiences which benefit themselves, their professions, communities, and the UK as a whole.

Each year, 100 Travelling Fellowships are awarded across ten broad categories, including medical, health and social services. For more information, go to wcmt.org.uk Look out for more details about Charlie's research in upcoming editions of *Macmillan Voice*.



Charlie Ewer-Smith, Macmillan Occupational Therapist

Update on information prescriptions

The information prescriptions service is now available on NHS Choices and Macmillan is working with the National Cancer Action Team and other partners to enable cancer care professionals to use it.

Information prescriptions are a mechanism for providing patients and carers with tailored information. The information prescriptions service hosted by NHS Choices provides direct access to cancer content from a range of sources, which can be printed, emailed or saved as an electronic file. This content is regularly reviewed and updated. Macmillan has been working with NHS Choices to develop the system, sharing learning from the prototype we developed with Cancer Research UK.

The NHS Choices information prescriptions service will be developed

on an ongoing basis for cancer and all long-term health conditions. There are four types of cancer content within the system:

- 1) introductory content from NHS Choices
- 2) short documents, videos and other materials from the cancer information pathways
- 3) local information, such as directories of services
- 4) short sections of text, such as definitions and diagrams, which can be compiled into a personalised summary (this feature is only available to users who have created an account).

You can access the information prescriptions service at nhs.uk/ips

There is also an e-learning programme available at macmillan.org.uk/learnzone

To support implementation, Macmillan is funding 15 facilitators within the National Cancer Action Team. These facilitators will work with every hospital trust in England to help develop processes and procedures for effective information prescriptions delivery. Macmillan is also extending the funding for cancer network information managers, to support integration of information prescriptions into their activity.

This activity is for England, but we are working with strategic stakeholders to develop the equivalent of information prescriptions in the other UK nations.

For more information, please contact Ruth Carlyle, Information and Support Policy Lead, on **020 7840 4698** or rcarlyle@macmillan.org.uk

Raising profiles, raising coffee cups, raising money

Despite being a busy unit, the Macmillan palliative care team at Basildon University Hospital has participated in the World's Biggest Coffee Morning for the past seven years.

Holding a coffee morning is a great opportunity for them to engage with the public and the rest of the hospital community.

'We work together to raise the bar each year. We added a quiz night last year and got one of our team members to get his legs waxed in the name of charity. There is a friendly rivalry to outdo each other in raffle ticket sales. The regional BBC radio station has even dropped in to interview us,' Sharon Quinn, Macmillan Lead Nurse, said.

Along with raising money for Macmillan, the team uses the event to raise awareness about what they do. The support has been tremendous and 200 people participated last year – from what we heard there was even a queue.

If you aren't already, please play a part in the World's Biggest Coffee Morning on **Friday 24 September**. The money raised will enable us to help more people affected by cancer. There's still time to contact your regional community fundraiser, or visit coffee.macmillan.org.uk to find out more or search for an event to attend.



The Macmillan palliative care team (from left): Karen Munro, Sharon Quinn, Julie Wardle, Virginia Campbell and Heather Wright

In conversation with ...

Julia Palca, Macmillan Chair



So, what brought you to Macmillan?

I was diagnosed with cancer of the upper right parotid (the saliva duct) in 1998. It's a rare form of cancer and there was no information available at all. I didn't have a Macmillan nurse and the doctors were very cold and clinical. I was often a bit of a wreck when I came away from seeing them. After my experience I wanted to get involved with a cancer charity so I joined Cancerlink in 1999, and we merged with Macmillan in 2001.

Being Chair is a pretty big job. What made you go for it?

Macmillan is in a fantastic place right now. I'm very excited to have the opportunity to help build on the growth we've already achieved in the nine years since I've been involved.

What's your vision for the future of Macmillan?

I want everyone who is diagnosed with cancer to know we're here for them. Not just to provide nurses, but for all their needs. I'm also very keen on helping carers get maximum input and support.

What do you do when you're not working with Macmillan?

I'm a solicitor in a predominantly media law firm. Some of my clients are quite well-known, including Tom Cruise. I'm semi-retired now so that gives me the time to follow other interests and devote more time to Macmillan.

The Chair and the board of trustees are responsible for the overall control and strategic direction of Macmillan, including ensuring that we are solvent, well-run and that we deliver our objectives.

Evaluating the impact of pelvic radiotherapy

Over 12,000 people in the UK undergo pelvic radiotherapy each year as part of their cancer treatment. Long-term side effects from this treatment can occur from six months to many years later, and may have a significant detrimental effect on quality of life.

At Cambridge University Hospital, we will be evaluating the impact of pelvic radiotherapy on quality of life as part of the National Cancer Survivorship Initiative's (NCSI) pelvic cancer project. This will include looking at the level and severity of gastrointestinal symptoms following intervention by a gastroenterologist, and the management of bowel symptoms.

This evaluation study will be carried out over the next six months and will include 10 participants who have received radiotherapy for a gynaecological cancer and who present with bowel complications such as diarrhoea, pain, rectal bleeding, urgency or faecal incontinence.

Our aim is to develop clear referral pathways within a specialist team for cancer survivors living with the consequences of their treatment. We hope to:

- streamline the management of chronic health issues faced by cancer survivors, providing cost-effective case

management with more appropriate referrals, investigations and treatment

- encourage self-management with appropriate education so people can self-refer if and when appropriate
- develop appropriate studies to evaluate service delivery and promote best practice
- reduce the number of inappropriate investigations undertaken by non-specialist health professionals
- facilitate novel practice and skill-mixing to improve patient outcomes
- facilitate future research studies.

This evaluation will contribute to the NCSI's work to develop a national model of care for this group of people. It will also inform development of similar services for people with complex needs following treatment for cancer.

For more information, contact Lisa Punt, Macmillan Consultant Radiographer in Gynaecological Oncology, on **01223 216580** or at lisa.punt@addenbrookes.nhs.uk You can also order Macmillan's booklets on the late effects of pelvic radiotherapy at be.macmillan.org.uk

Online tool helps people prepare for late effects

People living with and beyond cancer often experience long-term effects as a result of their cancer treatment. Current research suggests they would benefit by becoming actively involved in managing these consequences. However, many are often not given enough guidance and information about the issues they may face and how to deal with them.

To improve this situation, the National Cancer Survivorship Initiative (NCSI), in partnership with service users, piloted the Livestrong Oncolink Care Plan, an online tool for cancer survivors in the USA. It generates summaries of potential consequences of treatment, whether they be physical, psychological, sexual or social in nature.

The project, named the '1000 People Project', set out to show that a tool such as this would help people think about issues which may affect them following treatment for cancer, and to make more informed choices about managing these.

A link to the Livestrong Oncolink Care Plan software was available on the NCSI website between April and August this year. People who completed the survey received a personalised care plan based on their cancer experience.

They were then asked to complete a satisfaction survey regarding the plan they had received.

'Cancer survivors believed it was important to take control of their health'

The large majority believed the care plan was worth doing and said they learnt something new based on the information they were given. The general feedback highlighted that cancer survivors believed it was important to take control of their health and many had not been informed about some of the potential side effects or consequences of their treatment.

The NCSI hopes this study will help create and define a tool available to all cancer survivors in the UK, ultimately helping individuals to self-manage their own care.

The 1000 People Project Report is now available on the NCSI website – ncsi.org.uk/consequences-of-cancer-treatment/oncolink-project

Pilot project helps women severely affected by cancer treatment

A project to help women affected by radiotherapy in the 1980s has improved their well-being and identified useful support services.

The women belong to a group called RAGE (Radiotherapy Action Group Exposure) and, as a result of their breast cancer treatment, have severe, radiation-induced conditions. These include extreme pain, lung problems, paralysis in the shoulder, arm or hand, and lymphoedema. However, they had been getting little or no recognition or help for these conditions.

'It really was such a relief to be able to talk to people who understood my situation'

Macmillan worked with the Department of Health and the National Cancer Action Team to find out what support these women needed. Following

consultation, the project team piloted self-managed grants and specialist multidisciplinary clinics with RAGE members.

The self-managed grant (£750) was offered to help with daily living or personal care. Recipients indicated that the grant could make a significant difference to their well-being. For many RAGE members, the grant represented a small but important recognition of a long struggle to have their condition acknowledged.

The project also set up 15 pilot clinics across the country. Seventy women attended the clinics and saw a minimum of an oncologist, a pain specialist and an occupational therapist. Clinics provided an assessment and care plan and, where possible, identified continuing local support.

This pilot found it's possible for people with complex injuries to self-assess and self-refer, and that effective assessment and care planning

can be carried out in regional centres. Women who attended generally found the experience very positive: 'It really was such a relief to be able to talk to people who understood my situation,' said one. Several pilot centres are keen to continue.

The project team has recommended a model of a specialist hub providing triage, assessment and intensive therapy. The hub centre could refer to local specialists and provide information for patients and health professionals. The National Cancer Action Team has submitted the model to the national specialist commissioning team for England.

This project forms part of the National Cancer Survivorship Initiative's Consequences of Treatment work stream. The RAGE project report is available at ncsi.org.uk/consequences-of-cancer-treatment/rage-project

Late effects: two survivors about life after treatment



Ann Muir

Ann Muir, 66, was diagnosed with cancer of the larynx 11 years ago. She had a total laryngectomy and radiotherapy treatment, and now speaks with the aid of a valve. She shares how the cancer and its treatment have affected her life.

Speaking with a valve has totally changed my life. Communication is so much part of living and, as I get older, my artificially-produced voice is getting weaker and I find it harder to talk.

'The very mention of cancer can throw us into a state of confusion and fear, and we don't register everything that's told to us'

Some people are unsure of how to react when they hear me speak – some are frightened, others think it's funny or want to know if I have a sore throat. I often give a short explanation on why my speech is different, but it can be upsetting when someone laughs. You learn to cope – at least most of us do.

I miss not being able to swim or walk as much as I'd like. I get tired from lack of air and find it impossible

to walk and talk at the same time. But I have been fortunate in that I could return to work.

Rheumatics have set in round my neck, arm and shoulder, which can be painful. Surgery has caused muscle loss in my neck. I take painkillers on a daily basis to help with this. As a result, I am often constipated and have to take medicine to counteract this.

With the help of the right medication and advice from caring health professionals, most of us manage well. We all need reassurance from time to time and this is where health professionals can help.

We need time to make ourselves understood. We may need to have things repeated several times, especially before and immediately after treatment. The very mention of cancer can throw us into a state of confusion and fear, and we don't register everything that's told to us.

My advice to health professionals would be to tell us in simple terms, anything we need to know, repeat if necessary, and have a little patience with us.

Wyn Jones, 46, was diagnosed with a nasopharyngeal cancer and a secondary cancer in his glands in 2004. He received radiotherapy and chemotherapy treatment, which cured the disease, but he is now living with the late effects of this treatment.

Having cancer totally changes your life, but so do the side effects of treatment. I had a dry mouth almost immediately after treatment. I've also had dental decay because my saliva glands were damaged by the radiotherapy and I am missing the natural enzymes that help clean teeth and prevent decay.

'I was told by my healthcare professional that they hadn't wanted to tell me about this problem earlier because they didn't want me to worry'

I have closure of the mouth, which will get worse with time if left untreated. I thought the food I ate was getting bigger, but my mouth wasn't opening



Wyn Jones

rs talk nt

Long-term effects

Side effects that continue for months after treatment and may become permanent.

Late effects

New side effects that develop months or years after treatment.

as much as before. I was told by my healthcare professional that they hadn't wanted to tell me about this problem earlier because they didn't want me to worry.

I have pain and stiffness in my neck, which is getting worse over time. I also suffer from fatigue. This can make work difficult and I need to sleep a lot, sometimes taking days off to do so.

Professionals still think the less they tell you the better. Late effects are a massive learning curve for both patients and professionals. It is important to keep people informed, because if something unexpected happens, you panic. If you break a bone, you are told what to expect after the healing, but with cancer treatment, nothing is said until you ask. The treatment is superb – it's just the next stage that needs to be addressed, and experiences shared in order to build up a wider picture of what to expect.

I have a strong family who have stuck together. I know it is a cliché, but I am thankful for what I have.

CAMPAIGNS

Beating fuel poverty

Macmillan has been campaigning for more support for people with cancer who are struggling to pay their fuel bills. Many people tell us they feel the cold more since their diagnosis.

Julian is 43 and was diagnosed with intestinal cancer in 2008.

'Because my cancer treatment makes me feel the cold so badly, I have to keep the heating on nearly all the time, even in the summer. The bills have gone up and with winter around the corner I am even more worried as I've had to give up work and have very little coming in.'

Macmillan is campaigning for particularly vulnerable people with cancer to be included in new plans for more support with fuel bills. The government is expected to hold a consultation on who will be eligible for this support. Go to macmillan.org.uk/fuelpoverty to back the campaign and for more information on how you can support your patients who are experiencing fuel poverty.

Getting back to work

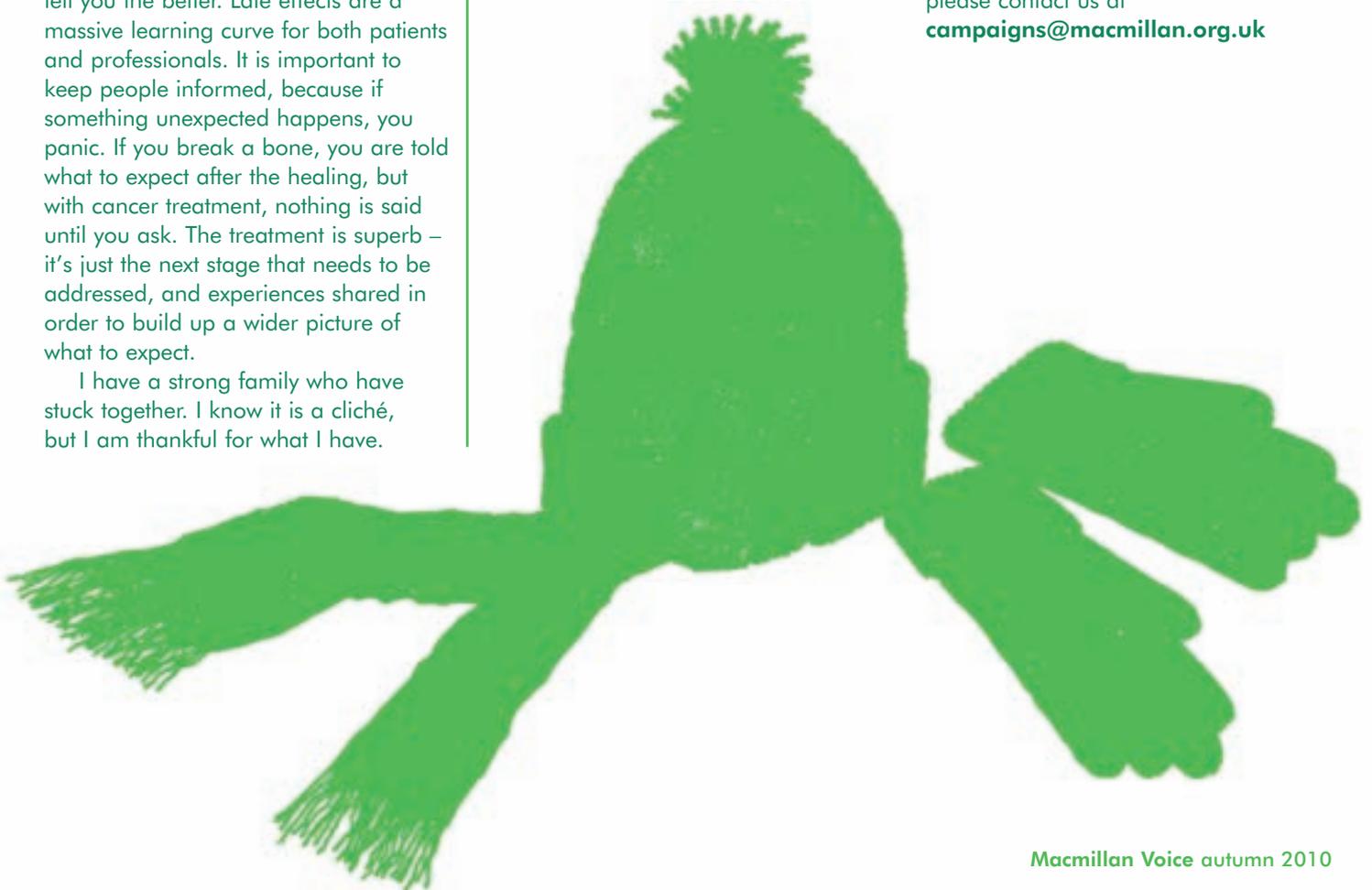
Rob, 48, lives with his family in Newcastle. He was diagnosed with chronic myeloid leukaemia in 2008. Focusing on getting back to work helped him get through treatment. But it was not without challenges.

'When I was diagnosed with cancer I wanted to get back to work to take my mind off what was happening.

'It was difficult to get any information about how long I might be off for after treatment or what the long-term effects of the illness would be.'

We are trialling a new model of vocational rehabilitation for people with cancer as part of the Work and Finance stream of the National Cancer Survivorship Initiative. Seven pilot sites around England are testing the model, which aims to support people with cancer to remain in, or return to work during or after treatment. To find out more about this exciting project go to ncsi.org.uk/vocational-rehabilitation

For more information on our campaigns and how to get involved, please contact us at campaigns@macmillan.org.uk



Dr Isabel White

Remedi/Macmillan Clinical Research Fellow in Cancer Rehabilitation

What will your research fellowship involve?

The main objective of my post is to develop and evaluate a clinical assessment system for women who have had pelvic radiotherapy. 50–80% of women undergoing pelvic radiotherapy will experience transient or more persistent sexual difficulties.

We will be designing and testing an assessment that can be completed on a touch screen. This will mean medical staff can receive the information before seeing the patient for their outpatient consultation.

Training for doctors on how to interpret results will be provided with locally-derived management and referral guidelines for female sexual difficulties.

Why are you targeting this patient group?

Women are more neglected in the provision of sexual rehabilitation and their sexual difficulties may be harder to address using biomedical strategies alone. The two main sexual concerns encountered are loss of desire and sexual pain disorders.

The majority of women should be able to get support from their clinical nurse specialist (CNS), but approximately 10% of women who experience sexual difficulties associated with cancer treatment may benefit from referral to psychosexual therapy. Most cancer centres don't offer this kind of therapy, but it may be available from wider hospital or community services. However, in terms of implementing the study's findings, the emphasis is on how we can use existing services and resources more effectively.

What is unique about the research project?

This assessment will be different from most because it links outcomes from the woman's self-assessment with local management guidelines and referral pathways. In this way, clinicians are supported to identify the most appropriate management and onward referral to meet the woman's sexual or relationship concerns.

How does your research link in with your clinical work?

I recently started a new role at the Royal Marsden NHS Foundation Trust. I will be exploring how a comprehensive sexual rehabilitation service can complement existing services offered by the Trust. An erectile dysfunction service is already offered for men, but the Trust recognise that this doesn't meet other types of sexual dysfunction experienced by men, nor do current services address the persistent and more complex female sexual difficulties encountered at the cancer centre.

This new service will cover the whole range of sexual and relationship consequences of cancer and its treatment. We also plan to engage staff involved in sexual rehabilitation at all levels, from ward staff who may need some foundation level training, to ensuring that CNSs are confident to address commonly encountered sexual concerns. I will be managing a smaller caseload of people with more complex and enduring sexual and relationship difficulties.

Who are you inspired by?

Robert Tiffany at the Royal Marsden – he was committed to improving cancer services. He fought tirelessly to raise the profile and professional credibility of oncology nursing.

Professor Sanchia Aranda, Director of Nursing Research at the Peter MacCallum Cancer Centre in Melbourne – she has developed an institutional philosophy and supportive infrastructure that promotes the conduct and use of research by clinicians and clinical researchers working in partnership to improve cancer care.

Professor Christine Norton at Imperial NHS – she is a clinical academic which is what I aspire to be. She works in bowel dysfunction (researching and seeing patients) using research to explain and solve complex clinical problems.



Location

Florence Nightingale School of Nursing and Midwifery, King's College, London

Isabel White is embarking on a post-doctoral research fellowship focusing on sexual rehabilitation within oncology. Isabel is a cancer nurse and psychosexual therapist, working in clinical practice and research. She has contributed to Macmillan's booklets on the late effects of pelvic radiotherapy, acted as an adviser for Macmillan's campaign on sex, relationships and cancer and is a member of the National Cancer Survivorship Initiative's Consequences of Cancer Treatment Collaborative.

In post

Since 2009

Further information

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Improving primary care for cancer survivors

What primary care professionals should look out for when caring for people after their cancer treatment

It has been estimated that there are now more than two million people in the UK living with a cancer diagnosis. Many of these people will experience long-term consequences of cancer, both of the disease itself and of its treatments.

A survey by Macmillan in 2008 showed that 44% of people with cancer weren't aware of the possibility of long-term physical side effects, but 78% of them had experienced at least one of a list of possible side effects in the preceding 12 months. The survey also indicated that a majority of people living with cancer would go to their GP in the first instance for help with their symptoms.

People with cancer will be increasingly discharged to primary care for follow-up and we need to be alert for treatable problems.

Consequences of treatment

Long-term and late effects can arise anytime from a few weeks or months after treatment, to 3–4 years later.

Physical effects include fatigue, weight gain, lymphoedema, neuropathic pain, heart damage leading to an increased risk of cardiovascular disease, lung damage, bowel and bladder dysfunction, and increased risk of osteoporosis. In addition, there is a risk of cancer survivors developing a second cancer. Many people also suffer from anxiety, depression, memory loss and problems with concentration, leading to lower educational attainment for childhood and adolescent cancers, and increased risks of job loss, financial problems, marital breakdown and divorce.

Cardiovascular disease Some cancer treatments for children, adolescents and adults can put them at risk for cardiovascular disease in later life. In particular, radiotherapy to the left side of the chest and some chemotherapy agents such as anthracyclines are known to increase the risk of the patient subsequently developing cardiovascular disease.

Osteoporosis Hormonal treatment, including the use of GnRH analogues for prostate cancer and aromatase inhibitors for breast cancer, is associated with an increased risk of bone fractures due to osteoporosis.

Bowel problems About half of the 80,000 cancer survivors with a history of pelvic radiotherapy will have bowel and/or bladder problems. Half of them will have severe problems including diarrhoea, faecal urgency and incontinence. See page 12 for more information.

The role of primary healthcare professionals

Be aware of the possibility of late effects for people with a history of cancer and keep them in mind when a patient presents with new symptoms. Patient records should be clearly coded with details of past oncological treatments and also coded as 'At increased risk of...' if appropriate.

Cancer specialists need to be very clear in the information they provide to both patients and GPs about possible long-term consequences. We then need to have systems in place to ensure that information is appropriately recorded and coded on the patient's GP records. Practices can create a register of people who have had oncological treatment so they can be highlighted on their computer system and alerts set.

'We should proactively ask patients about possible treatment-related problems and psycho-social effects as part of any regular review'

We should proactively ask patients about possible treatment-related problems and possible psycho-social effects as part of any regular review. As second cancers can occur in people who have already had one cancer, it's vital to give strong lifestyle advice to all people with cancer to try to reduce that risk. For people with increased chance of developing cardiovascular disease or osteoporosis, we need to actively identify and manage other risk factors.

We need systems in place to ensure those identified at increased risk of long-term consequences of cancer or its treatment are given appropriate care and support to lead as healthy and active a life as possible, for as long as possible.

This article originally appeared in *GP* newspaper. Reproduced with permission from Haymarket Medical.

Further reading

It's no life, Macmillan's report on living with the long-term effects of cancer, is available at macmillan.org.uk/campaigns (in the research and publications section). We also produce booklets to help people manage the effects of cancer and its treatment. See the back page for more details.



Further information
Dr Cathy Burton
 Macmillan GP Adviser
calburton@gmail.com

Managing the effects of bowel cancer treatment

Alison Whiteford, Expert Information Development Nurse, highlights some of the bowel problems people may develop after treatment for bowel cancer

More than 37,500 people in the UK are diagnosed with bowel cancer each year. With improvements in diagnosis and treatment, about half of people diagnosed will live for at least five years after diagnosis.

Most people have side effects during and for a few weeks after their treatment. Usually these effects lessen and disappear. But sometimes side effects can continue for months and may become permanent. Some people who've had radiotherapy, may develop new side effects months or years later.

Data from clinical trials suggest that after surgery for rectal cancer, up to 25% of people have significant long-term issues. For people who have surgery combined with radiotherapy, the proportion with long-term problems may be as high as 50%. These problems may include fatigue and changes to bowel, bladder and sexual function.

'Some people describe limiting visitors to their home and avoiding going out or attending social occasions because of the unpredictability of their bowel habit'

One of the most challenging symptoms people may have to cope with is altered bowel habit. With newer treatments, such as sphincter preserving surgery, now most people won't need to have a permanent colostomy. But there may be long-term changes in their bowel function. People may experience bowel frequency (sometimes 12 times a day or more), they may be less able to hold on when they feel the urge to go, and sometimes they may not be able get to a toilet in time or may have leakage of stool (incontinence).

'There are many things that people can do to manage and improve their bowel symptoms, for example, by making dietary changes'

These symptoms can cause emotional as well as physical effects. Bowel function is a sensitive issue. People can find it difficult or embarrassing to talk about and this may lead to withdrawal and isolation. Some people describe limiting visitors to their home and avoiding going out or attending social occasions because of the unpredictability of their bowel habit.

There are many things people can do to manage and improve their bowel symptoms, for example by making dietary changes such as modifying fibre intake and reducing caffeine. Some people keep a food diary to help them

identify foods that can trigger problems so that they can avoid or cut down on them. If changes to diet aren't sufficient, taking antidiarrhoeals such as loperamide can reduce diarrhoea and incontinence. Healthcare professionals can offer advice on how to use these drugs for optimum effect. Planning ahead for a trip out by making sure there is easy access to a toilet and carrying a change of underwear and wipes in a sealable bag can increase confidence about going out.

'Learning how to control and cope with bowel symptoms can take time and perseverance'

Learning how to control and cope with bowel symptoms can take time and perseverance. Healthcare professionals can be an invaluable source of information and support. In addition to giving advice on bowel retraining, diet, skin care, drugs and continence products, they can also discuss how to talk about symptoms to friends and family and provide contact details for support groups.

It's important that people coping with bowel symptoms are reviewed regularly. If symptoms continue, referral for specialist assessment of additional measures is appropriate. These may include specialist dietary assessment and management, pelvic floor retraining, using electrical implants to improve bowel control (sacral nerve stimulation) and counselling.

Related information

Our booklet, *Managing the late effects of bowel cancer treatment*, can be ordered through be.macmillan.org.uk or by calling 0800 500 800.

Further information

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Developing sustainable exercise programmes for people with cancer

Physical activity contributes to good health and well-being, and the benefits of exercise during and after cancer treatment are now well-documented.^[1]

Despite clear recommendations on how to integrate exercise into clinical practice settings,^[2] few cancer centres in the UK offer comprehensive exercise programmes.

Below are details of two clinical research projects which are helping to fill this gap.

Exercise during treatment

The physiotherapy department at Bart's Hospital, and the School of Sports and Exercise Medicine at Queen Mary's University, London have successfully tested an exercise programme for women undergoing treatment for breast cancer.

'Many women wanted to improve their fitness, but with proper supervision and instruction'

The team at Bart's has been developing its services for almost three years. They see women immediately after surgery and as outpatients to ensure they can move and function well.

Many women wanted to improve their fitness, but with proper supervision and instruction. They also wanted to exercise in a 'safe environment', ie where they didn't feel self-conscious or vulnerable. This led to the development of a new exercise programme.

Women were recruited from follow-up clinics and asked to attend a circuit-style class for six weeks. Women were also encouraged to increase their activity at home.

The classes were evaluated by measuring physical fitness, arm mobility and psychological health. Results showed that all women improved their fitness and arm mobility, and they enjoyed exercising with their peers.

This was a small study with many limitations, but it showed real benefits

for these women. The physiotherapy team is now trying to generate funding to continue and develop the classes.

Exercise after treatment

Macmillan has funded a programme addressing the benefits of physical activity and lifestyle information for people who have finished cancer treatment in NHS Lothian.

The project consists of two, 12-week physical activity rehabilitation programmes. It is being evaluated with physical and psychological measurement tools such as the Hospital Anxiety and Depression Scale.

Programme participants meet weekly for two hours. Each session consists of 45 minutes of exercise followed by an information session on lifestyle. This covers topics such as managing stress, healthy eating, financial issues and the importance of breathing technique.

At the end of the 12 weeks, participants are given help to create their own activity programme if they want to continue. They are also given a free, three-month membership to a gym of their choice within the local area. In addition to the programme, a four-day workshop for fitness instructors already working with clinical populations (eg pulmonary and cardiac rehabilitation) has been run with the aim of developing sustainable programmes.

Although we are only half way through the study, preliminary results are positive. Participants have increased physical ability and confidence, and are motivated by others to improve their fitness level, as well as gaining valuable mutual support from the group.

This has been a positive experience for the research team, who have been amazed by the enthusiasm and drive of the group.



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Related information

Our booklet, *Exercise after cancer treatment*, can be ordered through be.macmillan.org.uk or by calling **0800 500 800**.

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Good transitional care for young cancer survivors

More and more children with cancer are surviving into adulthood. With increased survival, health services face the challenge of providing care for this group as they move into adult life. Accurate information about their problems and a realistic view of the future are essential.

Tanya Urquhart, Macmillan Clinical Nurse Specialist at Sheffield Children's NHS Foundation Trust, coordinates the transition of young people in their region from paediatric to adult care. Diana Greenfield, Macmillan Nurse Consultant at Sheffield Teaching Hospitals, coordinates the service and late effects care in the adult hospital setting. Both Tanya and Diana are part of a wider late effects team.

At around 16, young cancer survivors are transferred from the children's hospital to a specialist adult late effects clinic at Sheffield Teaching Hospitals. Timing is flexible and transfer depends on the needs of the young person and their growth and pubertal status. Paediatricians are trained to deal with any problems that can arise during these stages. The time since the end of treatment, and emotional and psychological readiness are also considered.

'The transition to adult care can provide a positive and optimistic sense of future'

At transition, Tanya produces a summary of diagnosis, treatment, complications of treatment, current problems and medication. This includes any problems the young person may encounter as a consequence of their treatment. Common medical problems for this group include disturbed endocrine function, neuropsychological difficulty, cardiomyopathy, obesity, osteopenia and second malignancy.

Details of previous or current investigations are recorded alongside relevant abnormal results. These form a care plan which is shared with the young person and clinical team. A psycho-social assessment is also included, as are any relevant family

concerns or issues regarding school or college. The team ratifies the care plan and makes decisions about appropriate follow-up.

The specialist late effects clinic is run by an experienced multidisciplinary team. Having a clinic like this has a number of benefits. The transition to adult care can provide a positive and optimistic sense of the future, and adult clinics provide a more suitable environment to discuss age-relevant health information (for example contraception and fertility). However, a young person may feel intimidated by the shift between care settings.

Talking to professionals

Being comfortable in adult healthcare means being able to communicate alone with health professionals – this can be a new experience for adolescents who are used to the close support of family members during clinical encounters.

To make the experience less alien for young adults, the paediatric team ensure they have some experience with lone consultations from around the age of 13. Allowing the adolescent to take more control of their health means urging parents to accept their child's role and learning to provide less direct support. This is especially difficult for people treated at a very young age, as they often have little or no memory of the severity of their illness.

Moving forward

The transition process can be concerning for young people and their families, particularly relinquishing the paediatrician they know and trust. For the parents or caregivers, the move to adult services marks a shift in the health perception of their child.



'Allowing the adolescent to take more control of their health means urging parents to accept their child's role and learning to provide less direct support'

Paediatrics offers a more holistic approach with a focus on the family, valuing their input throughout the care of the young person. In contrast, the adult healthcare environment encourages the individual to take control of their health. A more formalised approach to transition is being developed. This will help further prepare young people for greater independence and allow their parents or carers to step back and address their own feelings. Encouraging young adults with chronic illness to be more autonomous regarding their health involves providing a suitable education programme and this is something Diana and Tanya are keen to develop.

There is increasing interest in appropriate provision of services for young adult survivors of childhood cancer. The development of these services will depend on a new generation of nurses and doctors who are informed about childhood illnesses and are interested in their consequences. Diana and Tanya take an active role in the teaching and education of colleagues locally and nationally.

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Late effects: recognising opportunities within the nurse specialist role

Claire Taylor and Lauren Wiggins offer some advice on how healthcare professionals can help support people after treatment

There are small differences we can make to improve the quality of life for people after cancer treatment. These don't have to be onerous or time consuming – there may be reported projects and ideas which you can simply replicate. The National Cancer Survivorship Initiative website – ncsi.org.uk – is a good place to start. It contains detailed information about the initiative's work streams and test communities.

You may be supporting cancer survivors already without realising or formally acknowledging it. If so, you could make this activity more explicit or turn it into a commissionable aspect of your service. You could routinely collect data about when and why you see patients after treatment, along with reported outcomes of any interventions offered. If you already have an established service for people suffering from late effects, then it is time to share your experiences and contribute to discussions on how nurse specialists can feasibly and effectively address this issue.

Case study

In the Macmillan Urology CNS (cancer nurse specialist) service at the North West London NHS Trust, we explored several ways to help people adapt to and cope with the side effects of treatment. Since people with prostate cancer make up the majority of this caseload, a focus group was conducted with men who had completed radical treatment within the past year to identify issues important to them for their recovery and survivorship.

'It is time to share your experiences and contribute to discussions on how nurse specialists can feasibly and effectively address this issue'

The main issue for these men was the impact of treatment on their sexual function and associated sexuality – a finding that is widely demonstrated in literature.^[1, 2] They wanted an erectile dysfunction service run by someone with specialist knowledge and skills in the field, ideally a member of their existing healthcare team. This particular service is not currently available within the Trust and these findings will be used to strengthen our proposal to develop services.

Joint working

Another approach may be to team up with other professionals to provide greater continuity and coordination of care along the disease trajectory. For example, the Macmillan colorectal cancer CNS at the Trust now liaises with the stoma care nurses to support people experiencing altered bowel function following treatment.

By working together, we can provide the most appropriate

information to these people before treatment, signposting to extra help should problems occur. We have also reviewed the information patients receive on completing treatment to ensure it details possible side effects, supports self-management and generates realistic expectations of what life will be like once active treatment is completed.

Follow-up

A more challenging issue for CNS services is how we can meet the needs of people who are no longer 'in the system' and/or not seen through our regular follow-up channels. It may be about getting ourselves known at the voluntary sector level, for example, at support groups and in primary care settings or the local branch of Citizens Advice Bureau. Or we could be more creative and flexible in how we deliver our care. For instance, the Macmillan breast care nurses at our trust have established a good working relationship with the charity Cancer Black Care. Through their visits into the community, they have raised awareness of the long-term effects of breast cancer.

We have a shared goal: to help people get through treatment comfortably, recover from it, and achieve a good quality of life beyond cancer.^[3] Survivorship care creates the opportunity for clinical nurse specialists to review and revise services, and improve the support people receive.

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Related information

See this issue of *Sharing good practice* for more information on commissioning services.



Further information

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The Croakies

Sarah Cost writes about supporting people with head and neck cancer

The National Cancer Survivorship Initiative's^[1] main aim is that by 2012, cancer survivors get the care and support they need to lead as healthy and active a life as possible, for as long as possible. The Croakies support group is proving to be a step in the right direction.

People with a head and neck cancer may have a variety of treatments, which can have devastating long-term side effects. Surgery can cause speech dysfunction, eating and swallowing difficulties, and facial disfigurement. This can then affect the person's confidence and lead to social isolation. Chemo-radiation therapy also produces incapacitating side effects such as dysphagia (difficulty swallowing), xerostomia (dry mouth), trismus (inability to open mouth normally) and dental damage.

Support groups help people with cancer feel less isolated and more empowered,^[2] and based on research and my own experience, I identified the need for a support group for any person diagnosed with head and neck cancer in my region.

I collaborated with colleagues, the Bradford Cancer Support Centre and people affected by cancer. We

invited all patients on my caseload to a meeting to explore their thoughts on setting up a support group. With input from the attendees, we were able to move forward and The Croakies (named by the group) was established quickly.

Meetings are held once a month and attendance can vary from 15–30 plus. Some people may only attend once, others for a period throughout treatment, and some on a long-term basis. The nurse specialist, dietitian and speech and language therapist are usually present.

We have organised speakers from health and other organisations based on what the group members ask for. I update the group about developments within the head and neck cancer service and consult the group on any service changes or new developments, many of which have been successful due to the group's help.

The group continues to evolve and we now have a committee who help organise social outings and other activities. One of the members has designed The Croakies website – thecroakies.org.uk and last year the group secured a Macmillan support group grant for outings and food for meetings. The money has also been

put towards purchasing a laptop, projector and digital camera. We produce a quarterly newsletter and encourage group members to contribute articles. The Croakies newsletter is offered to all new patients during their pre-treatment holistic assessment, when they're also invited to the support group, and again after treatment has finished.

'The Croakies is a revelation and a very important leveller for us all'

The Croakies are becoming recognised at many different levels, not only for the support and friendships they extend to each other and every new member, but as a reference group for a variety of research projects, service developments, and as co-teachers in delivering education programmes with staff.

By learning how others cope with the diagnosis and treatment side effects, people with cancer may remain hopeful.^[3] Spouses and significant others also gain from the experiences of other family members.

As one new member points out: 'The Croakies is a revelation and a very important leveller for us all.'

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Nursing advice just a phone call away

A telephone follow-up and support clinic has improved access to lung cancer nurse specialists

The caseload for lung cancer nurse specialists (LCNS) at Oxford Radcliffe Hospitals NHS Trust is well above the national average. In 2009, there were 431 (approximately 143–144 per LCNS/year) new patient referrals for three LCNSs compared with a national average of 127 per LCNS/year.^[1] The network standard is 90 referrals per LCNS/year.^[2]

Due to this high caseload the team realised that during busy medical clinics some patients were not seen. There can be 5–6 doctors seeing patients, but there are only three LCNSs – so we cannot see everyone. Although patients have access to the LCNS telephone helpline, they may be reluctant to use this service. Many patients don't phone for help even when they know us and have our number, and despite our encouragement, they often wait until their next appointment. This has resulted in some patients having limited access to a LCNS, which is recognised as a vital source of information and support.^[1]

Methods

In January 2009, a telephone follow-up and support service was established to ensure that all people with lung cancer in Oxford have regular access to a LCNS. An electronic appointment diary was set up to ensure regular patient contact. All LCNSs could access the diary and arrange patient appointments.

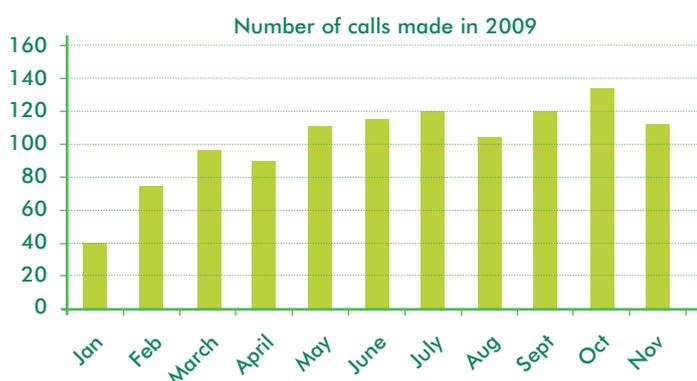
The nurses agreed on the following minimum points of contact for all people with lung cancer referred to the service:

- at diagnosis
- 2–4 weeks after diagnosis
- during treatment
- four weeks after treatment
- every three months during follow-up.

All patients are booked into the diary at the above intervals or more frequently if required, and telephone appointments are cancelled if the patient is reviewed in clinic or on the ward.

Findings

The number of telephone appointments in 2009 increased from around 40–100 per month (see below).



We analysed calls made over a two-week period to establish interventions made as a result of the telephone appointments.

Interaction following telephone appointments	Total calls
Psychological support	19
Routine follow-up and support: no specific intervention	18
Symptom management advice	14
Liaison with district nurse/Macmillan nurse	10
Disease related information/advice	9
Bring forward clinic appointment	6
Liaison with oncology	5
Financial advice	4
Treatment related information/advice	3
Referral to palliative care	3
Referral to GP	3
Chasing of investigations/treatment	2
Admission to hospital	2
Bereavement support	2

Informal feedback from patients and carers has been positive: One patient's wife said: 'I'm glad you have rung. I didn't know who to call – my husband is in a lot of pain.' From this call, the team provided symptom management advice, liaison with oncology and Macmillan nurses, and an urgent scan was requested and follow-up brought forward.

Conclusions

The telephone follow-up and support clinic is an effective way of ensuring all people with lung cancer receive regular contact with the LCNSs. It often leads to specialist interventions, including early intervention in response to problems, early referral onto other specialist services, information giving, symptom management advice, financial advice and psychological support.

Despite the significant impact on the team's time, we feel that the new service greatly improves the quality and equity of care. It is viable in terms of current workload and the nurses would like to continue to offer the service. We are in the process of gaining formal patient feedback on the clinic.

References

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Dealing with requests for wills

Dr Russ Hargreaves, Macmillan Cancer Information and Support Manager, says conversations about wills and legacies don't have to be awkward

People with cancer often want to know that their loved ones are provided for, wherever their cancer experience leads them. But knowing what advice to give about writing a will can be tricky.

Will writing

Will-making packs available in stationers may seem fine, especially if someone's wishes appear straightforward. But these packs can be inappropriate if a family set-up is complicated, the distribution of someone's worldly possessions is complex, or where legal procedure isn't followed.

Many of the people I've spoken to feel that solicitors' charges are too high. However, a little investment early on can avoid a lot of issues later, and Macmillan always recommends consulting a solicitor. A professionally drawn-up will is key to ensuring that it is legally binding and that loved ones will be provided for as intended.

Best practice means that we never recommend any one solicitor, and Macmillan doesn't currently offer a will writing scheme. However, the Legacy team is happy to print and provide a list of local probate and will solicitors to approach, who are registered with the Law Society.

Being clear about your wishes before meeting a solicitor may help minimise the cost. The Legacy team has a simple *Step by step guide* to help people answer some of the important questions, like what they have to pass on and who should they include in their will.

Bedside manner

One of my most recent requests came from a gentleman who was struggling to find a solicitor who would visit him in hospital to discuss his will. Not all solicitors will make 'house calls', but he was keen to remember Macmillan in his will and I didn't want to turn him away without any support. I sought permission to pass on his details and referred him to the Legacy team. A Macmillan legacy adviser soon met



Dr Russ Hargreaves: getting advice from the Macmillan Legacy team

him over a cup of tea to talk through his concerns. Though Macmillan can't give legal advice, the meeting was of comfort to him.

Witnessing a will

On a number of occasions I've been asked to act as witness to people's wills. Having taken advice on this, I now politely decline getting involved, especially as anyone who could be seen as a benefactor should not witness a will. Although not personally benefitting, my centre may have done, so I suggest approaching others less involved in the person's welfare.

Executorship

Witnessing is different from Macmillan acting as executor to someone's estate after they've died, which we can often be asked to do if the patient has no family or friends to rely on.

Macmillan doesn't have the resources to provide a dedicated executorship service as some other charities do, but we do have the necessary legal status to be appointed as one. So again, I turn to the Legacy

team to advise the patient directly on a case-by-case basis.

By asking the experts to talk to enquirers directly, I no longer worry about giving misleading advice. It means peace of mind for me, as well as for patients.

Related information

Legacy fundraising leaflets, postcards, and display posters are all available to order free on be.macmillan.org.uk Macmillan's guide to wills and legacies, *Family. Friends. Macmillan?*, includes a *Step by step guide*, and is available from the Legacy team.

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Prioritising cancer medicines

Developing a process for funding cancer drugs

A new tool to rank and fund cancer treatments has improved the South East London Cancer Network's recommendation process.

In 2007, oncology and haemato-oncology consultants in the network were asked to choose the medicines they would like to see funded during 2008–2009. A small group then developed a scoring tool to evaluate each selected drug or regimen based on the following factors:

- magnitude of benefit (eg, survival)
- quality of life
- cost-effectiveness
- alternative available treatments
- strength of evidence.

Comprehensive literature searches were conducted for all regimens and the results were taken to clinical scoring panels. The group assigned a score to each of the regimens. The first four items were scored with a numerical value and the strength of evidence was assigned a letter. The highest score – 20A – reflecting good evidence to prove good clinical benefit, the lowest score – 0A – indicating good evidence to prove poor clinical benefit.

The preliminary scores from the panels were sent to lead clinicians who were asked to consult with their colleagues and confirm whether they agreed with the scoring or not. A seminar was then held with lead clinicians, commissioners, patients and carers. The scoring for each regimen was discussed and agreed at this event. The final scoring led to a colour-coded priority list:

- red – low scoring regimens
- green – highest scoring regimens
- amber – medium scoring regimens
- blue – regimens where the patient experience is improved or there are service delivery savings.

A recommendation was then made for the regimens listed as green or blue to be funded once they had a positive London Cancer New Drugs Group (LCNDG) review. The LCNDG has made recommendations about the efficacy of cancer medicines to acute Trusts and primary care trusts (PCTs) in London since 2002. However, access to high-cost cancer medicines in England and Wales is largely governed by the National Institute for Health and Clinical Excellence (NICE) and PCTs are required to fund medicines which have been approved by NICE.

Of the 34 regimens considered, five were recommended for immediate funding as they had already received a positive recommendation from the LCNDG. A further four regimens were recommended for funding, should they receive a positive LCNDG review during 2008–2009.

The Pan-London process for 2009–2010

In the summer of 2008, the London Cancer Networks Board proposed to the London Commissioning Group that a similar piece of work should be undertaken across London for commissioning cancer drugs for 2009–2010. The methodology was derived from the scoring tool used in south east London in 2008–2009.

The process was overseen by a steering group from the five London cancer networks. A list of new cancer regimens was compiled by reviewing the NICE work plan for cancer drugs up until April 2010; the work plan of the LCNDG; and by asking cancer clinicians in the five networks to recommend new cancer treatment regimens they wished to use in 2009 and 2010. This produced a list of 94 regimens.

Scoring panels were completed and a seminar including lead cancer clinicians, commissioners and users took place in November 2008. In a similar manner to the year before, recommendations for funding were made and agreed. All recommendations to fund new treatments were dependent on a positive assessment by the LCNDG.

Unfortunately the recommendations made for funding were not universally taken up across London during 2009–2010. Despite this, the work has continued and the process has been repeated for 2010–2011. In addition, four cancer networks in south east England joined the five networks in London to participate in the process, thereby providing a single process for the prioritisation of cancer medicines for around 13 million people living in greater London and south east England.

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Empowering professionals to improve cancer services

A group of information and support managers are improving their services through reflective practice. Named PRACTISS, the group aim is to learn from the workplace using Action Learning methods or 'focused conversation' (listening, questioning, clarifying, reflecting back and helping). A key part of PRACTISS is the opportunity to reflect on work issues with peers.

What is the Action Learning process?

Presenters talk through an issue, problem or opportunity, expressing feelings as well as stating facts. The presenter should decide on what to bring to the Action Learning set using the following guidance:

- Is the challenge important, significant, complex and real?
- Does anyone need to approve my choice of issue?
- Am I certain I will be able to take action on the dilemma?
- What is the time frame for making progress on the issue?
- How would I feel if I were not able to resolve this problem?

Supporters then ask questions to clarify the issue and help the presenter to think their problem through. The presenter then agrees some action points to be worked on before the next meeting. The actions should be realistic and focus on the issue, problem or opportunity presented.

Learning review

The whole group discusses what was learnt during the session. Often newcomers are surprised at how the supporters learn as well as the presenters in the process.

Key skills honed during the PRACTISS sessions include:

- listening
- being objective
- thinking about work
- assessing what we hear
- sitting with our confusion until it clears
- mulling over the scenario presented
- asking good questions/challenging/resisting giving advice
- holding silences when silence is the best thing we can offer.

An example of reflective practice – promoting a service and its identity

At a recent PRACTISS day, a cancer information and support manager presented a work-based issue for exploration within the group and came away with ideas of her own on what to do next.

'As part of my remit I have to promote and market our service. Despite all my best efforts I still find that there is a real awareness gap around the Trust and primary care about what we offer.

'When I do presentations to health professionals about the centre, I struggle to state what it is we do that's different. I expect from a business point of view I am trying to find our "unique selling point".

'If we could identify our distinct qualities, we could promote ourselves more effectively. If I could just identify that exclusiveness, it would help me to develop a plan on how we could better fit into the cancer team.

'We have over 3,000 contacts a year and our feedback from those contacts is excellent, but how can we raise our profile?

'What do we really do that's different and unique and how can we use that to raise our profile?'

Macmillan information and support manager

Following on from the group discussion she is now planning to conduct an audit among her service users to look at expectations and perceptions of the service.

The session helped her identify what her service had to offer and she was now going to see how that fitted with what service users needed and wanted.

Positive feedback

Group members have found the PRACTISS sessions very useful, commenting: 'It allows me to feel part of a team. It fulfils clinical supervision for nurses, allows for problem-sharing, and provides colleague support, which is important in a job that is often isolating.'

PRACTISS may not make perfect, but it can help and encourage professionals to improve cancer support services.

Related information

Macmillan's *Promoting your service* toolkit can be found at macmillan.org.uk/learnzone



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Building palliative care services in Tanzania

Palliative care teaching workshop in a rural health centre

Macmillan GP Adviser Dr Charles Champion-Smith and his wife Sue, a nurse, spent 14 weeks volunteering in the country's Tanga region

The aim of our visit was to help introduce palliative care to the Korogwe district. We were determined to build local capacity by mentoring local health leaders in teaching, clinical assessment and treatment, bringing about improvements that would be sustained after our stay.

Korogwe, with its 110-bed hospital, is the centre for a rural area with many villages scattered across the plain and in the Usambara mountains.

The *Palliative Care Toolkit*, developed by Help the Hospices and the World Palliative Care Association, provided excellent resources for our teaching. Its message, 'there is never nothing you can do', was appropriate for an area where health resources are limited. There is a KiSwahili translation of the tool kit and this proved invaluable as many of the healthcare workers had limited English.

Presentations at the hospital's interprofessional clinical meetings introduced the concept of palliative care and the need for this to embrace physical, social, psychological and spiritual aspects. Later we explored pain assessment and the use of oral morphine (previously not available locally) and other drugs and approaches for managing symptoms.

A core local palliative care team was formed with a charismatic nurse coordinator, a skilled clinical officer,

the hospital pharmacist, an HIV/AIDS NGO representative and the newly-appointed hospital matron.

Many people in palliative care were based in the community so we decided to hold a series of meetings in local health centres and dispensaries.

The teaching was delivered in KiSwahili by the local healthcare professionals with our support. Participants shared their views of the care they would wish for themselves or a family member. Presentations about the concept of palliative care and teamwork followed. Participants were asked to reflect on the relevance of this to their own working situation. Practical tools for the assessment of pain were demonstrated in role plays and we used role play to show non-verbal aspects of good and poor communication.

One hundred and sixty health workers participated in the six sessions. We also taught nursing students, a local HIV/AIDS patient group and the local interfaith religious leaders group. This resulted in Muslim and Christian faith leaders agreeing to work together to provide spiritual care.

In addition to the formal teaching, a practical palliative care approach was modelled by working alongside the nurses and clinical officers in the wards and clinics. A supply of oral morphine was obtained and procedures put in place to safely dispense and

administer it. A local palliative care register was established; most patients received only symptomatic care but a few were referred for palliative radiotherapy.

With huge and competing demands for the time, attention and energy of health workers in Tanzania, there were concerns that the work established might not continue. However, three months after we returned to the UK, more people have been identified in need of palliative care and received appropriate assessment and care as a result.

We came away impressed by the enthusiasm and passion to improve services shown by the professionals we worked with. We were also struck by the stoicism of local people whose expectations of the health service are very modest. The welcome we received and friendships we made created a special experience for us both and helped us focus on what is truly important in caring for people, wherever they are.

Further information

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Photodynamic therapy explained

Carol Goodman, Clinical Nurse Specialist, provides an overview of the treatment and its uses

Photodynamic therapy (PDT) combines non-toxic photosensitising drugs and visible red wave-length light (or a laser) to kill cancer cells. It's well-suited as a palliative treatment for some internal tumours that block the airway or gullet, providing symptomatic relief. It can be used before or after chemotherapy and radiotherapy. PDT is particularly effective in treating early tumours and pre-cancerous lesions where chance of morbidity is low. This is because there is less tumour to treat or it may prevent the pre-cancerous cells from becoming cancer.

The drug can be applied topically as a cream on the skin and systemically via injection into a vein. The addition of oxygen (in the atmosphere) produces a cytotoxic effect that causes cell death. Systemic PDT is used in:

- advanced bronchial carcinoma for palliative symptomatic relief
- bronchial carcinoma in situ
- cholangiocarcinoma (bile duct cancer)
- fluorescence guided resection/surgery in brain (glioblastoma, pituitary adenoma)
- high-grade dysplasia/Barrett's oesophagus
- head and neck cancers
- dermatology.

In dermatology, a topical photosensitising cream is applied to the skin surface and then a red light or laser illuminates the lesion. It is very effective in actinic keratosis, superficial basal cell carcinoma, Bowen's disease, and thin nodular basal cell cancer with good cosmetic effect.

Systemic PDT is not suitable for every type of cancer because it relies on tumour accessibility, via endoscopy or surgical resection, where a light can be focussed onto the tumour. Light transmission through tissue is also a limiting factor because PDT is only effective to a depth of 1cm from surface. This restricts the use of PDT for larger or more invasive tumours.

Side effects

Skin sensitivity is an easily controlled side effect of systemic PDT. Patients have to avoid very bright, direct indoor light or direct sunlight for around 6–8 weeks. They can experience sunburn if exposed to sunlight, but this is readily treated and easily avoided with careful counselling on simple precautions. These are minor adverse effects compared to those associated with other forms of cancer therapy.

PDT does not damage surrounding tissue and scarring is minimal. It can be repeated as often as necessary.

The future of PDT

The future of PDT continues to be positive with its place in the increasing choice of suitable treatment for specific conditions.

There are trials in the UK, USA and Europe looking at the use of PDT to treat pancreatic cancer, ureteric and bladder cancer. These tend to be in the early phases of the disease



Consultation: discussing photodynamic therapy

and have very strict inclusion criteria and are therefore not always a viable option.

'The future of PDT continues to be positive with its place in the increasing choice of suitable treatment for specific conditions'

In the PDT centre in Dundee we have been investigating the tumour detecting possibilities of Photodynamic Detection (PD). This is when a tumour is made to glow or fluoresce in areas of non-tumour tissue. This happens when a PDT drug is administered but an ultraviolet light is shone on the tissue. This light does not treat the tissue but it makes cancer cells glow so that they can be removed safely. This is particularly useful in the bladder, ureter and in the brain where we can identify small spots of cancer cells left following surgical resection of tumours.

PDT can be accessed through the NHS if the trust offers it as a service, or health professionals can refer their patients to a centre in the UK.

Related information

You can find more information about PDT on our website at macmillan.org.uk/cancerinformation

Further information

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Information

Long-term and late effects of cancer treatment

For professionals

NHS Improvement

www.improvement.nhs.uk/cancer

NHS Improvement is working to deliver and build sustainable improvements across cancer care, including late effects. Its publication *Providing the evidence to achieve improvements for patients*, includes improvement stories from the 10 children and young people test sites.

National Cancer Survivorship Initiative (NCSI)

www.ncsi.org.uk

The NCSI is working to get survivors the care and support they need. Seven work streams have been established, each focusing on either a stage in the 'survivorship pathway' or a cross-cutting theme. A vision document can be downloaded from the website and more information on the NCSI's work in late effects can be found at ncsi.org.uk/consequences-of-cancer-treatment

Scottish Intercollegiate Guidelines Network: Long-term follow-up of survivors of childhood cancer, 2004

www.sign.ac.uk/guidelines/fulltext/76/index

This guideline is aimed at primary care staff who look after cancer survivors, as well as secondary care and long-term follow-up clinic staff who manage the long-term care of this group.

The Children's Oncology Group: Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers, Version 3.0 October 2008*

www.survivorshipguidelines.org

These guidelines provide recommendations for the screening and management of late effects. The recommendations are based on a thorough literature review and the collective clinical experience of the task force members, panel of experts, and multidisciplinary review panel.

Macmillan Cancer Support: It's no life, 2009

www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Campaigns/itsnolife.pdf

Macmillan outlines some simple measures that can, and should be, introduced to support cancer survivors.

National Cancer Institute: Office of Cancer Survivorship* cancercontrol.cancer.gov/ocs

The Office of Cancer Survivorship conducts and supports research which examines and addresses the long and short-term physical, psychological, social, and economic effects of cancer and its treatment among paediatric and adult survivors of cancer and their families. Its website contains a wealth of information on cancer survivorship for both health professionals, patients and the general public, including information and research on the late effects of cancer treatment.

Research studies

There is a wide range of research on the late effects of treatment in cancer survivors. For a list of studies recently published in medical and healthcare journals, email Edward Wallace, Library and Information Specialist, at ewallace@macmillan.org.uk

For the public

Cancer.Net: information on the late effects of cancer treatment*

www.cancer.net/patient/Survivorship/Late+Effects

Cancer.Net brings the expertise and resources of the American Society of Clinical Oncology to people living with cancer and their carers. All content is subject to a formal peer-review process.

LiveStrong: information on the after-effects of cancer treatment*

www.livestrong.org/Get-Help/Learn-About-Cancer/Cancer-Support-Topics

Founded by champion cyclist and cancer survivor, Lance Armstrong,

LiveStrong works to identify the issues faced by cancer survivors to improve the quality of life for everyone living with cancer.

The National Coalition for Cancer Survivorship (NCCS): Cancer Survival Toolkit*

www.canceradvocacy.org/toolbox

The award-winning *Cancer Survival Toolbox* is a free, self-learning audio programme developed by leading cancer organisations to help people better meet and understand the challenges of their illness. The programme contains a set of basic skills to help navigate a diagnosis and special topics on key issues faced by people with cancer, including dealing with the after-effects of treatment.

CureSearch*

www.curesearch.org

The CureSearch website provides information on the late effects of a range of childhood cancers.

* An asterisk indicates an American organisation; therefore some of the information on these websites may not apply to cancer treatments or healthcare systems in the UK.

Upcoming events

September

24 September 2010

World's Biggest Coffee Morning
coffee.macmillan.org.uk

October

Breast Cancer Awareness Month
www.breastcancercare.org.uk

November

4–5 November 2010

Macmillan professionals event,
Heathrow
www.macmillan.org.uk/learnzone

5–6 November 2010

Event for Macmillan Information Professionals, Heathrow
Email rcarlyle@macmillan.org.uk

Lung Cancer Awareness Month
www.macmillan.org.uk/lung

WE SHARE RESOURCES

Updated resources



Men and cancer MAC5768_10

This comprehensive booklet looks at cancer from a male perspective. It discusses the stages men go through when they have cancer and provides information on specific cancers affecting men.

Cancer survivor's guide MAC5769_10

This booklet provides emotional and practical information for people who have finished their cancer treatment. It also lists sources of further information and support.

I'm still me MAC6706_10

This booklet is for 12–21 year olds living with cancer. It answers some of the questions they may have and offers tips to cope. It also includes insights from young people who have lived with cancer.

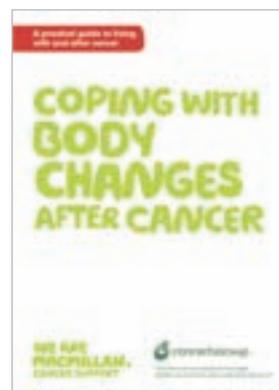
'I will definitely use this resource in my teaching'

Professional reviewer for *I'm still me*.



Macmillan resources catalogue MAC5782

Look out for your updated copy of the resources catalogue in the post. It lists our full range of publications, including information for people affected by cancer, professional development resources, and materials to promote your service.



Coping with body changes after cancer treatment MAC12525

This booklet explains some of the ways in which your body can change after cancer treatment. It covers the physical and emotional effects, and suggests ways of dealing with them.

Late effects of cancer treatment booklets



We have two new booklets for people who are experiencing long-term or late effects of cancer treatment.

Both titles cover the emotional and practical issues people may face while living with long-term or late effects, and suggest other useful organisations that can provide further support.

Managing the late effects of breast cancer treatment (MAC12161) provides useful information on some of the physical changes women may experience following treatment, for example a change in arm sensation or shoulder strength, plus advice on how to cope with changes.

Managing the late effects of bowel cancer treatment (MAC12162) explains what changes can occur to bowel, bladder and sexual function following surgery, plus tips on making changes to your diet. The booklet includes a food chart with advice on which foods to eat or avoid depending on the late effects experienced.

Visit be.macmillan.org.uk or call **0800 500 800** to order these resources for free.