Issue 48 spring 2009

Macmillan VOICE

for Macmillan professionals

In this issue

Celene Doherty
Macmillan Cancer Information Nurse Specialist

Sharing good practice
Professional development

Cancer genetics
Nurse prescribing
Look Good...Feel Better

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 freelance editor Katie Woolley at **katiewoolley@gmail.com** or call her on **07810 252658**.

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.

Note: we hope that you will share news and learning, but we are not able to promote books that you may have had published outside of the NHS.

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PRESCRIPTION CHARGES EXEMPTION COMES INTO FORCE

Macmillan is delighted that people living with cancer are now entitled to free prescriptions.

Macmillan has been campaigning since 2005 to ensure people with cancer do not have to pay prescription charges. The prescription charges exemption came into force in England on 1 April 2009 and applications for certificates received by 24 March were processed in time to be used for 1 April. Anyone who did not apply for a certificate in time will be refunded any prescription charges they have paid since April. Exemption certificates last for five years (but can be reapplied for) and cover all prescriptions, not just those relating to cancer. They must be countersigned by a GP, hospital doctor or service doctor.

Thanks to everyone who got involved and helped make this campaign a success.

For more information go to www.dh.gov.uk/helpwithhealthcosts

Our campaign led to the abolition of prescription charges in Wales in April 2007; Scotland is phasing them out by 2011, and from January 2009, the cost of prescriptions in Northern Ireland will be reduced to £3 per prescription and will be free by April 2010.

Developing a kitemark for good cancer facilities

In December 2007, the Cancer Reform Strategy for England was launched. It included details of the Department of Health and Macmillan working together to develop a kitemark for good cancer facilities.

Nicola Cook was appointed as Project Manager for this area last autumn and work is now underway to develop the kitemark, which we hope to launch UK-wide in 2010. It will be open not just to NHS cancer facilities but also to those in the private sector, hospices and other charities. The kitemark will be the first national, cancer building award in the UK. The award will recognise excellence in healthcare environments and will be be used as a tool to improve the quality of the buildings used by people affected by cancer.

We are currently working with local cancer networks in England, and their equivalents in the other nations, to make an assessment of the quality of current cancer facilities and to identify the criteria/standards of the kitemark. In late spring we will be holding a series of workshops for people affected by cancer and key stakeholders, including NHS Trusts and other charities, to share our thinking and test the criteria to be included in the kitemark.

A small pilot will take place in November before the kitemark is launched in 2010.

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Macmillan nurse sets the standard abroad

Mr Mitchell and Julie Hoole from the Yorkshire team with Dr Abdul-Hakim and team in a clinic setting in Misurata Dental Centre, Libya

Macmillan Head and Neck Cancer Nurse Specialist Julie Hoole has travelled a long way since she was appointed as a Macmillan project nurse in 2001.

She has worked extensively with the head and neck team at the Mid Yorkshire Hospitals NHS Trust, piloting a nurse specialist role to develop a first-class service. Her work has been recognised by a sabbatical to California, where she participated in an exchange programme for one month. She has also been invited by the director of Sabratha Teaching Hospital in Libya to be part of a team looking at developing a similar head and neck oncology service there. Julie flew to Libya in January and hopes to report back soon.

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Free DVD encourages user involvement

A film about user involvement – *User Involvement and You* – is now available free of charge to all health professionals, thanks to the User Partnership of the West London Cancer Network. They found that healthcare professionals may sometimes need help in understanding how to involve users and why, beyond simply asking users to fill in a questionnaire.

The film was developed with the help of one of the network group members, BBC-trained Theatre Director, Lou Stein. Although Lou's company, Lou Stein Associates Ltd., was instrumental in developing the film, Lou credits the group as a whole, who wrote and researched it, and took part in the role play sessions, for giving the film its spirit and humour.

The idea was not to produce a definitive report, but to show the partnership aspect of users and professionals working alongside each other to reach a shared goal. The team received support along the way with financial backing from the West London Cancer Network and advice from Macmillan.

The film comprises a series of interviews with three experts in user involvement - a cancer nurse consultant, a consultant surgeon and a user. They comment on the advantages of getting patients and carers involved, and some of the difficulties too. Their interviews are interspersed with excerpts from a day of filmed role playing, starring Macmillan Lead Nurse for Cancer and Palliative Care, Lorraine Barton. The role playing involved users playing the part of healthcare professionals and vice versa. The idea was to introduce a series of light-hearted interludes that help illustrate what the three experts say in the interviews.

The DVDs will be distributed to healthcare professionals, those who train them, and those who plan, develop and deliver healthcare services.

For a free copy please contact the West London Cancer Network on 020 7150 8084.

Online cancer family history course

Macmillan and the Department of Health's Cancer Genetics Partnership have recently published an interactive e-learning module called *Cancer and genetics: an up to date guide*.

The guide is published as a free online learning course by BMJ Learning. It is designed to give GPs, practice and community nurses, secondary care doctors and doctors in training a basic understanding of cancer and genetics, emphasising the importance of family history as a risk factor for cancer. There is no charge for access to the course, although a short registration form needs to be completed to enable access to the material.

To access the course visit http://learning.bmj.com/cancergenetics

For more information about the Macmillan/Department of Health's Cancer Genetics Partnership contact Janice Koistinen j.koistinen@warwick.ac.uk

MACMILLAN'S AMBITION

Following research completed in 2008 we now know that there are two million people living with cancer. We also know that people are not just affected whilst having treatment, but often long after this has completed. The impact of a cancer diagnosis is much wider than the physical symptoms; it impacts on the practicalities of day-to-day life, and can have serious financial and emotional effects.

'Our ambition is to reach and improve the lives of everyone living with cancer.'

We estimate that in 2008 we reached one in two people living with cancer. We also want to ensure that we are reaching their carers and families as well. Our ambition is to reach and improve the lives of everyone living with cancer.

What does our ambition really mean?

Reach – we are developing many integrated ways for people affected by cancer to get the help and support they need, eg through our Macmillan professionals, our information materials and services, our helplines and our website.

Improve – we want to improve lives by being a source of support (via our services) and a force for change (via campaigning and influencing policy makers at national and local levels).

Everyone – we want to improve the lives of everyone affected by cancer regardless of age, type of cancer, where they live or what community they are a part of.

Living with cancer – we encompass the whole cancer journey from the point someone suspects they might have cancer, to living with and possibly dying of cancer.

Macmillan's corporate strategy

Often people who are dealing with a cancer diagnosis or undergoing treatment are not aware of Macmillan and the broad range of support that they can receive. They often associate Macmillan with nurses and palliative care only.

'Macmillan is about 'living with cancer' throughout the whole cancer journey.'

Our strategy is to help people understand that Macmillan is about 'living with cancer' throughout the whole cancer journey.

We will focus our work on the needs of people affected by cancer in terms of:

Healthcare – developing new services that address gaps/inequalities in current provision to improve well-being, experience and outcomes for people affected by cancer.

Information & Support – developing a world-leading cancer information and support system for the whole of the UK, enabling us to support people coping with the medical, emotional, financial and practical consequences of their cancer. For those contacting Macmillan directly there will be a new Direct Cancer Information and Support Service providing access to specialist nurses and other healthcare professionals, as well as benefits advisers.

Lifecare – focusing on both financial support and advice for people living with cancer, their carers and families, and new models for providing emotional and practical support mainly through the use of volunteers. One such pilot project in 2009 will be Macmillan Solutions (see the winter 2008 edition of *Macmillan Voice*).

Thought leadership – we will concentrate on raising our profile as a thought leader in survivorship, information, end of life care and inequalities.

Research – we want to build our evidence to understand more about the impact of our work and to drive forward our services in the future.

'In 2008, we raised a staggering £118.6m'

Of course none of this is possible unless we have strong fundraising. In 2008, we raised a staggering £118.6m. As we face a declining economic environment this becomes more challenging. While Macmillan is in a strong position to face this challenge we do need to monitor the situation closely and have contingency plans in place that will ensure we spend in line with our core strategic priorities.

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Cancer services team commended for new rural care services

From left: Cathy Brown, Breast CNS, Nicholas Owen and Barbara Maxwell, Macmillan CNS, collecting the award on behalf of the team

Image courtesy of Pfizer Limited

A team of Macmillan nurses has been highly commended for providing top-class care to a rural population in Scotland.

The team was selected as a finalist at the Excellence in Oncology Awards in Birmingham in October 2008. The event was organised by the British Oncological Association and Pfizer and hosted by BBC News 24 presenter Nicholas Owen – a survivor of kidney cancer.

The service, provided by the Dumfries and Galloway cancer services team in the south west of Scotland, was held up as a 'shining example' of how patients who live far from cancer centres can be cared for.

The team were instrumental in setting up clinics at Dumfries and Galloway Royal Infirmary. These are staffed three days a week by visiting oncologists from Edinburgh – the nearest cancer centre, which is more than 75 miles away.

To further strengthen the services available to patients, the team developed nurse-led chemotherapy prescribing and ovarian screening clinics.

In October 2008, a nurse-led chemotherapy outreach service was also launched at rural Stranraer. This service saves some patients a 150-mile round trip for treatment in Dumfries.

Over the next three years, Macmillan will contribute £224,000 to establish the outreach service at Galloway Community Hospital.

The judges said:

> **'The oncology nurse team from Dumfries and Galloway should be praised for providing an excellent service to patients in a challenging geographical situation.'**

> **'Their hard work has resulted in a vast improvement in access and uptake of chemotherapy within a very rural population.'**

> **'This well executed and worthwhile initiative is understood to be ahead of national guidance and therefore should be recognised and commended.'**

Further information
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Bedfordshire Macmillan Welfare Rights Team win award for partnership initiative

The newly developed Bedfordshire Macmillan Welfare Rights Service was recently recognised for its excellent service at an awards ceremony celebrating the best in local government service delivery.

The service came first in the category of best public/voluntary partnership working initiative at the 2008 Association of Public Service Excellence (APSE) Awards hosted by Nottingham County Council. APSE is a not-for-profit local government body working with over 300 councils throughout the UK to promote excellence in public services.

In 2006, a need was identified by Bedfordshire County Council for a benefits advice service specifically for people living with cancer. The service was launched in April 2007, building on the reputations of Macmillan and the Bedfordshire County Council Welfare Rights Service, who have both proven that providing good-quality, informed advice at a vulnerable time can make a difference financially and improve a person's quality of life. The welfare rights service works alongside the Macmillan nursing team to ensure that clients receive the most up-to-date advice and support available.

The service employs two experienced benefits advisers, and one dedicated administrator. Its success is due to excellent procedures to process new referrals, swift contact being made with clients, and a triage system to prioritise home visits for clients to receive comprehensive benefits advice and assistance with making claims. The service has gone from strength to strength, gaining over £2.2m in benefits and grants for clients in its first year 2007/8.

From left: Annabel Croft, Glenda Clark, Gary Johnson, Madeline Russell, Anne Furlong, Peggy Meredith, Karen Handscomb, Charlie McNally and a representative from the sponsor, Eversheds

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Award-winning research shows the benefit of regular swallowing assessments

Katy Gray, Macmillan Speech and Language Therapist at the Edinburgh Cancer Centre at Western General Hospital, recently came to the attention of experts at a laryngeal cancer conference in London. Katy was awarded the prize for the best short paper presentation at the Laryngeal Cancer Treatment and Functional Outcomes Conference in October 2008 for her work involving a clinical audit project.

Katy's research looked at head and neck patients with early laryngeal cancer who develop swallowing problems during radiotherapy treatment.

She found swallowing assessments at the start of radiotherapy, and regularly during treatment, can help to identify difficulties early on, and help reduce the impact of serious problems related to swallowing.

Some patients who receive radiotherapy can develop complications such as chest infections. However, regular contact with a speech and language therapist can mean problems are picked up early, before they require hospital admission or antibiotics.

> **'I really enjoy the clinical work as part of my Macmillan post, but I have also been grateful for the dedicated time within the post to carry out clinical audits and a research project with a dietitian'**

Katy said the speech and language therapist is an important part of a multidisciplinary team offering support and treatment to head and neck cancer patients with communication and swallowing difficulties.

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Legacies change lives – you can help

'What an eye opener. I had not appreciated what a wide field Macmillan supported. It was an excellent and very informative presentation.'

Legacy event attendee

Fundraising Manager Heather Walkington speaks at a legacy event at Browsholme Hall, Clitheroe

This was the reaction to a presentation by a Macmillan professional at a legacy event in November 2008. These events are a great way for our supporters to hear about the inspirational work that you and Macmillan do – and for the Legacy team to explain the vital importance of legacies to our funding. Legacy events take place at venues of special local interest (stately homes, art galleries, museums etc) across the country. We aim to host a further 20 events during the spring and summer of 2009.

What happens at legacy events?

The events are an opportunity to inform our supporters of the broad range of work Macmillan carries out, and in particular to tell them about what we're doing in their local area. At previous events, Macmillan professionals have helped bring to life the local picture by talking about their roles and day-to-day work. Supporter feedback has shown that there is nothing more inspirational (or indeed motivational) than to hear firsthand about the real difference Macmillan makes to people's lives.

We're always looking for Macmillan professionals to get involved and share their experiences of supporting people affected by cancer, so please get in touch if it is something you'd like to consider.

'Every gift is precious. Even the smallest gifts can make a vital difference to the lives of people living with cancer.'

How you can help

We know that not everyone will have time to get involved, but there is another very straightforward way that you can help. Macmillan professionals tell us that they occasionally receive queries about will-making and legacies. This can be a legal minefield, so we always suggest that you refer any queries to the Legacy team, who will be happy to help. It is best to seek advice to avoid compromising situations, such as being asked to witness a will by a patient (which can invalidate a will due to your professional position).

With gifts in wills accounting for over a third of all the money given to us by supporters each year, we're sure you can appreciate the vital role they play in allowing us to provide our services. Every gift is precious. Even the smallest of gifts can make a vital difference to the lives of people living with cancer.

The Legacy team is here to help both you and our supporters and can offer specialist advice, guidance and support to anyone who is considering remembering us in this way.

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CAMPAIGN PRIORITIES FOR 2009

Getting back to work

You probably know that there are two million people living with or beyond cancer in the UK, but did you know that this includes 774,000 people of working age? These people often have a strong attachment to the labour market; they need to work to earn a living and want to work because to do so is 'normal'.

Sadly, the after effects of cancer and its treatment can be 'work-limiting' and people affected by cancer tell us that they are less likely to be able to work in their preferred job. Many talk of the deterioration of their working life. Despite these facts, it is unusual for a person affected by cancer to receive any advice about returning to or remaining in work as they go through treatment.

NHS rehabilitation services have the expertise to help but it remains rare for someone with cancer to receive such support. Rehabilitation services are patchy and often do not have the capacity or the focus on return to work that is necessary to support someone with cancer.

Macmillan has launched its Working Through Cancer campaign to develop solutions to these problems.

Fuel poverty

According to an online survey for Macmillan, more than two-thirds of people with cancer who are struggling financially say that paying fuel bills is their biggest money worry.

For cancer patients spending more time at home during treatment or recovery, this means higher energy use leading to higher bills. Our survey found that nearly 70% of those using more fuel blame the increase on feeling colder since their diagnosis.

We are calling on the Government and energy companies to provide more support for people with cancer struggling to cope with rising fuel bills. A research survey for Macmillan found that 71% of the public agreed that people with cancer should get help with their fuel bills.

People across the UK have got involved to help freeze out fuel poverty and almost 1000 online pledges of support have been made to raise the issue with MPs and local papers.

Sexual relationships

In May, we are launching our new sexual relationships campaign. This campaign is informed by a survey Macmillan conducted to find out if people with a cancer diagnosis were spoken to by their health professional about the potential impact of cancer on their sexual relationships. We found that nearly 70% of patients were not spoken to, yet a third of those experienced problems in their sexual relationships as a result of having cancer.

The NICE clinical guidelines have specific recommendations about sexual function, but our research suggests that these are not being fully implemented by clinicians. We are calling for health professionals to talk to patients about the impact of cancer on their sexual relationships at the earliest possible opportunity and for professionals to direct patients to information and support services specifically about sexual function and cancer.

Social care and cancer

Many people affected by cancer need access to practical services. These services can include help with housework, emotional support services and information and support. In May 2008, the Government launched a six-month consultation on the future of social care for adults in England. Macmillan took this opportunity to tell the Government what people living with cancer need.

Our research found that people with cancer and their carers are not being referred to social care for assessment, and struggle to access the services they need. The consequences of this lack of support are that people's needs can escalate, resulting in costly and inappropriate hospital admissions.

Our response was that people living with cancer and their carers must be better supported by health and social care services. We want commissioners and social care staff to better understand the needs of people living with cancer. Commissioning needs to be improved by having joint priorities across health and social care, shared outcome measurements and involving users in the whole of the commissioning cycle. Local authorities need to recognise that investing in preventative services can save money in the long run and services can be effectively delivered by innovative partnership services involving volunteers.

The Government will publish a green paper setting out its plans for reform of the social care system this spring. We hope any new system will better support people living with cancer and their carers.

Celene Doherty

Macmillan Cancer Information Nurse Specialist

What is your current role?

I am a cancer information nurse specialist with the Direct Cancer Information and Support Service, now part of Macmillan but formerly Cancerbackup. Before this, I was a ward manager in the NHS. After 12 years of shift work in the NHS, I wanted to work normal hours again. This post appealed to me because I wanted a new challenge that would encompass all aspects of my knowledge and expertise in cancer care and I could continue to support people affected by cancer.

What does the work on the helpline involve?

My role involves answering phone calls and responding to written and email enquiries to the service. I work part-time and work from home on Mondays answering emails and written enquiries. This helps to achieve our target of answering 98% of emails within two working days, as many emails arrive over the weekend.

What else does the role involve?

I organise all the study days and conferences for our London-based nurses, ensuring they attend the required number of days to keep up-to-date with cancer information. I mentor new nurses, respond to media enquiries and do some radio interviews. I also do outreach talks for community groups and support others within Macmillan who require clinical input to their work. The team are involved with writing some of the former Cancerbackup factsheets and reviewing information booklets, but our publications are mainly produced by our Information Development Team.

What are the biggest challenges?

We have to keep up-to-date with all aspects of cancer information, from new treatments and drugs, to national initiatives and NICE guidance. We are able to answer the majority of questions immediately, but occasionally a reply needs more research and we arrange a call back or an email reply. Listening to some of the callers can be very emotive and you can often hear the distress in their voices. We have strategies to cope with this, such as peer support, reflective practice and regular clinical supervision.

How has the merger affected your role?

Together with Macmillan, we can reach more people affected by cancer. Our information has always been free to people affected by cancer but we have recently been able to provide our information free to health professionals. There are further support services within Macmillan, including the Macmillan benefits advice line and Macmillan grants, which we can now work more directly with. As an employee we can now access Macmillan staff benefits.

What do you most enjoy?

Hearing the understanding in callers' voices when they have taken new information on board makes me feel we offer a very worthwhile service. I recently took a call from someone with secondary breast cancer who was in pain. From her description, I recognised that she might have a potentially serious condition called spinal cord compression and advised her to go to hospital. She was extremely grateful for this information.

How would you like the role and service to develop?

I envisage the service will continue to grow so that we can support more people affected by cancer. This might involve reaching people in new ways such as through online chat forums. We'd also like to do some more work to reach those with learning difficulties and on survivorship issues. This is exciting for me as I learn new skills and gain knowledge, and the ongoing education and training provided will ensure we are all up-to-date and accurate in the information we give.

Location
Macmillan Cancer Support
Bath Place, London

In post
March 1998

'Hearing the understanding in callers' voices when they have taken new information on board makes me feel we offer a very worthwhile service.'

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The way forward: what we've achieved and where we're heading

The achievements of a cancer family history service improvement programme

As you may have read in previous issues of *Macmillan Voice*, Macmillan and the Department of Health worked in partnership to co-sponsor a cancer family history service improvement programme during 2004–2007. The programme explored new ways of identifying people concerned about a family history of cancer and providing them with appropriate advice, support and care.

In this final article about the programme, we provide a brief portrait of the West Yorkshire project, which aimed to access hard-to-reach groups. We then outline how Macmillan is sharing learning to inform the development of NHS cancer genetics services.

Service innovations in West Yorkshire

Led by the Yorkshire Regional Genetics service, this project targeted inequalities in access to cancer family history services. The project's two sites in North Kirklees and Bradford have large ethnic minority populations and high levels of deprivation.

'We knew from audits that our services weren't reaching people from ethnic minority and lower socio-economic groups. So we adopted a proactive approach,' Project Lead Dr Carol Chu said.

In North Kirklees, the project brought a cancer genetic service into the community. 'One-stop shop' clinics were set up in four GP surgeries and PCT health centres. Project staff assessed patients' genetic risk and, when necessary, organised surveillance and provided culturally sensitive genetic counselling. The project recruited staff with South Asian language skills, and worked with the Asian community and health professionals to raise awareness of the service.

> **'There are still inequalities to address, but we're very pleased with what we achieved'**

A clinic has also been set up at Bradford St Luke's Hospital. Project staff worked with clinicians to ensure that Asian patients referred to cancer units had easy access to cancer family history services when needed (the service also saw non-Asian patients). Again, the project sought staff with South Asian language skills.

Glyn Purland
Macmillan Lead, Cancer Genetics Partnership

At both sites, significantly more ethnic minority patients accessed services than in previous years. In North Kirklees the project also reached far more patients from deprived areas. 'There are still inequalities to address, but we're very pleased with what we achieved,' Carol said. Services in both sites continue.

Looking forward

Macmillan continues to disseminate learning from the cancer family history programme in its aim to improve NHS services. In November 2008 we published a new online learning course for healthcare professionals, *Cancer and genetics: an up to date guide*, in association with BMJ Learning (see news item on page 4).

In partnership with the Department of Health, we have written a chapter for the Cancer Commissioning Guidance on cancer family history services, which will be available in early 2009. The Cancer Commissioning Guidance was a key commitment in the Cancer Reform Strategy.

We have worked closely with the NHS National Genetics Education and Development Centre throughout the partnership programme, most recently contributing to their 'Genetics in mainstream healthcare: A toolkit for developing services' -www.geneticseducation.nhs.uk. The new Macmillan Community of Practice for Cancer Family History Services is picking up speed in its work to promote NHS service improvements in England.

All of this builds on Macmillan's existing involvement with cancer genetics. For instance, Macmillan now provides information specifically about cancer genetics and hosts OPERA, the Online Personal Education and Risk Assessment tool - www.cancerbackup.org.uk/aboutcancer - where people can assess their level of risk for inherited breast and ovarian cancer.

For more information on cancer family history go to www.macmillan.org.uk/genetics-programme

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Questionnaire reveals how cancer networks view Macmillan's role

Senior Macmillan Development Manager Ed Murphy investigates how cancer networks in England view Macmillan's contribution towards effecting change and improving cancer services

In 2003, the Department of Health launched *Making Partnership Work for Patients, Carers and Service Users*. This publication acknowledged that the 'NHS and the voluntary sector share a commitment to the fundamental values of equity and person-centred care' and that 'greater co-operation and partnership creates an opportunity for those values to be turned into practice'.[1]

As part of my MBA, I wanted to investigate and identify:

- Macmillan's contribution to cancer services in the NHS (Macmillan has worked with the NHS since the 1970s)
- Macmillan's contribution to bringing about change and improving cancer services
- where cancer networks see the main role of Macmillan in improving cancer services.

Research methodology and response rates

I sent a questionnaire to key senior individuals within each cancer network in England. There was a 36% response rate, with the highest number of responses coming from nurse directors. 83% of respondents were currently working with Macmillan. Respondents identified their views using a 6-point scale where 1 equals very good and 5 equals very poor. Point 6 indicates that the respondents did not know.

Research findings

When asked about Macmillan's contribution to improving cancer services in the NHS and other organisations, a huge range of answers was seen. Reassuringly, all respondents replied positively (points 1–3) about Macmillan's role in funding healthcare professionals in partner organisations. However, the respondents' views on Macmillan's support for social care professionals and its influence on improvement in cancer services were less positive. Grades in this category ranged from 2–5 and almost a quarter said they didn't know. There was also a broad range of answers about Macmillan's role in providing financial advice for people affected by cancer and the provision of patient grants.

Respondents were more positive about Macmillan's role of encouraging people affected by cancer to get involved and have their say on how services could be improved. Responses were highly positive (virtually all 1–3) about Macmillan Cancer Voices; user and support groups set up by Macmillan professionals in partner organisations; funding of user involvement facilitator posts at cancer network level; and access to small grants and resources for cancer support groups.

There were mixed answers about Macmillan's contribution through funding research, although most respondents (53%) thought that Macmillan-funded research supported and informed Macmillan's own campaigns. This might suggest there is a lack of awareness about Macmillan research and how we identify what people with cancer say their needs and wants are.

Macmillan's role in developing Macmillan professionals in partner organisations was less clear, with a range of scores for the professional resources available, education grants, regional teams and education and support.

Three priorities (from 12 categories) were rated as the highest for Macmillan in the future:

- to increase its campaigning profile to ensure cancer care is high on the agendas of all organisations with influence
- the provision of practical and emotional support for people affected by cancer
- the provision of reliable information for people affected by cancer.

No category scored as a low priority, suggesting that Macmillan's broad range of activities should continue.

Need for increased awareness of Macmillan's role

The findings indicate that Macmillan's contribution to improving cancer services is good, but there continues to be a need to raise awareness amongst cancer networks about many areas of Macmillan's work. These results may provide Macmillan with an understanding of how cancer networks view charities roles in effecting change, and could help identify areas of working in partnership in the future.

Reference
[1] Department of Health, *Making Partnership Work for Patients, Carers and Service Users*, Carolyn Heaney Grants Administration Unit, 2003.

Further information
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Food for thought

Macmillan Dietitian Fiona Ross runs a successful nutrition workshop at the Lodge Cancer Support and Information Centre in Torquay

About the workshops

The workshops are intended to be fun interactive sessions, with recipes, discussion and patients sharing their experience. They have been running on a monthly basis since 2006 and provide access to all cancer patients and their carers (within the South Devon area) to an oncology specialist dietitian. This is an important resource in an era when patients and carers are often confused by some of the conflicting nutritional information available in the media and on the internet. I am always very interested to hear how a patient might have changed their diet following a diagnosis of cancer.

Patient empowerment

The nutrition workshops are open to all patients who have had a diagnosis of cancer, and their carers, at any stage of their treatment and beyond. This presents its own challenge in that the workshop has to be general enough to meet every patient's needs but specific and flexible enough to answer individual questions. I start every session by trying to obtain topics which the group would like to cover. The questions are often very challenging, but the workshops are one of the most enjoyable aspects of my job as every group has a different dynamic and will want to discuss a different topic in-depth, such as taste changes, alternative diets, poor appetite, organic farming, and mega doses of vitamin supplements or probiotic drinks.

The workshops are designed to make the patient and their carer feel empowered and enable them to take ownership of one aspect of their own health. We have handouts on balanced nutrition, superfoods, guidelines on diet and cancer and a recipe booklet based on recipes from the World Cancer Research Fund - www.wcrf-uk.org We also provide symptom-specific information on nutritional issues related to chemotherapy or radiotherapy and advice on food fortification and nourishing diets.

Maureen, Anne, Marion, Fiona Ross, Gill and Shirley from the 'Moving On' group for patients after treatment for breast cancer

Tailored nutrition

One specific group of patients who require an individual session on nutrition are the patients who have completed treatment for breast cancer. This has been facilitated in part by doing a workshop specific to nutrition and breast cancer as part of the 'Moving On' programme run by one of our psychologists, Dr Christine Ward, and the breast care team. We can focus on issues such as weight gain during and after treatment, soya and phytoestrogens, bone health and dietary calcium. Women are provided with written information on breast cancer and diet based on recent research.

Workshop feedback

Evaluation forms have provided very positive feedback, ranging from carers finding the group a source of support, to patients being inspired to try new foods. Patients will often post or email recipes they have written after the session. I always leave a workshop having learned something new and feeling inspired and motivated by what patients have brought to the group. It has also become an efficient use of my time as I have been able to see up to 10 patients in a group who might have been individually referred otherwise.

One development which would provide an added dimension to the workshop would be the ability to do a cook and taste session for patients in the future. Watch this space!

The session is provided within my NHS time and is fully supported by Julia Steer, Lead Cancer Nurse at Torbay Hospital. Thanks to Gail and Nicky at the Lodge who book all the sessions and keep me organised.

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Related information:

You can order our *Cancerbackup recipes* booklet and our *Diet and Cancer* booklet through be.macmillan.org.uk

LOOK GOOD... FEEL BETTER

BUILDING PATIENT CONFIDENCE

The Belfast Trust's Macmillan Support and Information Centre has been working with Look Good...Feel Better to help people with a diagnosis of cancer feel good about themselves

When we were teenagers it took us a while to get the hang of make-up (remember the mistakes?). Imagine having to figure all that out again because your skin colour has changed and your eyebrows and eyelashes aren't there, and you're so exhausted from chemotherapy you haven't the concentration to read. Or perhaps you are learning to use make-up for the first time in your forties because you've never worn it in the past. Look Good...Feel Better™ (LGFB) really comes into its own, with expert make-up artists who know and understand what people with cancer are going through.

Belfast City Hospital has worked with LGFB for over eight years, formerly in the inpatient wards and now in the Macmillan Support and Information Centre, which opened in 2006. The centre hosts a monthly LGFB workshop and each session can accommodate 18 participants. The standard capacity in other parts of the UK is 10–12, but there is such demand that we have accommodated the extra people.

We support LGFB by offering a venue and hospitality; we order and take delivery of the patient gift and stock items, organise administration of the sessions, take the bookings and manage the invitations. LGFB is part of our group programme. It's about offering patients a choice to elect which service will be most helpful to them at that time in their cancer journey. Empowerment and being able to take control are really important when facing a life-threatening illness, especially when patients feel like their lives are out of control.

> **'Empowerment and being able to take control are really important when facing a life-threatening illness, especially when patients feel like their lives are out of control'**

Our Receptionist, Collette Carson, organises the bookings, and cancellations are always filled quickly. The LGFB Regional Coordinator, Marcus Hunter-Neill, and LGFB local volunteer beauty consultants have been amazing with our clients and are very skilled at building rapport with people. From 2009, Marcus plans to offer two workshops per month at the centre in response to the demand. He also hopes to expand the service to at least one of the cancer treatment sub-units so more patients from across the province can access this service. Volunteers have been an integral part of LGFB's success at the centre. They work alongside the LGFB coordinator and the beauticians during the workshops by helping the women settle in and serving refreshments. They also set up the room beforehand, help the clients fill in their evaluation sheets at the end, and tidy the room afterwards. It's very much a team effort and a positive example of collaboration and partnership working.

The service is open to all patients, but women undergoing chemotherapy find LGFB particularly helpful, especially those experiencing chemotherapy-induced hair loss. Women can lose their head and body hair, eyebrows and eyelashes, and their skin colour can change. Alongside radical surgery such as mastectomy or hysterectomy, this is an incredible amount of change in a short period of time. A life-threatening illness can challenge many of the assumptions people with cancer have about themselves and their futures, as well as their sense of self.

About Look Good...Feel Better™

LGFB is a charity itself and works closely with the beauty industry. They provide workshops for 10–12 cancer patients in 52 locations across the UK and will be opening in more venues this year including Blackpool, Manchester, Luton and Kingston. The sessions are designed to help women combat the visible side effects of their treatment. Most women know that they may lose their hair during chemotherapy, but they don't always appreciate that they may also lose eyebrows and eyelashes, their skin and facial shape can be adversely affected and their self esteem can plummet. Each workshop is hosted by three professional beauty consultants (often volunteers from high street stores) who take ladies through a two hour, 12-step programme and the women come out laughing, looking fantastic and full of self confidence.

An LGFB expert teaches Belfast workshop attendees the tricks of the trade

LGFB responds to this and alongside the wide range of services within the centre, we can help people adjust.

Benefits to the patients

It's great to see how the patients benefit immediately from the workshops. They love to see the before and after. Their eyes seem to light up and their whole face is smiling. The workshops give people with cancer their confidence back.

‘I know I have cancer and I've accepted it, but it doesn't mean I want to look like I have cancer’

LGFB can help people to feel normal when everything is far from normal. Small things make a big difference, such as how to wear perfume if you are feeling nauseous from chemotherapy (spray some on a tissue and pin it to the inside of your clothing), how to subtly apply an eyeliner and how to fill in eyebrows that are thinning so your face has expression. It's guidance like this that can be invaluable, particularly for woman with young children who want their mum to look and smell familiar.

‘I feel like a new woman’

If people choose not to wear a wig or wear make-up that's fine too. Our services are not about making people conform to societal norms – they're about giving choice in a situation where people have had to make decisions they didn't want, or expect they would have to. A LGFB client said recently: ‘I know I have cancer and I've accepted it, but it doesn't mean I want to look like I have cancer. I get distressed when I look in the mirror and see a cancer patient, someone with no hair, eyebrows and pale skin.’

To find out about LGFB workshops in your area, refer a patient or get involved, please call LGFB head office on **01372 747500**, email **info@lgfb.co.uk** or visit **www.lgfb.co.uk**

LGFB works with over 40 key beauty companies and retailers including Estée Lauder, Chanel, Boots, Revlon, Max Factor and L'Oreal to bring this service to people with cancer. Each participant is given a superb gift bag of 17 donated products, with over 150,000 products donated by the beauty industry each year.

From March 2009 LGFB will be making a ‘Confidence Kit’ available to all women. This comprises a fantastic DVD featuring four workshop participants – International Make-up Artist Caroline Barnes, LGFB Vice President and renowned Hair Stylist Charles Worthington, Nail Technician Marian Newman and scarf and head coverings expert Kate Tijou. The pack also has a 48-page booklet covering skincare, step-by-step make-up, nail care, wig selection and wig cutting, and scarf tying and head coverings. To reserve a copy, for a suggested £5 donation, please email LGFB at **info@lgfb.co.uk**

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The benefits and barriers

Our next two articles look at nurse prescribing in practice. The nursing team at the Berkshire West Primary Care Trust found the use of nurse prescribing helped improve services, yet a Macmillan study has found that many nurse prescribers are not prescribing

Implementing nurse prescribing across a community

A fundamental part of the community CNS role has always involved assessing patients with complex symptoms and advising GPs on prescribing issues. However, because the nursing team for Berkshire West Primary Care Trust have been unable to prescribe, there has been a delay between our assessment of a patient, the medication being obtained, and the achievement of optimum symptom control.

During our annual review of services in 2006, the Macmillan community CNSs at the Trust identified non-medical prescribing as an educational and developmental need for the team. This was supported by our clinical director and line manager and by the medical consultants who encouraged the training and agreed to be designated medical practitioners.

Potential benefits of nurse prescribing

For patients:

- immediate access to specialist symptom management and medication, potentially reducing hospital admissions
- greater choice regarding who to access to discuss health-related issues
- improved safety – the prescribing Macmillan CNS would reduce the incidence of discrepancy between what medication is suggested to the GP and what is prescribed.

For Primary Health Care Teams:

- relieves demand on members of the team, promoting more effective use of resources.[1]

For Macmillan CNSs:

- develops expertise and broadens experience
- offers a complete episode of care for patients
- CNSs function as a more credible profession.

Training

Some team members attended the 'Independent and Supplementary Prescribing for Nurses, Midwives and Health Visitors' course at Reading University. They successfully completed 12 days 'learning in practice', during which a designated medical practitioner provided us with supervision, support and opportunities to develop competence in prescribing practice.[2]

A key aim was to avoid errors around communicating our prescribing activities to primary care colleagues and ensuring that patients' practice records are updated, including informing other non-medical prescribers.[2]

Developing necessary processes

The community Macmillan nursing team for Berkshire West Primary Care Trust is based in three different sites across the county. As we cover several practices over a wide geographical area it would be impractical for the non-medical prescriber to update the patient's GP practice records in person following any prescribing activity.[3] Therefore, we developed a process using a faxed form to inform the patient's GP and other non-medical prescribers of any prescribing activity. It requests that the recipient acknowledge they have received the form and that they put it on their computer system.

> **'We believe that nurse prescribing has improved the service – patients are able to obtain their medicines more quickly and therefore have faster symptom control.'**

We designed two new forms, called 'prescription-issued fax forms', to serve as a communication tool between ourselves and GP practices. During the development stage, the forms were presented at practice meetings to gain feedback and suggestions from primary care colleagues. One fax form is used to record information about parenteral medication that has been prescribed, eg syringe drivers, while the other fax form records other medications that have been prescribed.

We believe that nurse prescribing has improved the service; patients are able to obtain their medicines more quickly and therefore have faster symptom control. Symptom management has also improved as we now have a better understanding of therapeutics, what works and what not to use.

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to nurse prescribing

Study finds Macmillan nurses hesitant to prescribe

A study investigating Macmillan nurses' views on nurse prescribing in cancer and palliative care has shown that half of the Macmillan nurses trained as extended formulary independent nurse prescribers were not prescribing.

The study, led by Bernadette Ryan-Woolley based at the Macmillan Research Unit at Manchester University, was one of the largest national surveys of its kind to date.

Many of you will have contributed to the research by responding to the study questionnaire. The results were published in *Palliative Medicine* and the paper dedicated to the family of Bernadette, who became ill with cancer during this study and died in March 2007. The work identified considerable resistance to extended nurse prescribing and training, suggesting that government targets in this area may not be reached.

The results

Of the 2,252 Macmillan nurses surveyed:

- 11% were trained as extended formulary independent nurse prescribers, but only half of those who could prescribe from the extended formulary were prescribing, representing just 6% of the sample.
- A quarter of prescribers suggested that the medical mentoring was not adequate and there were further concerns about the training – mainly around the length and depth of the nurse prescribing course, including the lack of relevance to cancer and palliative care.
- Among Macmillan nurses who had not undergone extended formulary independent nurse prescribing training, 25% (335) perceived that prescribing was not part of their specialist nursing role. A further 40% (538) expressed reluctance to undergo training.

Existing barriers

When asked what factors they perceived would encourage specialist nurses to prescribe in cancer and palliative care, nurses identified a supportive organisational and team network and having medical support. Another issue was having appropriate arrangements in place by their employing Trust. Some Macmillan nurses employed in secondary care indicated that mechanisms to enable them to prescribe were either not in place, or were not properly developed, and that they were therefore unable to put their prescribing training into practice. This suggests that the acquired skills have not been consolidated and may also provide misleading indicators concerning the take-up and success of nurse prescribing in cancer and palliative care. Also, should these nurses decide to prescribe in the future, they will require additional training and/or support if patient safety is to be ensured.

Respondents suggested providing more cancer and palliative care specific training and support. This included time off to attend the course and cover of workload and improving resources to encourage more nurses to undergo training. Some respondents also commented that their nursing colleagues were sceptical about the benefits of nurse prescribing.

Conclusions

Although the authors acknowledge the limitations of their study, they suggest that this work indicates that additional training, support and mentorship after training may be required, and that at the moment, prescribing in cancer and palliative care may be best done by doctors.

The authors concluded that these findings raise important questions concerning whether extended nurse prescribing is likely to be a successful initiative in cancer and palliative care.

To read the full paper: Bernadette M Ryan-Woolley, Gretl A McHugh and Karen A Luker. Prescribing by specialist nurses in cancer and palliative care: results of a national survey. *Palliative Medicine,* 21: 273–277, 2007.

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Patient focus group helps shape cancer services

Involving patients is not only essential – it's also fun and enormously satisfying for all involved

There are very few healthcare documents or initiatives that do not call for the involvement of patients in the development and evaluation of clinical and other services. Suffice to say that the UK's healthcare delivery programme is now built around the core requirement that patients are at the heart of improving every aspect of the NHS.

We at the Liverpool Women's Foundation NHS Trust Centre are a team dedicated to the treatment and support of patients with a gynaecological malignancy. We fell upon the idea of a patient focus group only to find that it was one of the best initiatives we had ever been involved in and would shape all future service growth.

Adopting a patient-centred approach

As a Macmillan multi-disciplinary team we feel we have always had the patient at the centre of our service delivery and growth. However, through a meeting on a development course, we ran a patient questionnaire past our Cancer Network Patient and Carers' Service Improvement Facilitator, Gloria Payne. Her enlightening suggestion of actually asking the patients to shape the questionnaire itself gave us food for thought. So in January 2005 we held our first patient focus group meeting and we have never looked back.

Setting up the group

Using the NHS Modernisation Agency guide on involving patients and carers,[1] we looked at what we were aiming to achieve and which patients to approach. We decided to canvass for interested patients from our gynaecology/oncology support group, and soon had a core group of 10 patients from each of the four gynaecological tumour sites who had recently completed treatment. The group is co-chaired by the Trust's service improvement facilitator and two Macmillan team members. It meets every 6–8 weeks.

Our achievements

Over the last three years our group has been extremely active. We have:

- reviewed all cancer information leaflets and the hospital website
- mapped the patient information pathway
- helped set up a patient 'buddy' scheme
- written a new booklet for local patients called *'We've been there too…'* to support patients through treatment
- worked with Macmillan, a marketing company and the Trust's modern matron for gynaecology on various quality developments
- suggested and shaped a nurse-led holistic follow-up clinic, after the group identified a gap in support at the vulnerable point of 6–8 weeks post-treatment.

> **'We've all found it to be quite therapeutic, emotional at times, but sincerely feel that our shared experiences will only serve to improve health services.'**

The group is currently involved in a national King's Fund project – Enhancing the Healing Environment Programme. This will provide a suite of rooms to offer facilities for families to stay with the patient. The patients have greatly influenced the building design.

As health care professionals we can get lost in the hurly-burly pace of clinical activity, but we have found that our meetings with the group are the highlight of our working lives.

One patient shared: 'I've thoroughly enjoyed being involved in the project and I'm sure that I can also speak for my friends on the group. We've all found it to be quite therapeutic, emotional at times, but sincerely feel that our shared experiences will only serve to improve health services. We've lost some special friends along the way but their valued contribution is a legacy to be proud of.'

Reference

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Integrated rehabilitation clinic helps improve patient care

An integrated clinic at York Hospital's Cancer Unit for head and neck cancer in North Yorkshire is providing support for people affected by cancer during the difficult period between treatment and follow-up

Research from focus groups has shown that patients and carers feel unsupported at this stage[1] and it is known to be a time when side effects of treatment are still worsening, peaking some 10 days after completion of treatment.[2]

We noticed that our patients were experiencing:
- delays in rehabilitation
- crisis admissions because of problems with swallowing and nutrition
- poorly managed pain, distress and uncertainty, and inconsistent follow-up
- multiple, separate telephone consultations and clinic appointments.

To combat these problems, we established a Nursing and Allied Health Professional Rehabilitation Clinic (AHP Clinic) in February 2007. Initially held on one afternoon fortnightly, it soon became established as a weekly clinic in response to patient numbers and need.

How the clinic works

The Cancer Unit provides surgery, while chemotherapy and radiotherapy are provided at neighbouring cancer centres. Patients traditionally had their first review appointment back in York 4–6 weeks after their treatment is completed.

Now patients are contacted a few days after they have completed their chemotherapy and/or radiotherapy treatment and are usually offered an appointment at the AHP Clinic within one week. In the first year we ran 28 clinics; 33 patients attended, some up to seven times. Most were not able to swallow at that stage, and so had to take their nutrition and hydration via a gastrostomy feeding tube. The primary aim of the clinic is rehabilitation of swallowing and safeguarding nutritional wellbeing. Together we are able to tackle a wide range of related issues including pain control, lethargy and fatigue, secretions, dry mouth, taste changes, mouth care, tolerance to food regimens caused by direct delivery to the GI tract, problems with feeding tubes, and weight loss. We are also able to identify specific concerns, such as possible recurrence and hearing loss, and obtain immediate medical attention.

Beyond the medical issues we also provide encouragement and reassurance about progress, support to carers, and information on financial and psychosocial issues.

> 'Attending the clinic was incredibly useful. Although I'd been given all the information at the beginning when I was diagnosed, it was good to have reassurance from experts that everything was going as expected.'
>
> 'It has been a good follow-on service after daily hospital attendances for treatment. I'd have felt cut off without it.'
> *Patient and carer feedback*

From left: Becky Davis, Barbara Machin and Patricia Henshaw

Reflections

The AHP Clinic has now become an established part of the head and neck service. It provides an integrated approach to swallowing, pain and nutritional management, and was recognised as an example of good practice by the recent Peer Review of Head and Neck Services in York. Our clear view, based on clinical experience, is that patients feel much happier and better supported, and their transition back to oral intake is better facilitated.

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Service for the future

A new service delivery plan shows the full scope of the CNS in palliative care

We are a team of five Macmillan nurses (hospital and community team members) working within Lincolnshire. After a period of staff changes, we decided to develop a plan for our future work.

Background research

We considered business plans, operational policy, and Macmillan service reviews, but after many discussions with a number of peers and health care professionals, we decided to develop a service delivery plan.

After a detailed search we could find no service delivery plan templates relevant to a clinical service or a clinical nursing service. In addition, many of our initial thoughts involved a framework to guide the document, but suggestions like the NICE guidance on supportive and palliative care[1] did not seem to fit our service, so we decided to use a more clinical nurse specialist framework supported by the Royal College of Nurses[2] and our own job descriptions.

Within the current health care climate of PCT and acute Trust changes and reorganisations,3, 4, 5 the importance of measuring outcomes and proving our role6 and the lack of evidence of the Macmillan nurse role,6 we wanted to produce a document that was going to be useful. We decided the document would need to be relevant, reflect our role and workload, and also be used as a team profile of work undertaken to support our own Knowledge and Skills Framework outcomes, and prove the role of our Macmillan nursing team.

The plan

The service delivery plan was developed with the vision that the team will work on it from 2008 to 2011. The document we developed begins with contextual information including information on operational policy, Mid Trent Cancer Network information, information and demographics on Lincolnshire and specific areas/populations covered by each Macmillan nurse.

The main part of the plan was developed with the following sections in line with the Clinical Nurse Specialist Framework[2] in mind: leadership, communication skills, quality assurance, clinical, education, research and grief/loss/bereavement.

Each section has specific sub headings of: target statements, how we are performing in relation to the target, objectives, outcome measures with review dates, team members to lead, and comments. For example, the target for communication skills is that each clinical nurse specialist will use advanced communication skills to assist the service user to adjust their disease process and care needs.

Developing and reviewing the plan

It is envisaged that as each objective/outcome is met then supporting evidence will be added to the document to develop a portfolio of work undertaken.

Each section/domain was allocated to different team members so that each domain had a lead Macmillan nurse responsible for coordinating the work and reviewing progress. The document received positive comments from our Macmillan service development manager and our local lead cancer and palliative care nurse. It was therefore distributed locally to all the other Macmillan teams within Lincolnshire and other interested stakeholders. The purpose of our service delivery plan is to direct and provide structure to our work, inform others of work ongoing, provide evidence and outcomes of work undertaken and show the full scope of the role of the clinical nurse specialist in palliative care.

For a copy of the document please contact the authors below.

> **‘The document received positive comments from our Macmillan service development manager and our local lead cancer and palliative care nurse.’**

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Developing a new lymphoedema service provides both challenges and rewards

Clinical Nurse Specialist Catherine Himan shares how North Devon PCT developed a lymphoedema service through Macmillan funding

CNS Catherine Himan (left), and Staff Nurse Julie Smith (right) with a patient

Our North Devon lymphoedema service is now almost two years old and I wanted to share some of the experiences, successes and challenges encountered along the way.

The lymphoedema service was a new venture for North Devon PCT. It came into being following a generous agreement from Macmillan to fund the service for three years, enabling us to offer a full lymphoedema service to all clients regardless of diagnosis. This included one clinical nurse specialist and one staff nurse, plus hosiery and set-up costs.

It was tremendously exciting setting up a service that I knew would make a difference to so many people, but I was daunted by the thought that we would quickly become oversubscribed and a victim of our own success. We were careful to start slowly and not become overwhelmed with referrals for treatments which we could not provide.

> **‘It was tremendously exciting setting up a service that I knew would make a difference to so many people.’**

One of the first challenges was to design and implement an equitable service for all clients across a wide rural area with poor road networks. We started by launching one clinic in a central location and encouraged clients to travel in. Home visits are provided for truly house-bound clients and we visit patients who are already in the acute and community hospitals and hospices. In future, we aim to provide some clinics at smaller, rural hospitals so that patients do not have to travel as far.

We first needed to find a suitable space to set up a clinic, with an appropriate space for a couch and all the other equipment required to undertake a useful assessment and provide ongoing treatment. Having changed venue a couple of times, we are now based in the District General Hospital in Barnstaple, which has led to closer working links with the breast care team. We have also forged good working relations with community nursing teams and social services. We are in discussions with dermatology, tissue viability and podiatry to run joint clinics to enhance the service we already provide.

Being a nurse prescriber has helped enormously, as many of the hosiery companies now have a range of appropriate lymphoedema hosiery available on prescription. This has eased the pressure of trying to fund these expensive garments through the service.

> **‘There is still a lot of work to do, but I feel that we have successfully embedded the service and will continue building links and networks to other services.’**

We have also become involved in the National Lymphoedema Framework Project and started the data collection in March 2008. This project takes data from London and other Trusts across the country to assess the prevalence of chronic oedema. The project has already provided useful information about the extent of the problem and the care and treatment of this particular group of patients. I believed it would be a useful tool for a new service to gauge the extent of the problem in North Devon.

We recently undertook an audit of the service and have had very positive feedback from patients. There is still a lot of work to do, but I feel that we have successfully embedded the service and will continue building links and networks to other services. The experience of setting up and running the lymphoedema service in North Devon has been challenging and rewarding.

Related information:
Our booklet, *Understanding Lymphoedema*, can be ordered on be.macmillan.org.uk

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Research prompts investigation into the future of patient follow-up

Macmillan Gynaecology CNS Claire Parkinson and colleagues are working to improve the current model for follow-up of gynaecological cancer patients in the Yorkshire Cancer Network

The five-year survival figures for gynaecological cancer vary depending on the site and stage of the cancer, ranging from 95% for stage 1 ovarian disease to as little as 15% for stage 4 ovarian disease. However, a study in our own network showed that the intervals at which patients are followed up is not determined by the type of cancer or the stages which determine their prognosis.

Follow-up for detecting recurrence

Follow-up is primarily aimed at detecting recurrence, but several studies suggest that many patients with a recurrence have symptoms prior to their follow-up appointment and some delay reporting their symptoms. The highest risk of recurrence was found to be within the first three years, but even when detected there was limited impact on survival. This would suggest that follow-up could be reduced to the first three years. At present patients without symptoms of recurrence are followed up for five years. Information should be given to patients regarding symptoms of recurrence and how to arrange a follow-up appointment sooner than scheduled if necessary.

> **'The highest risk of recurrence was found to be within the first three years, but even when detected there was limited impact on survival.'**

Other reasons for follow-up

Apart from detecting recurrences, there are many other reasons for follow-up, including:

- audit
- symptom control and management
- patient information and health education
- education of symptoms of recurrence and how to access the team quickly
- psychological support
- to discuss and provide advice surrounding sexual issues
- to decrease anxiety through therapeutic discussion
- liaise and refer cases to other agencies
- to coordinate care delivery and ensure consistency of contact.

Routine follow-up is not holistic

Several government policies[1-5] pertaining to the follow-up of patients suggest that routine follow-up may be unnecessary, waste valuable resources and is not evidence based, and that we should instead be providing patient-centred, holistic care. While CNSs strive to achieve a holistic approach, much of the support, advice, communication and education usually takes place after the consultation with the doctor and also on the phone before or after their three to four month follow-up.

There are several different methods of follow-up, apart from the normal medical follow-up, that have demonstrated to be effective and acceptable to patients, eg nurse-led, telephone, patient instigated and GP follow-up. These models have not been investigated within gynaecology, and all patients within our network are followed up using the current medical model. However, the nurse specialist at Harrogate and I are undertaking training to enable us to carry out clinical examinations, so in the future we hope to undertake nurse led follow-up. At Calderdale they are planning to trial telephone follow-up.

The future of follow-up

There appears to be little evidence to support the ritualistic follow-up of patients with a gynaecological cancer. Patients need to be empowered to recognise symptoms of recurrence and know how to seek prompt medical advice. The type of follow-up should not be prescriptive, but instead take into consideration the stage and type of cancer and the patients' individual wishes and requirements. More research should be undertaken in this area so that the changes made are evidence based and the services provided can be improved.

In our own network, we are undertaking a piece of research looking at the views of staff and patients regarding follow-up to see how we can meet patient needs in this area. We also have a network sub group looking at the follow-up of patients with a gynaecological cancer.

References

[1] *Improving Outcomes in Gynaecological Cancers*, NHS Executive, 1999.
[2] *NHS Cancer Plan*, Department of Health, 2004.
[3] *Ten High Impact Changes for Service Improvement and Delivery*, NHS Modernising Agency, 2004.
[4] *Applying High Impact Changes*, Cancer Collaborative Improvement Partnership, 2005.
[5] *Supportive and Palliative Care Guidance*, National Institute for Clinical Excellence, 2004.

Further information
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GETTING INVOLVED

Diary of 2009 events

April

Bowel Cancer Awareness Month
www.bowelcanceruk.org.uk

May

12 May
International Nurses Day
International Council for Nurses
www.icn.ch/indkit.htm

15 May
Fruity Friday
World Cancer Research Fund
www.wcrf-uk.org

31 May
World No Tobacco Day
World Health Organization
www.who.int/tobacco/en

June

Everyman Male Cancer Awareness Month
Everyman
www.everyman-campaign.org

1–7 June
National Volunteers Week
www.volunteersweek.org.uk

8–14 June
Carers Week
www.carersweek.org
www.macmillan.org.uk/getsupport/informationforcarers

15–21 June
National Men's Health Week
www.menshealthmonth.org/week

Macmillan events

May

May–July 2009 Nationwide
Big Sports Day
A fantastic way to encourage young people to be active, improve their health awareness, and raise money to help people affected by cancer.
0845 601 1716
www.macmillan.org.uk/bigsportsday

August

1–2 August 2009
Mazda London Triathlon
Swim, cycle and run your way round the world's most popular triathlon.
020 7840 7875
londontriathlon@macmillan.org.uk
www.macmillan.org.uk/londontriathlon

September

14–19 September 2009
Romania Hiking Challenge
This trek takes us to the heart of eastern Europe to explore the remote mountain region of the Carpathians, finishing with a visit to Bucharest, the vibrant capital city of Romania.
hiking@macmillan.org.uk
www.macmillan.org.uk/romania

17–21 September 2009
Alps Cycling Challenge
Tackle tough mountain climbs, made famous by the Tour de France, on this brand new Macmillan challenge.
020 7840 7875
biking@macmillan.org.uk
www.macmillan.org.uk/alps

25 September 2009
World's Biggest Coffee Morning
Help create a huge stir by having a coffee and a slice of cake with your friends and colleagues.
0845 602 1246
coffee@macmillan.org.uk
www.macmillan.org.uk/coffee

October

4 October 2009
Baxters Loch Ness Marathon
One of the UK's leading marathons, run through stunning Highland scenery, and you may even be lucky enough to catch a glimpse of Nessie!
020 7840 4965
lochnessmarathon@macmillan.org.uk
www.macmillan.org.uk/lochnessmarathon

November

21 November–3 December 2009
Trans Central America Cycling Challenge
The sights and sounds of lush rain forest, rugged coastline and smoking volcanoes will ease your aching legs as you tackle this brand new cycling challenge.
020 7840 7875
biking@macmillan.org.uk
www.macmillan.org.uk/centralamerica

WE SHARE RESOURCES

All Macmillan and former Cancerbackup resources are available free of charge to health and social care professionals, as well as to people affected by cancer. You can view and order from our whole range of information resources at be.macmillan.org.uk. Simply visit the website, register your details and select what you need, or call 0800 500 800 to place an order.

Relationships, sex and fertility for young people affected by cancer

MAC11679

This guide, aimed at young people who have had cancer, explores sex and sexual relationships after cancer. It explains how cancer treatments can affect your ability to have children, covering fertility testing, fertility treatment and pregnancy after cancer treatment. There is also advice on helping yourself and obtaining further support.

Sexuality and cancer

MAC11644

This booklet explains the effect that cancer and its treatments can have on your sexuality – and ways of coping. It describes how different treatments can affect sexuality, and offers solutions to various sexual problems. It also discusses fertility issues, and contains a general Q&A on sexuality and cancer.

The best cancer information for everyone from Cancerbackup and Macmillan Cancer Support

Cancer, you and your partner – relationships leaflet

MAC12157

This leaflet, written in collaboration with Relate, discusses how cancer can affect your relationship with your partner. It can help you understand how cancer and its treatment could affect your emotions, communication and sexuality, and discusses what may help. It also lists sources of further information and support.

Cancer Factfile 2009

MAC12149

The Cancer Factfile 2009 is now available on CD and contains over 300 factsheets including 18 new titles. Topics include all the commonly used treatments for cancer, information on site-specific cancers and aspects of living with cancer.

If the Cancer Factfile 2009 CD is not attached to your copy of *Macmillan Voice*, you can order a copy through be.macmillan.org.uk