

Macmillan

Issue 47 winter 2008

VOICE

for Macmillan professionals

In this issue

Focus on social care

Manjula Patel

Manager, Bridges Support Service

**WE ARE
MACMILLAN.
CANCER SUPPORT**

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Contributors this issue

Charlotte Argyle | Fran Carter
Louise Evans | Dr Maggie Grundy
Doreen Hall | Janet Irvine
Lisa Johnstone | Shradha Lakhani
Sindeep Lehl | Frances McKay
Jennifer Mitchell | Louise Pothier
Wendy Sawers | Irina Vieira
Caroline Williams | Hilary Wilson

We welcome feedback!

Let us know your views on *Macmillan Voice* or have your say on any of the topics.
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 katiwoolley@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.

Editorial Team
Ruth Carlyle, Genevieve Osei-Kuffuor, Sajjad Shah, Katie Woolley

Editorial Board
Charlotte Argyle, Lifecare Transition Manager
Margot Buchanan, User Representative
Helen Foy, UK Postholder Support and Development Manager
Alison Hill, Nurse Director South West London Cancer Network
Beverly Hurst, Macmillan Gynaecology/Oncology CNS
Yvonne McKenna, Macmillan Lead Cancer Nurse
Peggotty Moore, Macmillan Specialist Radiographer
Ed Murphy, Macmillan Development Manager, C,SWE&W
Esther Murray, Acting Consultant in Psychosocial Oncology
Heather Nicklin, Macmillan Specialist Palliative Care Social Worker
Terry Priestman, Consultant Clinical Oncologist

Designed by Grade Design Consultants, London
www.gradedesign.com

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THE BEST CANCER INFORMATION NOW FREE FOR MACMILLAN PROFESSIONALS

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

As you know, Cancerbackup and Macmillan Cancer Support merged in April this year. Together, as Macmillan Cancer Support, we are providing the same high-quality, expertly developed information about cancer, but now this is available free of charge to health and social care professionals, as well as people affected by cancer.

The National Institute for Clinical Excellence (NICE) issued guidance (recommendations) on supportive and palliative care services. One of their key recommendations is that information should be available, free of charge. **People with cancer cannot be fully involved in decisions about their treatment and care if they are not well informed. Most patients want to learn about their particular cancer, possible treatments, and the full range of support available to them. Information is part of a patient's treatment and should always be free of charge.**

Macmillan's vision is for all people affected by cancer to have the information they want, when they want it.

In October we produced the new Macmillan resources catalogue for health and social care professionals. The catalogue lists all Macmillan publications and also includes Cancerbackup booklets, which are now free to health and social care professionals for the very first time. These publications provide useful information for people affected by cancer, aid professional development and help raise awareness of Macmillan's services.

You can view and order from our whole range of information resources at www.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. Please make sure, though, that you only order the amount of resources that you currently require. This will help us manage our stocks efficiently and ensure you always have the most up-to-date editions of our publications.

The resources on offer include:

- Cancer type booklets: brain tumours/lung cancer
- tests and treatments booklets: pelvic radiotherapy in men – possible late effects/understanding chemotherapy
- living with cancer booklets: cancer survivor's guide/controlling cancer pain.

References

- [1] Supportive and palliative care services for adults with cancer Understanding NICE guidance – information for adults with cancer, their families and carers, and the public, NICE 2004.

Macmillan forces change in out-of-hours care

Macmillan recently funded a team of researchers in Exeter to explore the impact of the new General Medical Services (nGMS) contract on access to out-of-hours care for people with cancer needs. The nGMS contract no longer requires GPs to provide out-of-hours care for patients on their lists – and the severing of the link between daytime and out-of-hours services has led to concerns regarding the quality of care provided to patients with complex needs.

The team explored changes in the use of an out-of-hours primary care medical service (Devon Doctors) by patients with cancer in Devon before and after the implementation of the new contract in 2004. The results from the study were published in the *British Journal of General Practice*¹.

The study found that although overall call rates to the service increased by 26%, the demand for out-of-hours care by patients with cancer-related needs remained relatively constant. Around half of these callers had advanced cancer needs (including palliative care). Other potential markers of service quality, such as the proportions admitted to hospital after contacting the service, or receiving a home visit, also remained constant across time. However, potentially adverse changes, such as a longer wait until triage and lower levels of inter-agency communication between out-of-hours doctors and in-hours clinicians, were observed.

These findings have had a direct impact on services in Devon. Devon Doctors has issued new protocols to call

operators to ensure that callers with palliative care needs are triaged more quickly. The service is also working with the Peninsula Medical School to improve the ways that daytime and out-of-hours services transfer important information regarding end-of-life treatment plans.

Further information

Dr Suzanne Richards

Senior Lecturer in Primary Care

Peninsula Medical School, Exeter

Tel 01392 262742

Email suzanne.richards@pms.ac.uk

www.pms.ac.uk/pms/research/macmillanout.php

Reference

[1] Richards et al. Accessing out-of-hours care following implementation of the GMS contract: an observational study. *British Journal of General Practice*. 2008 May; 58(550): 331-8



Feedback for outstanding service

Following his article in spring's *Macmillan Voice*, Macmillan benefits adviser Glenn Dawson has been inundated with feedback from all sides.

Immediately after publication, Glenn was contacted by other Macmillan professionals who had read about his work and were keen to hear more. These ranged from one professional who was interested in his role and was considering a job change to a benefits adviser, to a nurse who wanted to use Glenn's article and case study as evidence of how useful a benefits adviser is so that she could apply for extra funding for such a role in her own service.

He's also had feedback from nurses in Manchester who have told Glenn how pleased they are that they can get on with their job while he takes care of applying for grants and money, instead of the nurses spending hours filling in forms.

Glenn's service goes from strength to strength, as is evident from a recent questionnaire he sent to his users once their file was closed. The feedback was overwhelmingly positive – virtually 100% top marks, with comments including:

'We were overwhelmed by the assistance we received from Mr Dawson at what was a very difficult time'

'Glenn was more like a friend'

'Glenn is a credit to your organisation – my stay in hospital was made so much easier'

'I didn't know how to go about it, Glenn did everything for me, I was very thankful'

'Tip top'

'Having your adviser hospital-based made the whole process trouble-free – I did not know such a service existed. It is excellent'

Glenn was thrilled to get such positive reactions, but was especially pleased by the impact of his article in *Macmillan Voice*: 'My interactions with other Macmillan professionals was limited to my own locality, so it was great to hear from people all over the country and share experiences and knowledge.'



Further information

Glenn Dawson

Macmillan Advice Worker

Wythenshawe Hospital

Tel 0161 291 2165

Email glenn.dawson@manchester.gov.uk



At the time of going to press, the figures showed that we have received £6.07 million and we are well on our way to reaching the astounding £8.5 million target set for proceeds from World's Biggest Coffee Morning 2008. So a huge thank you to all who took part and raised their mug in support.

Our flagship event, now in its 18th year, is one of the UK's largest fundraising events and on 26 September 2008 over 39,000 people had registered to host coffee mornings. Support for the event came from both celebrities and large companies alike. John Lewis got involved again with their grid game offering three lucky winners a shopping spree at their stores. Starbucks provided a venue and free coffee to people holding their coffee morning in store and Somerfield sold a coffee morning recipe booklet to their customers, as well as promoting the event in various ways. Macmillan Chief Executive Ciarán Devane dropped in on a coffee

Creating a Stir at the Dolphin Shopping Centre, Poole, Dorset Chrissie Wathen-Neal and Dawn Hooper from Macmillan Cancer Support with Lisa King, Dolphin Shopping Centre management team, and staff from Beales, Costa Coffee, Druckers, Lumin-Essence and Marks & Spencer.

morning held in Surrey, where PR guru Max Clifford was also in attendance and classical artist Jonathan Ansell made a surprise visit to a coffee morning at Helm Godfrey Partners in London!

If you took part and haven't yet sent in your money, please do so and help us reach the target and help even more people living with cancer.

Further information

www.macmillan.org.uk/coffee

Give us your feedback on our new toolkit

We need your help! Please let us know what you think of *It All Adds Up*, our toolkit about financial issues, which is designed to help you in your work. *It All Adds Up* provides information on a wide range of financial issues which affect people affected by cancer, such as problems getting insurance. Each section comes with a booklet which you can pass on to those affected by cancer.

You should by now have received or have access to a copy, and we need to know if the resource is as good as it could be. We would be really grateful if you could spend 15 minutes completing an online survey – your input is invaluable.

Please visit www.macmillan.org.uk/Get_Support/Financial_help

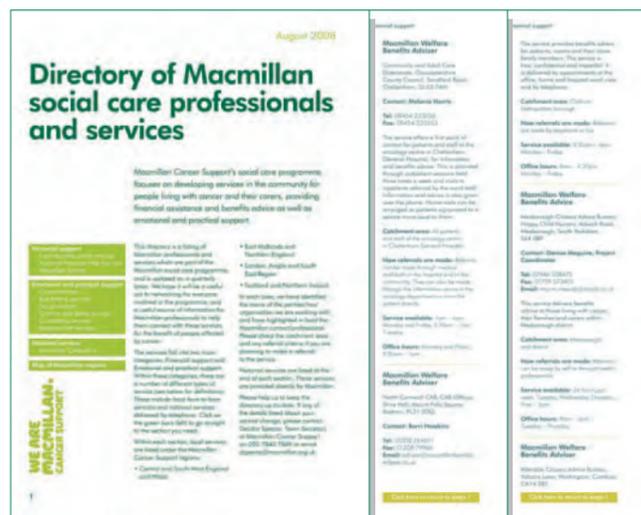


New Macmillan Social Care Directory

The Macmillan Social Care Directory contains details of all Macmillan's social care services and professionals, including benefits advisers, carers services, social workers and befriending and bereavement services. It includes a description of each service, contact details, catchment area and referral criteria.

The directory has been updated and is now available on the Macmillan Learn Zone (<http://learnzone.macmillan.org.uk>) in the General Resources section, under Macmillan items.

The directory is updated quarterly, with the next edition due at the end of February. If you wish to add or amend the details of a service, please contact Deirdre Spence at dspence@macmillan.org.uk or on **020 7840 7869**.



Macmillan Solutions – helping people to take control

'It would be great if I could pay for the same person to pick up my child from school, rather than my daughter worrying which face was picking her up this time'

'My lymphoedema could have been greatly improved by bandaging which fitted properly, I applied for a Macmillan patient grant, but I was refused as I had savings, but these savings were to send my son to University and there was no way I was touching that'

'I used to be a Managing Director of a large regional company, I got cancer, had to give up work and now feel that I am on the scrap heap, it would be great if I could give something back'

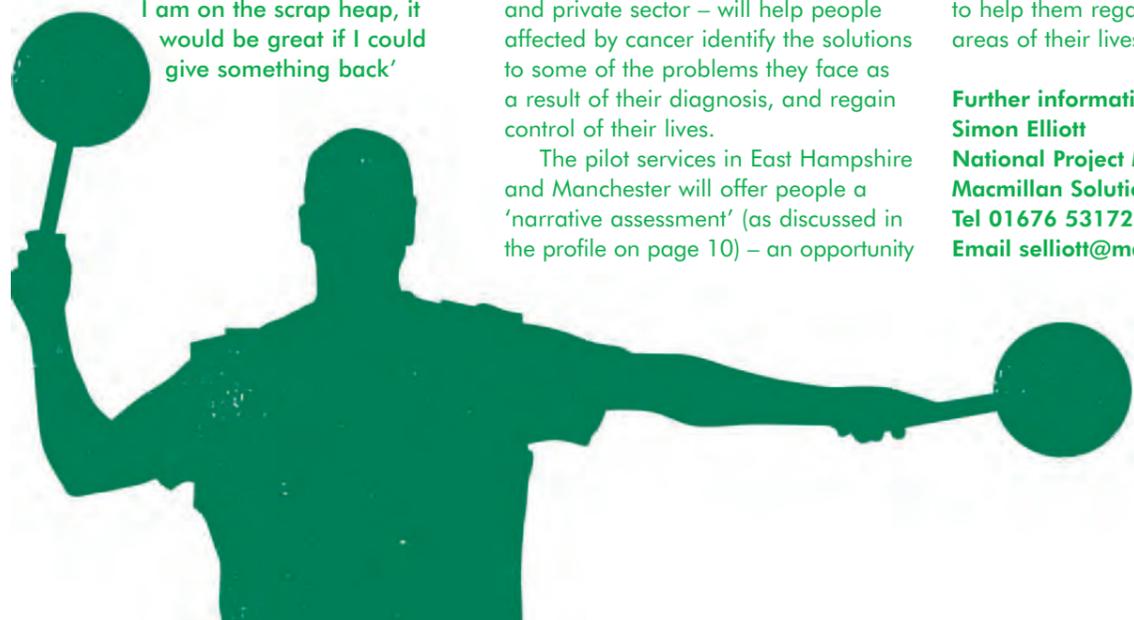
These are just some of the experiences people affected by cancer shared with us during extensive stakeholder consultations and research we have carried out. They reflect the desire of many people affected by cancer to regain independence, control and choice in their lives. We commissioned the New Economics Foundation to talk to people affected by cancer about our ideas for a service which would help put back into their lives a sense of independence, control and choice so often lost after a cancer diagnosis. Macmillan Solutions is a pilot service which, with the help of local volunteers and the bringing together of existing local services – statutory, NHS, voluntary and private sector – will help people affected by cancer identify the solutions to some of the problems they face as a result of their diagnosis, and regain control of their lives.

The pilot services in East Hampshire and Manchester will offer people a 'narrative assessment' (as discussed in the profile on page 10) – an opportunity

to think through the areas of their lives where they may want to regain a sense of control, and how this may be achieved. The trained volunteer carrying out the narrative assessment may identify services from other local providers who can address this need or offer access to buddying and befriending, skill swap schemes or a Macmillan Personalised Budget.

Macmillan Solutions will be flexible enough to ensure that an individual's needs are met at different times in the journey. Some people may access all the support elements available; others will find that having the space and time to think about what they need during the narrative assessment is enough to help them regain control in key areas of their lives.

Further information
Simon Elliott
National Project Manager
Macmillan Solutions UKO
Tel 01676 531722
Email selliott@macmillan.org.uk



We help self-manage healthy eating

Macmillan is running a healthy eating workshop to help people with cancer, or people caring for someone with cancer, to take control and explore how healthy eating can benefit them. The workshop will help people affected by cancer to learn more about using food to increase energy, aid digestion and boost the immune system.

By the end of the workshop, participants will be able to consider a basic healthy eating plan – 'conscious eating' – that has been designed with the cancer patient in mind. This is an excellent way for professionals to give their patients some options for 'self management', or possibly arrange for this training to be put on in your own support groups.

Although primarily designed for people affected by cancer, professionals who are involved with self help and support groups may also be interested in applying. The next course will be held in London on 27 January 2009.

Further information
Heather Petty or Katy Walker
Learning and Development Training Administrators
Tel 020 7091 2010
Email workshops@macmillan.org.uk

Turning it around

How our User Support and Involvement programme helps people affected by cancer use their experiences to help others

Macmillan Cancer Voices

Cancer Voices is a growing network of over 1,400 people affected by cancer who use their experience to make a difference, this ranges from co-designing local cancer services, to reviewing cancer resources, to supporting national campaigns. We encourage our Cancer Voices to become community activists who identify inequality in local services and then challenge this with our support.

Macmillan professionals can help people take the first step to turning their cancer experience into something positive by directing them to our Cancer Voices website at www.macmillan.org.uk/cancervoices, or by getting them to call our Cancer Voices team on **020 7091 2007**. Why not take a look at the website too to find out more about how the network works?

'Men come to our group devastated, but what they soon realise is that everyone around them is in the same boat. The change you see after a few meetings is incredible. Speaking about their illness to others takes them from negative to positive.'

Calvin Wood, Wirral & North Cheshire Prostate Cancer Support Group

Award winner retires

Rosie Hayes commenced in her post as a Macmillan Specialist Palliative Care Clinical Nurse Specialist with the Cornwall Macmillan Service in 1982. The Service is part of Cornwall and the Scilly Isles Primary Care Trust. Rosie spent several years as Team Leader for the North and East Cornwall Team and as joint Professional Lead for the Service.

Over the last two years Rosie has stood in as Macmillan Professional Lead for the Cornwall Macmillan Specialist Palliative Care Service. Some of Rosie's major focuses were on maintaining and developing bereavement services, developing Specialist Palliative Care Clinics within Community Hospitals and supporting and developing complementary therapies.

During the last two years Rosie has steered the team through a time of great change with the formation of the new Cornwall and Scilly Isles PCT. Rosie has been a fair and honest leader for the team, always caring for their needs, not afraid to challenge or support in difficult times. She will be missed by all those who worked with her. Rosie was recently awarded the Henry Garnett Award by Macmillan in recognition of her work.

'My mother and I have both had breast cancer. By joining Cancer Voices we've met lots of people also affected by cancer at regional conferences. We've also been on courses to help improve our day to day health through nutrition. It's been inspirational and has helped us go out and raise awareness in the Asian community too.'

Toral Shah, 31, Surrey

Our self help and support work involves helping people affected by cancer set up and run groups at which they can share their experiences. These groups could be for anyone who has been affected by cancer or have a more specific purpose. For example, a group could bring together people who have a particular type of cancer, or it could be for carers, or it may be set up specifically for employees of an organisation.

If you would like to discuss the User Support and Involvement programme further, please contact Jagtar Dhanda, User Support and Involvement Programme Manager, at jdhanda@macmillan.org.uk or call **020 7840 7847**.

New addition to Learn Zone makes learning fun

As mentioned in the last issue of *Macmillan Voice*, we recently introduced the Leadership and Management Toolbox on the Learn Zone. This adopts a new approach, pulling together three existing sets of high quality materials, rather than producing our own. It brings together the best leadership and management thinking in the world from Ashridge and Harvard Business Schools and 50 Lessons, and comprises everything from short video interviews with international leaders and brief book reviews to academic journals, substantial learning guides and multimedia modules. Our aim has been to produce a comprehensive compilation of resources covering a broad range of generic leadership and management knowledge and skills, which Macmillan professionals can access free through the Learn Zone.

By the end of September there will be a new addition to the Toolbox which will give access to training materials from Video Arts, a company initially established in 1972 by a small group of television professionals, including John Cleese, who pioneered the use of humour in training. The ethos reflected in the Video Arts learning material is that it has to be entertaining. They argue: 'If it is entertaining, it will also be engaging. And the more engaging it is, the more memorable it becomes.'

Consequently their materials feature many well-known television faces and are produced to a very high standard.

Future plans include the development of new courses for professionals which draw on the materials that are already part of the Toolbox. One of the first courses planned using this approach is

'Equality and Diversity', which we hope to have ready for the start of 2009.

A reminder that the Learn Zone can be found at

<http://learnzone.macmillan.org.uk>

and the toolbox is available at
<http://learnzone.macmillan.org.uk/course/view.php?id=71>



Support and self-help groups study



The Manchester Macmillan Research Unit is currently undertaking a study of cancer support and self-help groups across the UK to help inform how these groups can best be supported in the future. Some of you may have already been contacted for information in what aims to be one of the largest studies of members and leaders of cancer support and self-help groups across the UK.

Little is known about how professionally-led and peer-led (self-help) programmes differ with regards to the content of meetings, perceived outcomes for participants, or training needs of leaders. Furthermore, there has been minimal research on this subject in the UK. This study is a postal survey aiming to obtain questionnaire data from a large sample identified through the Macmillan Directory of Cancer Self-help and Support Groups 2007-2008.

Information collected will increase understanding of group features and participant characteristics. We also plan to look at the influence of structural features (e.g. size, membership type, leader type) on perceived outcomes and psychosocial variables (e.g. coping style, social support).

Participants will also be given the opportunity to volunteer for telephone interviews where issues of support group membership and leadership will be further explored.

The results will help inform how best to plan support group interventions, and train leaders, in order to optimise the benefits for people with cancer in the future.

Further information

Dr Clare Stevinson

Macmillan Research Unit
University of Manchester

Tel 0161 306 7786

E-mail clare.stevinson@manchester.ac.uk



A force for change – Fuel poverty

This summer saw the big energy companies impose double digit price increases

Unsurprisingly, this has sparked concerns about the number of people who will face hardship this winter. So much so that the Prime Minister announced plans to tackle this problem as part of his economic relaunch package in September.

People with cancer are particularly vulnerable. Each year, a considerable number of Macmillan grants are given to help people pay their energy bills. But people with cancer are struggling more than they were – we've already assisted an additional 1319 people and given out an extra £324,596 this year compared to last.

People undergoing cancer treatment or those who are terminally ill appear to feel the cold more acutely as a consequence of their illness and treatment regardless of the time of year or season. They are at home for longer periods of time with the heating and lights on. All this forces energy

consumption and therefore bills up.

Couple this with other increased costs, such as travel to hospital and prescription charges, and an often reduced income'; and it's not hard to see why cancer patients face the stark choice of sitting in the dark and cold or heading into debt.

Those living in rural areas, especially large parts of Wales, Scotland and Northern Ireland, face additional difficulty because they are unable to connect to the main gas network. They are left using oil or coal to heat their homes and therefore face even higher energy bills. Northern Ireland and Scotland also suffer from a colder climate and longer hours of darkness.

The government, along with the energy industry, has committed to tackling and eventually eradicating fuel poverty – defined as where a household spends more than 10% of its income on energy costs. People over the age of 60 receive a winter fuel payment to help with the cost of heating, and if the winter is markedly cold some benefit recipients receive additional payments (cold weather payments). There are also government and energy company schemes which offer help to increase the energy efficiency of homes through loft lagging and wall insulation. In addition, some energy companies operate lower-priced energy tariffs (called social tariffs) for vulnerable households. However, there are many people with cancer who do not qualify for, or are unaware of, this help and will slip through the cracks this winter.

Macmillan will be pressurising both the government and energy companies to ensure people with cancer receive the help they need.

We are currently compiling case studies to demonstrate how people affected by cancer are struggling to cope with rising fuel costs. We want to make sure these untold stories are heard and can no longer be ignored.

You can help by asking people you work with who are affected by these issues to tell us their experiences at campaigns@macmillan.org.uk

Keep up-to-date with the latest campaign actions and get involved at www.macmillan.org.uk/campaigns

If you would like to direct your patients to information about the help available, please ask them to contact Macmillan Cancer Support on **0800 500 800**.

Reference

[1] Cancer costs. Macmillan Cancer Support; June 2006.



Further information

Jennifer Mitchell

Policy Analyst

Macmillan Cancer Support

Tel 020 7840 4962

Email jmitchell@macmillan.org.uk

Manjula Patel

Manager, Bridges Support Service

What does your service provide?

The Bridges service provides support to both cancer patients and carers (and patients with other palliative care needs). The aim is to help people remain at home as long as possible, and to die at home if that is what they want. The service provides a wide range of practical support including domestic help, transport, childcare, respite breaks, advocacy and complementary therapies. There is also a strong emotional support element, including befriending provided by volunteers. Where there are gaps in statutory services, Bridges provides appropriate support.

Why did the post appeal to you?

This post was for a completely new project. I had not worked in this area previously but the challenge of setting up something from scratch appealed to me, and it was within a remit that I felt passionate about. With a grant from Macmillan in 2004, we expanded from two to six towns within Sandwell borough and then in 2007 to parts of Birmingham.

What does the service offer?

We use a narrative-based assessment to evaluate how we can help patients and carers. The development of the Bridges service has intrinsically been linked to patients' and carers' stories, and we pioneered this assessment to provide tailored support based on the patient's story. We pick up on cues in conversation and explore these further. As part of my MA I have recently carried out some qualitative research on this approach, which revealed its effectiveness. Many people simply don't know the systems or what they're entitled to, so it's a matter of getting in touch with the right people.

What does the role involve?

As well as the day-to-day running of the service, I have several ongoing projects which all feed into developing the service. For example, Bridges volunteer drivers provide transport support to help people access treatment and outpatient appointments. Macmillan jointly funded a study to evaluate transport needs with CENTRO (who are the organisation responsible for bus, rail and Midland Metro Tram transport in the West Midlands). This study produced a report that outlines a new innovative model of providing transport, which we hope to pilot in the future. All the separate projects inform on how to take the service forward as a whole.

What is most rewarding?

We regularly receive positive feedback from our users and they seem to feel supported by the presence of our service. Our service model has been used as an example of best practice in the recent End of Life Care Strategy, which validates what we do. We've had many visitors from Macmillan who are interested in our model of working. Our complementary therapy support was recently mentioned at a national conference as a good example, which was very flattering.

Can you describe a typical day?

I now spend a fair amount of time in meetings and am rarely found in the office! In between I catch up on paperwork and the various projects that are running but I still like to visit people at home and be involved in the support group meetings.

How would you like the role and service to develop?

We are currently re-structuring the service to accommodate our recent expansion to a second PCT in Birmingham. I really want to develop the role of the care co-ordinator, to ensure better recognition of their wider role of advocate, navigator, and companion. The service continues to evolve and develop, hopefully to offer a better quality of support and care.



Location
Bridges Support Service, Birmingham

In post
April 2001

'The development of the Bridges service has intrinsically been linked to patients' and carers' stories, and we pioneered this assessment to provide tailored support based on the patient's story. We pick up on cues in conversation and explore these further.'

Further information
Manjula Patel
Murray Hall Community Trust
West Midlands
Tel 0121 612 2939
Email manjulapatel@nhs.net

Supporting survivors through peer support

I've been a urology clinical nurse specialist at Medway Hospital in Kent for over four years and during this time people have often asked about any possible peer support and experience sharing. For me, I was concerned that once patients had finished their treatment and had all their follow-up, there was no more support for them.

Whilst they're in the system – from first being diagnosed through treatment and follow-up – there is continuous support from the team and myself, but after that they're on their own. With more and more people living with cancer, there needs to be more emphasis on looking after the person's emotional needs as well as their medical, especially beyond their treatment.

For a long time I had wanted to start a support group for patients attending the Urology Clinic – but it wasn't until one of my patients offered to run it with me that I was inspired to do something about it.

We began by sending out a questionnaire to patients, asking them whether they would find a support group beneficial. From the responses we received we realised just how important this facility would be. 100% of the respondents said they felt they would benefit from such a group – and so Chatham Area Patient Support (CHAPS) began.

At our first CHAPS meeting 32 people attended, all at different stages in their cancer journey, from diagnosis to being given the all clear and beyond. Everyone had the chance to talk about their experience. Urology covers bladder, penile, testicular, prostate and kidney cancers, and although the management and treatment varies for these five cancer types, the concerns patients raised were very similar.

'With more and more people living with cancer, there needs to be more emphasis on looking after the person's emotional needs as well as their medical, especially beyond their treatment'

I think this type of support can be particularly beneficial for patients who have a cancer type that can be difficult to talk about or for whom it may normally be socially unacceptable to discuss because of its private nature; people feel more comfortable discussing their concerns when they realise they're not alone.



Further information
Irina Vieira
Macmillan Urology Clinical Nurse Specialist
Medway NHS Foundation Trust
Kent
Tel 01634 838918
Email irina.vieira@medway.nhs.uk



'I think this type of support can be particularly beneficial for patients who have a cancer type that can be difficult to talk about or for whom it may normally be socially unacceptable to discuss because of its private nature'

Once someone talks about an issue and it resonates with someone else, it's surprising how often others suddenly chime in: "You know I had that problem too - what did you find worked?" They want to know how other people coped and how they live with it and I was really pleased to see how the partners of patients became involved and took an active role in talking about their concerns too.

I think support groups really improve the experience of cancer survivors and help to meet their needs. It's a wonderful opportunity to have an informal chat, ask questions and discuss individual issues. After the first session, everybody said it was great and since then they've all called me back asking when the next one is!

The theme for our next meeting is entitled 'Erectile Dysfunction – Myth or Reality?' We plan to discuss this topic and help address any questions, issues and concerns people may have.

Life is never the same again after cancer and people want to know how to get on with their lives; so that's why we set up CHAPS.

The stress and rewards of palliative care nursing

Nursing has been identified as one of the four high-stress public sector occupations, alongside the police, social work and teaching¹. In addition, studies suggest that the emotionally intense work that nurses do in palliative care is associated with high levels of stress and burnout².

We set out to examine the experience of stress of CNSs and Macmillan nurses in Oncology and Palliative Care in order to provide effective structures and supports to retain these valuable specialist skills.

All fully qualified CNSs and Macmillan Nurses working in Oncology and Palliative Care within the Walsall Hospital Trust and the Teaching Primary Care Trust were invited to participate. A total of 17 out of 23 (74%) eligible nurses answered a brief questionnaire to provide information about their levels of experience, caseload and amount of clinical supervision. Individual semi-structured interviews probed topics of role, nature of stress, coping with stress, exacerbations of stress, missing supports and future plans. There has been a move to include qualitative methods such as this in studies of stress, which can capture the rich data that are individual personal experiences and perceptions. The interviews were recorded, transcribed and analysed thematically.

Relationships with colleagues

Nurses reported experiencing moderate to high levels of stress. Despite this the role was seen to be rewarding, with many wishing to remain in post.

Colleagues played a significant role in affecting well-being. Working in close proximity brought the inevitable conflicts inherent in human relationships. Staff absences increased workloads and stress levels for those remaining. However, both informal communication and more formal channels seemed to be invaluable for camaraderie and support. Isolation was marked for those nurses who were unable to communicate with their colleagues when they were feeling vulnerable, or who did not believe their colleagues could detect their signs of stress very easily.

Rewards and stressors

The nurses generally accepted the stress associated with the demanding role of working with sick and dying patients, as their ability to provide help and support in this way was intrinsically rewarding for them. An interesting link between rewards and stressors was made. Nurses seemed to report feeling most stressed and overworked when they were prevented from providing the highest standard of patient care because of personal, managerial and organisational factors, for example, poor staffing levels, poor practice, personal shortcomings, poor environment or through policy.

The rewards that nurses associated with their role fell under three broad categories, namely the nature of their contact with patients, the positive feedback received during the course of their work and their internal feelings that being in such a role generated.

Importance of good management

Many narratives related to management. While immediate managers were mentioned favourably, the narratives relating to upper management were generally quite critical. The nurses appeared to lack confidence that such managers could effectively support the work they did, as they were seen to be too far removed to appreciate the many practical and qualitative aspects of the role, let alone the emotional ones. There was also a thread of cynicism that ran through the accounts around exercises and policies proposed by management to promote efficiency. These were perceived as preludes to or justifications for job cuts.

Recommendations

From this research, various supports were perceived to be missing. We have developed the following recommendations:

- increased dialogue between specialist nurses and management
- a review of missing or inadequate resources, for example, staffing levels and working environments
- increased levels of supervision offered more flexibly and more regularly, that CNSs can access alongside clinical obligations
- introduction of more flexible working policies, such as working from home
- introduction of more flexible working policies, such as working from home
- commitment from the Trusts to continue to monitor stress levels in the workplace and to find ways to reduce these.

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Further information

Shradha Lakhani (Clinical Psychologist) and Sindeep Lehl (Assistant Clinical Psychologist)
Walsall PCT
Tel 01922 858450
Email shradha.lakhani@walsall.nhs.uk
and sindeep.lehl@walsall.nhs.uk

The work of a Macmillan speech and language therapist



Developing resources to provide information and support for head and neck patients

The rewards of the role

From early in my career I knew that I wanted to be a head and neck speech and language therapist. In particular, I was inspired by the Macmillan head and neck speech therapists that I met. I felt that helping people with head and neck cancer to speak and swallow sounded like something I would love to do. I finally had the opportunity to become a Macmillan speech and language therapist in 2007 when a post was advertised in Bath.

I work with a fantastic team – in particular, the specialist head and neck Macmillan cancer nurses have been a fabulous resource so far. The clinical side of the job is very rewarding. The moment when a patient speaks their first words after a laryngectomy or when a patient is able to swallow again after treatment are the best moments as a speech therapist.

Choosing the right treatment

I have been involved in developing many patient therapy tools, and recently created a DVD for patients who have to choose between radiotherapy or laser treatment for early vocal cord cancers. On the DVD patients, who have undergone these treatments, discuss their experiences. There is also a section that

gives more information about the treatments. Patients with a diagnosis of early vocal cord cancer can now make a more informed decision about the treatment options available.

The need for the DVD was highlighted through a research project that is looking into the outcomes of different treatments (laser surgery compared to radiotherapy) for early vocal cord cancers. It was very easy to find people who were willing to share their experiences of treatment and recovery with other patients. The DVD has not been formally evaluated yet but anecdotal feedback is very good, with many newly diagnosed patients saying they found it informative.

Other initiatives

Another recent initiative has been to reintroduce a laryngectomy support group in the area. Patients have enjoyed catching up and giving each other tips and tricks on coping with a laryngectomy. I have also provided training and information talks to GPs and doctors within Bath NHS Trust, and created a website for all the head and neck speech therapists in the south west (www.headandneck.org.uk). In addition, I have hosted a regional training day for speech therapists in the area.

Making a difference

The post has allowed me to raise issues of importance relating to head and neck speech therapists at our professional association (the Royal College of Speech and Language Therapists) board meetings. My aim is now to improve the services further by introducing more advanced methods of swallow and voice assessments, and to get long-term funding for this post.

It has been a very fast-moving and exciting job so far. I believe my post has been beneficial to the patients and in supporting the head and neck team. Being a part of Macmillan is very special. I believe that being a Macmillan speech and language therapist is about making a unique contribution to people who are living and surviving with cancer. Helping patients through Macmillan has given me the opportunity to make a real difference in people's lives.

Further information

Louise Pothier
Macmillan Speech and Language Therapist
Royal United Hospital Bath NHS Trust
Tel 01225 824319
Email louise.pothier@ruh.nhs.uk

NHS Scotland leads the way in professional development



NHS Education for Scotland (NES) is a Special Health Board with a remit to provide educational solutions for workforce development for NHS Scotland. In 2007 NES published the document *Working with individuals with cancer, their families and carers. Professional development framework for nurses and allied health professionals. Core level*.¹

This document addressed an action set out in *Nursing people with cancer in Scotland: a framework*² to develop a structured approach to support the continuing professional development and education of nurses in cancer care. Following discussion it was decided that the document should include AHPs, who have similar development needs.

Recent work in partnership with Macmillan has resulted in the publication of two additional documents:

- **Continuing development framework for health care support workers**
- **Professional development framework for nurses. Specialist and advanced level.**

Together the three documents provide a comprehensive professional development framework for healthcare practitioners working with people with cancer, their families and carers. The framework was built on the concept of capability, which describes the ability to apply, adapt and generate new knowledge from experience, and emphasises the potential for individuals to develop further in the future and to continue to improve their performance.^{3,4} Capability combines the competence required to do the job now with the potential for future development as job roles and situations change. The framework documents detail capability statements, related practice learning outcomes linked to the NHS Knowledge and Skills Framework⁵ and indicative key content for education and work-based learning.

The two latest documents were produced following extensive consultation with a wide range of stakeholders in a series of workshops, consultation events and working groups across Scotland. Contributors included healthcare support workers,

nurses, managers and educationalists. The projects were also supported and guided by two separate steering groups.

The documents link to other work currently being undertaken in NHS Scotland, specifically:

- the Advanced Practice Toolkit being developed by the Scottish Government Health Directorate under the auspices of the UK-wide Modernising Nursing Careers (MNC) initiative⁶
- a toolkit for healthcare support workers being developed in a partnership project between the Scottish Government and NES.

It is anticipated that the development framework will provide practitioners, managers and educationalists with a tool to support and guide:

- self assessment
- personal and professional development
- team development
- education and training
- work based learning.

Work is currently ongoing in NES to determine how best to support implementation of the framework. Future evaluation of the framework is also planned to determine its value and usefulness for healthcare practitioners working with people with cancer, their families and carers.

Where to get copies

The specialist and advanced level document was published in August 2008 and distributed to Macmillan Cancer Support, all NHS Boards, HEIs, Colleges of Further Education and other relevant stakeholders in Scotland. Additional copies are available by emailing ellen.stuart@nes.scot.nhs.uk.

Copies of the documents are also available for download at www.nes.scot.nhs.uk/publications.

The healthcare support worker document will be published later this year.

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Further information

Dr Maggie Grundy
Programme Director Cancer Care
NHS Education for Scotland
Tel 01224 558932
Email maggie.grundy@nes.scot.nhs.uk

Better care in the final days

The care of dying patients often falls short of what they and their carers might wish for. They might be admitted to hospital as an emergency and then die in this inappropriate setting, or delays in discharge from hospital might mean that they do not die at home as they may have wished.

To address these problems our team at the Wigan Infirmary within the Wrightington Wigan & Leigh NHS Trust set up a working party to look at how to make improvements to two processes that were causing particular problems within our hospital.

Emergency admissions

A number of patients are admitted to the acute hospital with a poor prognosis and life expectancy due to advanced disease. Some of these patients may have been cared for by family members who are now feeling exhausted, unsupported and emotionally drained. Symptoms may arise that the carer was not prepared for, causing them to panic and call for an emergency ambulance. The patient is then admitted to the emergency department and can die in this inappropriate setting.

A choice of where to die

The discharge home of dying patients may also be problematic and can be delayed for many reasons. It is an important part of care to identify the patient's preferred place of care/death, in order to plan a safe, rapid discharge home for patients if that is their wish. This is a challenging but rewarding part of my role. It also, if managed effectively, frees up acute beds and uses valuable, scarce resources in the best way possible.

Identifying key issues

The working party consisted of two members of the palliative care team, a ward manager, two members of the district nursing service, a pharmacist and a member of the clinical case manager's team. This working party met monthly and identified the issues by brainstorming. These included:

- communication problems – the palliative care team not knowing that the patient had been admitted
- delays in issuing take-home medications and the need for a fast track system to be put in place
- medical staff not diagnosing dying
- lack of clear individual responsibility
- issues around continuing care, district nurse follow-up, and social services involvement.

Developing new procedures

After reviewing the literature, there seemed to be no protocols developed that are available that would address the issues the group had identified. Instead we developed our own flow chart to clarify procedures and to allow for the rapid discharge home of dying patients who were already on the Integrated Care Pathway for the Dying. The flow chart clearly states areas of responsibility for each health professional involved in the rapid discharge process of their patient. The wards have now successfully discharged 10 patients home to die, who had previously expressed a wish to die at home.



Janet Irvine (left) and Edna Wilcock (right), Lung Cancer Specialist Nurse, won the first prize for Innovative Practice from the Trust as part of the Recognising Excellence Awards.

We followed up this project by piloting a flow chart for the rapid admission of dying patients from the emergency department. The effort around improving the care for this group of patients proved more problematic as the area was so busy and the staff identified problems such as lack of training regarding end of life issues, syringe driver management and not enough time to talk with patients' families regarding place of care/death. However, with perseverance from all parties the work that evolved now means that the patient can be fast-tracked through the department from a hospital trolley to a bed and then, after assessment, to their place of choice. If that choice is to die at home then the rapid discharge flow chart can be used effectively.

Patients carry a palliative care alert card giving the name of their hospital key worker, who can then be informed of the admission and be contacted for advice, making identification easy for Accident and Emergency staff.

Award winning

This process has been eventful and there have been problems, especially in the early days. However, with support and continuing educational sessions for the staff involved, this work continues to flourish.

We have gone on to win an award from the Trust for this work and are very proud of what we have achieved. However the real reward comes from knowing that patients and families are at last able to realise that their voices are heard and their wishes acted upon at this very important time in their lives. Feedback from all involved has been positive with relatives taking the time to let us know the difference our work has made at the end of life.



Further information
Janet Irvine
Hospital Macmillan Nurse
Cancer Care Suite
Wrightington Wigan & Leigh NHS Trust
Tel 01942 822 009
Email janet.irvine@wvl.nhs.uk

A strategy for daily living

Charlotte Argyle, Macmillan's Lifecare Transition Manager, gives an overview of Macmillan's approach to meeting the needs of carers

Macmillan currently supports carers of people with cancer in a number of ways. This includes information, financial help and self-help and support groups, such as the Lung Cancer/Mesothelioma Patient and Carer Support Group featured on page 22. Carers receive support from a range of Macmillan professionals, like Family Support Worker Hilary Wilson (page 16). We also fund local carers' services that provide support such as respite care, personal care and domestic help, and emotional support for the carer and patient. Louise Evans (page 18) and Wendy Sawers (page 17) are both working in partnership with Macmillan to deliver local carers' services.

The Daily Living Programme

Feedback from users and referring professionals confirms that Macmillan's network of local carers' services deliver excellent high quality services. In 2007, however, we commissioned an evaluation of the services which focused on their cost, reach and sustainability. Based on the findings of the evaluation, and our strategic aim to reach more people affected by cancer, we decided not to develop and fund any new carers' services of the existing type. Instead, we will develop new ways of meeting the needs of carers as part of our wider Daily Living Programme of work.

Macmillan remains very committed to its existing carers' services, and our Macmillan/Crossroads Strategic Partnership Project Manager, Astrid Campbell, is working closely with many of them and their Macmillan service developers to support their development and delivery. Astrid has a national strategic overview of the carers' services, and her remit includes sharing good practice and networking the services.

The aim of the Daily Living Programme, managed by Barbara-Anne Walker, is to meet the practical and emotional needs of people living with cancer and their carers by promoting independence, control

and choice. Macmillan's strategy for local service provision is to develop and innovate where there are identified gaps in service provision. This includes piloting new ways of delivering services through volunteers.

Meeting emotional needs

The Macmillan Bereavement Service (featured on page 21) is a good example of a service that meets the emotional needs of people affected by cancer. We plan to develop further services of this kind using volunteers, as well as other emotional support services such as self help and support groups and befriending services. These services can all meet the needs of carers as well as people living with cancer. Other services will be developed exclusively for carers, to meet their specific needs. On page 20, Fran Carter a carer describes her experience of attending a support group specifically for carers of people with cancer and children under 16.

Practical support

We also plan to develop more services that provide practical support for people affected by cancer, over and above what is available from statutory services. The type of support offered can include domestic help such as cleaning, cooking and gardening; maintenance and repairs in the home; transport – for example, to appointments; and respite for carers. These services can be delivered by volunteers, which will help to increase Macmillan's reach to people affected by cancer, including carers. The Macmillan Bridges Support Service featured on page 10 offers a wide range of this kind of practical help to support people at home.

Direct services

As well as local service delivery, Macmillan will continue to support carers via our direct services such as Cancerline and the Macmillan Benefits Helpline. Our merger with Cancerbackup has enhanced our information provision to people affected by cancer, including carers. We also continue to lobby and campaign on issues affecting carers of people with cancer, including the New Deal for Carers; the green papers on adult social care and welfare reform; and the Cancer Reform strategy.

In all our work to support carers, we are guided by carers themselves to ensure we meet their needs and those of the people they care for.



Further information
Charlotte Argyle
Lifecare Transition Manager
Lifecare Department
Macmillan Cancer Support
Tel 020 7091 2041
Email cargyle@macmillan.org.uk

Care for the whole family

Macmillan Family Support Worker Hilary Wilson on supporting families, including the children of patients

A gap in provision

The need for a Macmillan Family Support Worker to offer cancer patients a broader range of support than had previously been available from existing Macmillan professionals was confirmed by a pilot project, established with local palliative care monies. I was fortunate enough to be the post holder for both the pilot and now the substantive post.

The pilot highlighted a gap in service provision for benefits advice and general ongoing, long-term support for the whole family, especially children, with bereavement support being provided if necessary. Much of the benefits support is now provided in benefits clinics held in our Cancer Information Centre. I am responsible for some of these, while the Suffolk County Council Financial Inclusion and Advice Service delivers the remainder.

As a shared post between Ipswich Hospital and the community Macmillan nurses, I initially only took referrals for patients known to them. However, as the role has evolved my involvement has been seen to be beneficial to patients and families before the palliative stage of their disease, and the majority of my referrals now come from Clinical Nurse Specialists.

Supporting families

The development of the support for families, and particularly the children of our patients, has been both challenging and exciting. Having previously been the social worker in the department, many colleagues looked to me for benefits advice and practical issues,

so I had to encourage them to use me in a much broader way. Once you have been involved with one family, so it grows, and as many of our families have never had any contact with the local hospice, which does offer support to families and children, this has become an ever-developing area of my work.

One of the advantages of the post is the ability to work where it is best for the patient and their family, helping them maintain some element of control at this confusing time. Appointments can be made in the hospital, as an inpatient or outpatient, at home, or by seeing children in school where constructive and supportive links can be made. Older teenagers sometimes prefer local coffee shops and leisure centres. Being able to be flexible about where to meet helps in our aim to make the meeting very person-centred.

The bulk of my caseload is with families where children have to cope with the illness and possibly impending death of someone special to them. Sometimes it is even more complicated than that, as the patient is having potentially life-saving treatment, but the risks of that treatment are so great that they might not survive. For the children of these patients they have to live in limbo, sometimes for a considerable amount of time.

A family room

During my time working with these families I recognised a need for somewhere families can be together, sharing in normal activities whilst one of them is an in-patient. From this I have planned and implemented turning a disused smoking room on the oncology ward into a children and family room. This offers a space away from the clinical environment, where books and resources are available for children to explore with either their parents or myself.

In addition to this I have been working with colleagues in paediatric oncology to organise workshops for children of all ages who have been bereaved.

I see my role as one that will continually evolve, responding to the constantly changing needs of patients and their families. It is probably one of the most challenging jobs I have ever had, but yet also the most rewarding.



Further information
Hilary Wilson
Macmillan Family Support Worker
Ipswich Hospital
Tel 01473 704932
Email
hilary.wilson@ipswichhospital.nhs.uk



Support and respite for carers

Delivering a Macmillan Crossroads service to the carer

Role of the service

I started my Macmillan post with Crossroads two years ago. Funded for four years, this is a specialist support and respite service for carers affected by cancer or caring for a person with a diagnosis of cancer. It is recognised that being a carer is a cause of great stress, which can lead to poor health. Crossroads provides 72 hours a week of respite breaks and support, to both the carer and cared for. Trained Carer Support Workers replace the unpaid carer to enable them to carry on working, attend their own appointments, sleep, pursue hobbies or just take a break. They are able to recharge their batteries to enable them to carry on in their caring role.

This preventative service has helped to avoid carer breakdown along with the associated unnecessary hospital/hospice admissions. It has also supported the carer, along with other services, in caring for someone who chooses to die at home. The service provides individual care packages with varying support tailored to the needs of the carer and cared for. This can include assistance with personal care, medication and preparing meals, as well as emotional support to the carer and cared for.

A dedicated team

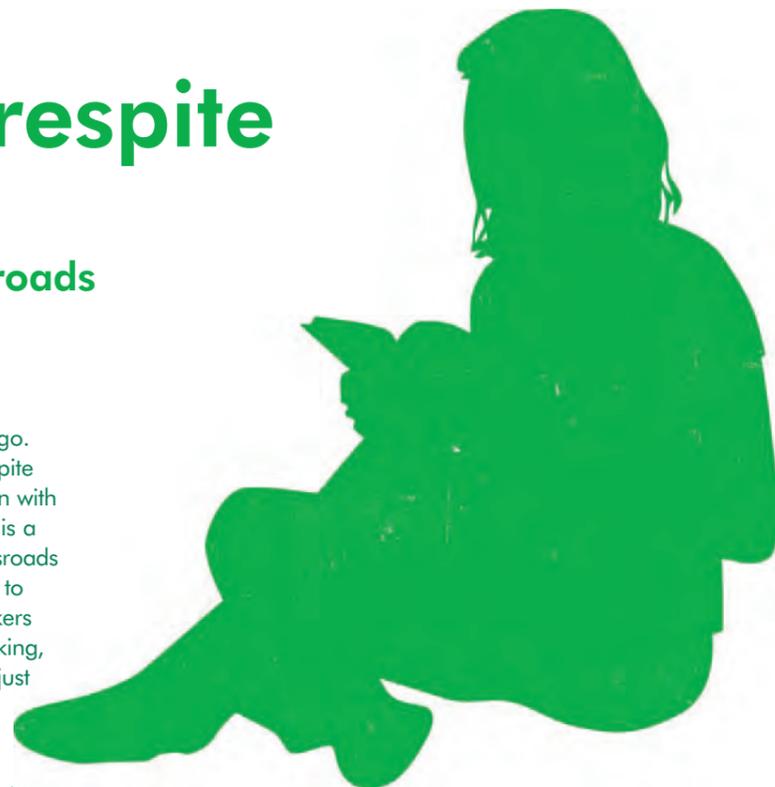
The response we receive from carers through evaluation and letters reflects the impact the Crossroads staff have had on both the carers and the patients' lives. They are a dedicated team who, at times at very short notice, have pulled together to support a new carer or increase support to an existing carer when their needs have changed. The staff are trained carers, with additional cancer and palliative care training provided by the local hospice. They also receive additional specialist training as required, such as administering oxygen.

'One of the big challenges for the service is reaching carers before they reach a crisis'

My first task on taking up the post was to set up a steering group. The group meets every three months and advises on the development and evaluation of the service, gathering evidence of its success in offering preventative support. We will hopefully convince commissioners to continue funding the project after the end of four years.



Further information
Wendy Sawers
 Crossroads Macmillan Coordinator
 Woking and Surrey Heath Crossroads
 Tel 01483 793737
 Email macmillan.woking@surreycrossroads.co.uk



Avoiding a crisis

One of the big challenges for the service is reaching carers before they reach a crisis. They themselves often don't acknowledge that they are carers and the pressure they are under. Their needs take a second place to the person with cancer. My job at the outset was to market the service to ensure we reached carers; there was an official launch, I was interviewed by a local radio station and the local paper wrote an article about the service. I produced posters and a leaflet and gave presentations to professionals and other carer support charities. The leaflets and posters were distributed to GP surgeries, district nurses, hospitals, social care teams, hospices and a centre that provides complementary treatments to people with a cancer diagnosis, within the geographical area. We take referrals from anyone, including the carer.

Funding for the future

Halfway through our funding there has been a major change in the way that charities receive their money, with the focus being on tendering for contracts rather than receiving grants. This has meant that charities have to take a more business approach to proving their value and competing for contracts alongside other providers. Macmillan has agreed to fund a consultant to present a business case, following the successful funding of a similar Crossroads Macmillan Project. If we are successful in obtaining funding we can continue and even increase our support to carers, as the service is already operating at capacity and I am sure we are not reaching all carers who need our support.

A hospice at home

Louise Evans tells us how she set up a three-year project to improve the service offered by Rotherham Hospice at Home

Ensuring equality of provision

I have been working with Macmillan and Rotherham Foundation Hospital and Rotherham NHS Community Health Services to offer people more choices around where and how they wish to receive care through Hospice at Home. Rotherham is one of the 88 most deprived areas in the country, as identified in the 2001 census, and we needed to develop a new way of working in order to provide our services to the entire population.

The project team

The project team involves service users, carers and professionals who are actively represented through local and statutory agencies, community networks and forums. In this way, the strategic direction of the project reflects the aims of local and national policy: 'putting patients, public and staff at the heart of everything we do'.¹

Aims and objectives

My aim was to complement existing services within our local integrated pathway of care (IPOC) (based on the Liverpool pathway of care model), by bringing together additional specialist palliative care and support. I decided to develop a Specialist Palliative Care Team so that an increased number of people with cancer or other advanced illnesses would be cared for in an environment of their choice by highly skilled professionals. This decision was based on a gap analysis and on extensive feedback with users and professionals, and I felt this was the best way to meet this need.

The three main objectives for the project are to:

- extend patient choice
- prevent avoidable admissions during palliative and end of life care
- promote equality and diversity across supportive and palliative care provision.

New posts

I initially tackled these objectives with the introduction of some new posts within our team, including: six Macmillan Generic Support Workers to increase hands on care and emotional support; a dedicated Macmillan Equalities Link Worker to promote palliative and end of life care within the Black Minority Ethnic (BME), learning disability and mental health groups; a Macmillan Specialist Palliative Care Occupational Therapist and Physiotherapist; and a part time



Further information
Louise Evans
 Hospice at Home and Marie Curie Service Manager
 Rotherham Hospice
 Tel 01709 308923
 Email louise.evans@rotherhampct.nhs.uk

'This is a scheme that brings the skills, ethos and practical care associated with hospices into the home environment and puts the patient and those who matter to them at the centre of care. It is an integral component of palliative home care, which forms a spectrum from advisory and educational roles to hands-on-care, in response to the changing needs of the patient and carers.'

The philosophy for Hospice at Home as determined by the National Forum for Hospice at Home (UK)
www.hospiceathome.org.uk

staff nurse that has been funded by NHS Community Health Service. Future plans to extend Specialist Palliative Care provision at home include trained nurses; a specialist social worker; a complementary therapist; and increased volunteer and bereavement support. At present, carers are offered 'time out' with the support of our contracted Generic Support Workers and a team of bank staff, who are available on demand. Volunteer bereavement support is offered to all our carers and their families and it is then their decision (following a first contact from us) if they wish to access the service. The bereavement service is based at the hospice and run by the voluntary services manager as part of specialist palliative care provision.

We have developed a carer questionnaire to evaluate the service, and we send this out at the same time as carers are contacted by the bereavement service so that they don't feel overwhelmed with contacts and this reduces emotional distress.

Future development

As part of future development we will extend the volunteer and bereavement support element within the Hospice at Home service. In the near future we also hope to address counselling skills and bereavement care through an educational programme for the Generic Support Workers.

As this project develops it will continue to require long term commitment, time and investment from the PCT and myself. Individual patients have different needs at different phases of their illness, and services should be responsive to patients' needs.²

Each project will be evaluated throughout the three years using a variety of methods (such as questionnaires and data collection). Continued funding via the PCT will depend on the positive evaluation of each project.

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A view from the other side

The Carers' Centre for Brighton and Hove is a local charity which exists to support anyone caring for a partner, relative or friend who needs help because of an illness or disability. Macmillan supports the work of the centre by funding two Macmillan Support and Outreach Workers, one of whom recently supported Fran Carter who was caring for her husband.

My husband, Richard, was diagnosed with bladder cancer two-and-a-half years ago. Although our Macmillan nurse mentioned the Carers' Centre, I found everything difficult to handle (such as arranging Richard's operation to coincide with me being induced with our second child!), so it went out of my mind. But one of the outreach workers, Sara, contacted me and asked how things were going. I wasn't sure whether to follow this up, but Sara's gentle and understanding approach persuaded me that it was worth a go.

I attended a carer support group specifically for carers with a partner or family member with cancer and children under 16. It was good to go to a group specifically for my situation, as the responsibility of young children does add a different dimension. At my first meeting there were only three others, and we were all at different parts of the journey – Richard had only just been diagnosed whereas others had been carers for years – but it made such a difference to my state of mind. It was amazing the things we had in common and the things that we could talk about that we couldn't tell friends and family – all the selfish thoughts and the 'what ifs', without fear of recrimination.

After that I attended the monthly meetings whenever possible. I had to find a childminder to attend the meetings, and the centre assisted financially with this. I felt guilty about the support offered to me – you feel that you're not the patient so you're not entitled to any help. Most times, I didn't approach the centre, but Sara followed up on comments I made and encouraged me to accept help. In the weeks when I was

looking after a newborn baby, a toddler and Richard, Sara contacted the council and arranged for a weekly clean of the kitchen and bathroom, which took a huge load off my mind. Later, our roof started leaking into our bedroom when Richard was still recovering in bed. I never thought we would get help with this sort of thing, but we were awarded grants from Macmillan and two smaller charities. Sara knew exactly who to contact.

My husband made a good recovery and even ran the London marathon a year after his operation. I continued to attend the support group, although I thought I didn't really need to. I was wrong! Eighteen months after Richard's diagnosis I found I was very depressed. I think it was a time when everything had settled back down (supposedly!), and the adrenalin just ran out. Again, the support group was invaluable and I learnt this was a perfectly normal reaction.

I still attend the support group. Whenever we have a follow-up appointment the old feelings of worry resurface and it's good to talk these through. I was also recently asked to join a steering group for one of the centre's projects. I've only been to one meeting so far but it looks like it's going to be interesting. We're looking at how to target carers so they know they can get the help they need. We had a representative from the Brighton Ethnic Minorities Group attend last time, and for the next meeting we're thinking of how to target male carers, who traditionally ask for less help.

Further information
Fran Carter
 C/o Carers' Centre for Brighton and Hove
 Tel 01273 234045
 Email info@thecarerscentre.org

Support for the bereaved

A Macmillan Bereavement Service is included as an example of best practice in the Department of Health's End of Life Care Strategy

Palliative care does not cease with the death of a patient, as was recently recognised by the Department of Health in their guidance supporting the development of specialist palliative care services.¹ Caring for bereaved relatives should be one of the three services provided by specialist palliative care providers, as proposed in the NICE guidelines. Despite the recommendation that bereavement support should be available nationally, it continued to be a neglected area of service provided by palliative care in North Tyneside.

For many years Doreen Hall, a Macmillan CNS in the specialist palliative care team at the Sir G B Hunter Memorial Hospital on Tyneside, had argued that not enough was being done to support carers and family members after the death of a loved one. Doreen conducted a qualitative research project which proved this need and helped secure Macmillan funding for a new service to provide support for bereaved people in North Tyneside. The Macmillan Bereavement Service was launched in late 2004, with Doreen as Operational Manager and Lisa Johnstone coordinating the service on a daily basis. Macmillan funded the service for three years and from 2008 North Tyneside PCT took over the funding of this now established service.

Referrals are made to the service by a range of healthcare professionals, including Macmillan nurses, GPs, district nurses and consultants. Lisa then carries out a holistic assessment to identify the bereaved individual's needs within their home setting and implements a care plan. Initially only referrals for individuals bereaved through cancer were accepted,

but the service now supports individuals bereaved through all illnesses and causes of sudden death.

Each bereaved person is allocated an appropriately trained and supervised volunteer, who will offer a supportive, confidential and non-judgemental relationship during this difficult period in their life. Visits will be made to the bereaved person's home for as long as necessary to provide them with support through the grieving process. So far 45 volunteers have been recruited and trained. Each volunteer goes through a recruitment programme of informal and formal interviews, Criminal Records Checks, training and monitoring before participating in the comprehensive two-day training programme. We run the programme together, covering basic counselling skills, listening skills, communication skills, confidentiality and the theory of grief and loss. Ongoing support and education is delivered through monthly meetings and supervision sessions, but volunteers are also able to contact Lisa at any time for support and guidance.

'My volunteer gave me hope and belief – without her I would have given up'

Service audits and satisfaction surveys sent to service users, health professionals and volunteers have demonstrated the success of the service, with 98% of client respondents stating that they had benefited from the service. One service user said: 'My volunteer gave me hope and belief – without her I would have given up.'

Most professionals – 91.7% – stated they would continue to refer to the service. One reported 'excellent feedback from patients about the level of support provided even in complex cases.' The inclusion of our service in the Department of Health's End of Life Care Strategy as an example of best practice provided further evidence that the service is delivering support how and when it is needed. The service plans to continue recruiting and training volunteers to ensure demand is met. In the future we plan to expand the service and develop a children's loss, grief and bereavement service.

References

- [1] *Planning and Funding Specialist Palliative Care Provision 2003/04-2005/06*, Department of Health.
- [2] *Improving supportive and palliative care for adults with cancer*, NICE 2004.
- [3] *End of Life Care Strategy – promoting high quality care for all adults at the end of life*, Department of Health, July 2008, Department of Health.



Further information
Doreen Hall, left, (Operational Manager)
 Tel 0191 220 5957
 Email doreen.hall@northumbria-healthcare.nhs.uk
Lisa Johnstone, right, (Co-ordinator)
 Tel 0191 297 9013
 Email lisa.johnstone@northtyneside-pct.nhs.uk
 Macmillan Bereavement Service
 Shiremoor Resource Centre Newcastle



Developing an award-winning support group

Macmillan was thrilled when the Lung Cancer/Mesothelioma Patient/Carer Support Group won a Best of Health award (see the autumn issue of Macmillan Voice). The group, which volunteers help to run, is for both patients and carers, and provides information and emotional support. In this article Frances McKay shares some of the challenges she encountered when setting up the group in 2005.

The need for support

Patients living with lung cancer and mesothelioma often experience significant difficulties around psychological morbidity and social isolation. It is important that this group of patients and their carers are given support and practical information as soon as possible so they can plan for their future needs. I formed a focus group, offering patients and carers the opportunity to voice their concerns, which then led to the formation of the Lung Cancer/Mesothelioma Patient/Carer Support Group.

Approximately one person is diagnosed with lung cancer or mesothelioma every 15 minutes in the UK, with a prognosis of four to six months. The impact on the emotional and psychological wellbeing of both patient and carer cannot be underestimated. In our Lung Cancer/Mesothelioma Support Group we offer a supportive and non-threatening environment where patients and carers feel safe and can discuss any concerns.

Finding a venue

The first thing to do was find an appropriate venue. I was based at a district general hospital where accommodation was at a premium, car parking facilities were overstretched and many patients were unable to walk very far. We wanted a venue offering easy access, good car parking (preferably free), comfortable chairs and refreshment facilities. The local hospice ticked all the boxes! I approached a member of the domiciliary Macmillan team to join forces and work collaboratively on this essential new service. The Day Hospice facilities were the obvious choice of venue. Fortunately both the Day Hospice Manager and Medical Director agreed we could use the room one afternoon a month when the Day Hospice group finished.

Funding and administration

Funding was the next issue. Generously, the hospice has not charged for the use of their facilities, so the only cost implications were refreshments and the cost of any speakers or entertainment. We successfully applied for a small Macmillan Grant and by keeping outgoing costs to a minimum have been able to stay afloat. Many speakers give their time and energies for no charge.

The administrative aspects of the group remain a challenge. It is crucial to update the membership list regularly to ensure invites for the next meeting are not sent out inappropriately to very sick patients or to those who have sadly died between meetings.



Time also remains a constant challenge. Although the group is only held for one-and-a-half hours a month, the time invested to arrange speakers or entertainment, produce and distribute invitations and update the membership list is very time-consuming.

Positive benefits

The group has always been well attended by both patients and carers, with sometimes over 20 people, and not one meeting has been cancelled since its inception. Positive benefits for staff include regular face-to-face contact and follow-up with patients in an informal environment; improved communications; opportunities for collaborative and partnership working; and the satisfaction of knowing that we are providing a very worthwhile and much-needed service. We also feel this group gives us opportunities to explore sensitive issues that would otherwise have been impossible to support by telephone or in the acute setting.



Further information

Frances McKay, right, (Macmillan Mesothelioma/Lung CNS)
Tel 01634 825391
Email frances.mckay@medway.nhs.uk
Caroline Williams, left, (Macmillan Lung CNS)
Medway Maritime Hospital
Tel 01634-825391

GETTING INVOLVED

Diary of events

December 2008

1-31 December
Children's Cancer Month
CLIC Sargent
www.clicsargent.org.uk

January 2009

26-30 January
Be Loud
Beating Bowel Cancer
www.beatingbowelcancer.org/new

February

15 February
International Childhood Cancer Day
Children's Cancer and Leukaemia Group
www.ukccsg.org

March

1-31 March
Great Daffodil Appeal
Marie Curie Cancer Care
www.mariecurie.org.uk

1-31 March

Ovarian Cancer Awareness Month
Ovarian Cancer Action
www.ovarian.org.uk

1-31 March

Prostate Cancer Awareness Month
Prostate Cancer Charity
www.prostate-cancer.org.uk

Macmillan events

January 2009

19-23 January
Cancertalk Week
Provides schools with the perfect opportunity to dispel the myths and misconceptions that surround the illness and encourage positive, healthy lifestyles. Sign up and we will send you two free teaching packs to help you plan your lessons or special assemblies and deliver them with confidence.
Tel 0845 601 1716
www.cancertalk.org.uk/cancertalkweek

April

26 April
Flora London Marathon

If there is one race that you just have to take part in then this is the one – the most famous and widely respected marathon in the world. Why not put on our green vest and take part in the 2009 Flora London Marathon on behalf of Macmillan Cancer Support? Here at Team Macmillan we understand what it takes to train for and complete a marathon. That's why we'll be there for you from the moment you sign up with a dedicated marathon team providing both fundraising and training advice. So, put on your running shoes and take part in the challenge of a lifetime!
Tel 020 7840 7878
Email londonmarathon@macmillan.org.uk

May

29 May-7 June 2009

Peru Hiking Challenge

Hike to the Lost City of the Incas, Machu Picchu – this challenge takes you through lush cloud forest, green valleys and high passes, up to 4,200m, with breathtaking views of snow-capped Andean peaks.
Tel 020 7840 7887 quoting MV
Email hiking@macmillan.org.uk
www.macmillan.org.uk/peru



August

1-9 August 2009
Iceland Hiking Challenge
Discover the land of fire and ice while trekking 110km through the varied and stunning landscape of southern Iceland.
Tel 020 7840 7887 quoting MV
Email hiking@macmillan.org.uk
www.macmillan.org.uk/iceland

Summer 2009

Big Sports Day

For 2009 we are launching a brand new schools fundraising event to replace the Big Hush. The Big Sports Day will take place in the Summer Term and focus on healthy living and getting pupils active. More information will be available in early 2009.

September

13-19 September 2009

Romania Hiking Challenge

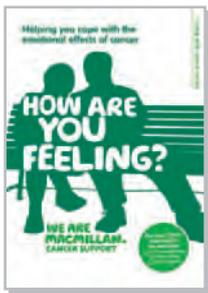
This trek takes us to the heart of eastern Europe to explore the remote mountain region of the Carpathians, finishing with a visit to Bucharest, the vibrant capital city of Romania. Boasting rolling hills, glacial lakes and stunning gorges, this spectacular region offers some of the best trekking in Europe.
Tel 020 7840 7887 quoting MV
Email hiking@macmillan.org.uk
www.macmillan.org.uk/romania

WE SHARE RESOURCES

Don't forget, Cancerbackup information resources are now available to order for free from Macmillan. Visit be.macmillan.org.uk or call 0800 500 800.

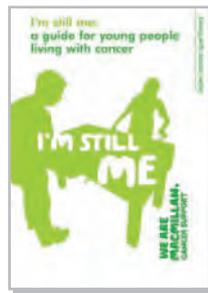
- 73 booklets on all main types of cancer; the key tests and treatments; as well as a range of titles on all aspects of living with cancer
- the Cancer Factfile containing more than 330 factsheets covering the main chemotherapy, biological and hormonal treatments, as well as some of the rarer types of cancer is available on CD ROM - all Macmillan Professionals will get a copy, which you should have received already
- a range of leaflets covering the familial risk of certain cancers; the effect of treatment on fertility; and questions to ask health professionals about cancer and its treatment.

New and revised Macmillan resources:



How are you feeling?
MAC11593

Offers advice and guidance to anyone affected by cancer who may feel isolated or lonely. The booklet discusses how you may be feeling, and provides information about sources of support.



I'm still me – revised edition now available
MAC6706_0808

A booklet answering questions and offering tips to 12-21-year-olds living with cancer. It includes insights from young people who have lived with cancer.



Survivorship
MAC11578

A report about Macmillan's cancer survivorship agenda. The report illustrates some of the problems faced by people living with or beyond cancer, and suggests potential solutions.



Hello and how are you – revised edition now available
MAC5767

Written by carers, for carers, this handbook contains information and tips for people caring for someone who has cancer. The handbook is based on carer's real-life experiences, the challenges they faced and the things they found helpful.



Macmillan Resources Catalogue
MAC5782_1108

A catalogue listing free Macmillan and Cancerbackup publications that can provide useful information for people affected by cancer, aid professional development and help raise awareness of Macmillan's publications.

