Focus on survivorship

In this issue
Stephen Guy
Manager, Macmillan Welfare Rights Service
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 Editor Rosie Cotter at rcotter@macmillan.org.uk or call her on 020 7920 7212.

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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NEW FORM OF FUNDRAISING RECRUITS OVER 9,000 SUPPORTERS

A six-month trial of door-to-door fundraising has recruited over 9,000 new supporters for Macmillan, who have pledged to donate over £1million every year. This makes door-to-door fundraising one of our most successful and cost-effective forms of supporter recruitment to date. The donations pledged will help pay for vital services for people affected by cancer.

The fundraising campaign involved teams of professional fundraisers (wearing Macmillan-branded clothing and carrying identification badges) calling at potential supporters’ homes to ask if they would like to support our work through a monthly donation. I know some of your patients have asked whether these fundraisers are genuine and if Macmillan does this form of fundraising – you can now confidently say we do.

Our fundraisers called at over 100,000 households. As well as recruiting a lot of new supporters for Macmillan, they have also been busy raising our profile within local communities and promoting our services to those who need our support.

On the whole, this fundraising campaign has been positively received by the public. A newly recruited supporter in Oldham sums up exactly why door-to-door is an effective form of fundraising for us: ‘I think Macmillan is fantastic and I’ve been intending to donate for sometime, but you know, it’s one of those things, I just never got round to it and when the lad knocked on my door, I thought it was a perfect opportunity to put my money where my mouth is.’

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2009 International Journal of Palliative Nursing Awards

Macmillan was proud to sponsor this year’s International Journal of Palliative Nursing Awards.

The awards celebrated the outstanding work carried out by palliative nurses worldwide. They were held in London in March, and were hosted by Peter Black, Editor of International Journal of Palliative Nursing, and Professor Jessica Corner, Chief Clinician at Macmillan.

Macmillan professionals were among the prize winners on the night. Macmillan Palliative Care Clinical Nurse Specialist Ann Brennan, who works out of ‘Y Bwthyn’ in Bridgend, won the Palliative Care Nurse of the Year Award, while the Children’s Haematology Oncology team at Royal Belfast Hospital came second in the Multidisciplinary Teamwork category.

The Lifetime Achievement Award, which was sponsored by Macmillan, was awarded to Kathleen Defilippi. Kathleen has been involved in the provision of palliative care since 1983, when she founded the South Coast Hospice home care programme in South Africa’s rural KwaZulu-Natal.
Macmillan cancer unit celebrated for its quality and design

The Macmillan cancer unit at Leighton Hospital in Crewe won the ‘Best Commercial Project’ award at the Cheshire District Built in Quality Awards Scheme 2009.

The unit, which opened in May 2008, provides outpatient clinics for people with cancer to see their consultant or multidisciplinary team member, and for chemotherapy treatments. It also provides support services to people affected by cancer, including a Macmillan information and support unit.

The environment is designed to be therapeutic and includes a courtyard for people to relax and have their own space. Macmillan were involved in many stages of the project including funding, development, project management, and sourcing users’ views on the initial design.

Macmillan is currently working with the Department of Health to develop a kitemark for good cancer facilities. The kitemark will be the first national cancer standard building award in the UK and will be launched in 2010.

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Dedicated conference for palliative care social workers

Each year the Association of Palliative Care Social Workers holds a conference for its members. This year the Midlands region will be hosting the conference at Lincoln University from 1–3 September 2009.

The conference is an excellent opportunity for social workers working in palliative care to get together and discuss current issues. The association operates nationwide and each area has regional representatives who attend regular meetings that include an element of training. Social workers in palliative care are often lone workers or based within a medical team. The association offers its members support from peers and is particularly useful to new workers coming into the field.

If you are a registered social worker in the field of palliative care, please contact the Membership Secretary Sue Smith at sue.smith@mdassociation.org, or you can contact the conference committee via Heather Nicklin, Macmillan Specialist Palliative Care Social Worker, at heather.nicklin@nlpct.nhs.uk

See page 13 for more information on oncology social work.

Correction
In the last issue of Macmillan Voice we featured an article on page 16 about implementing nurse prescribing across a community. This article was written by Macmillan Clinical Nurse Specialists Mary McSweeney, Pat Jacob and Ellen Goodall, as a reflection of their experience of implementing non-medical prescribing.
Award-winning Macmillan professionals at Northampton General Hospital

Macmillan professionals shine at annual oncology conference

The Royal College of Nursing’s 15th annual oncology conference provided an excellent forum for Macmillan professionals at Northampton General Hospital to showcase their work.

The conference theme was ‘Collaboration in a time of change’, and oncology ward nurses along with three Macmillan professionals from the hospital attended.

Macmillan Social Care Coordinator Jan Bolton gave a presentation and Macmillan Lung Cancer Nurse Specialist Lisa Wells presented a poster on her work (a display poster communicating work or research).

My colleague Karen Lemoine, Senior Radiographer, and I (a Macmillan Head and Neck Cancer Nurse Specialist), presented a poster for the first time. We were unexpectedly awarded a prize of an oncology book donated by the pharmaceutical company Hospira UK. It was given for the multidisciplinary approach we took to our weekly review clinic for people undergoing radiotherapy for head and neck cancer.

We set the clinic up in September 2007 and haven’t looked back since. Our approach allows patients and carers to have a holistic assessment and review during and after their treatment. We use an evidence-based tool and work together to improve standards of care. At the conference we received a lot of interest and feedback from other delegates.

The conference was held over two days in January at Chester Race Course, and was organised by Clatterbridge Centre for Oncology NHS Foundation Trust and the Royal College of Nursing.

Outstanding personal dedication earns award for Macmillan occupational therapist

Macmillan Occupational Therapist Julie Reece was awarded the ‘Positive About Patients’ award by Northampton General Hospital for making an outstanding personal contribution in helping one of her patients.

When an ambulance was unable to take a dying patient home due to red tape rules, Julie borrowed a wheelchair, jumped into her car and drove the young woman herself, granting her last wish to die at home.

The annual awards, held in March, recognise the achievements, hard work and gestures made by hospital staff who make a real difference to people when they need it most.

Julie has worked in her current role on the oncology and haematology ward for a year. She helps patients with life-limiting illnesses back into their homes once they are discharged from hospital. She also works two days a week at Cynthia Spencer Hospice and has been an occupational therapist for over 20 years.

Julie said: ‘Part of my role is problem-solving. I always like to find a way around an obstacle because I have to go all out to improve the quality of people’s lives. I won’t take no for an answer.’

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Obituary
Derek Spooner – cancer environment expert

Derek Spooner, the man who established Macmillan’s expertise in cancer buildings, died peacefully at home on Tuesday 21 April. Some people at Macmillan may not have had the opportunity to meet Derek personally, but he was one of the giants of the charity in earlier days.

Those who knew him will remember among his many virtues – his wisdom, kindness, and the time he had for everyone he met, as well as his deep empathy for people with cancer and those who cared for them.

His influence on the environment of palliative care remains to this day and, to echo Christopher Wren’s epitaph, ‘if you seek his monument, look around you’.

Derek is survived by his two sons, daughter and several grandchildren.

Group educational grant helps Macmillan radiographers

In December 2007, a number of Macmillan radiographers attended Macmillan’s first UK-wide event, ‘Supporting and engaging professionals’. We were particularly inspired by a presentation about leadership skills from Sue Machell, a King’s Fund Lecturer, which left us wanting more opportunities to develop this side of our role.

We found ourselves reflecting on the usefulness and structure of our own twice-yearly meetings for Macmillan radiographers. These started about 10 years ago when Macmillan began funding information and support posts for therapy radiographers. Membership to our meetings now includes non-Macmillan professionals working in a similar role. Having ascertained that we would be eligible for funding from a new Macmillan group educational grant, I contacted the King’s Fund to find a facilitator to organise a one-day workshop for us. I then approached my regional Macmillan Learning and Development Manager, Julie Latimer, for assistance.

Entitled Leadership Skills for Information and Support Radiographers, the workshop was held last October in London and was facilitated by Judy Taylor, King’s Fund Senior Fellow. A key element of the day centred on the importance of Myers-Briggs personality types within our role as leaders. This was explored by completing individual questionnaires to identify our own type, and by doing some practical group exercises. These were hugely entertaining, but more importantly they demonstrated how and why we react to our patients and colleagues in different situations.

The day was deemed a great success and attendance was double that of our previous meetings. It was also good to share some of our learning and development opportunities with non Macmillan-funded peers. All feedback was very positive.

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Macmillan Voice online
Did you know that Macmillan Voice is available electronically?

Simply log on to the Learn Zone learnzone.macmillan.org.uk and click on Professional Tools and Resources, then Macmillan Information Resources. Editions dating back to 2006 are available.
Macmillan celebrates volunteers

Macmillan celebrated some of its most dedicated volunteers at the Macmillan National Volunteer Awards in March.

When young entrepreneurs Megan and Elizabeth O’Shea set up their own Christmas card company – Megan & Elizabeth Just Kidding – the original intention was to sell cards to earn pocket money. Instead, the identical twins decided to donate all the profits to Macmillan, having learned about it at school and knowing that their grandpa had cancer.

Since setting up their business three years ago at age six, it has grown to include key rings and calendars. The girls have now raised over £4,000 for Macmillan.

The girls have also spread the word about Macmillan and have secured extensive media coverage in their local newspaper. They recruited their school to take part in The Big Hush (where children were sponsored for every minute they kept quiet) which raised £3,244. When the senior school found out how well they had done, the sixth form also chose to support Macmillan by holding a fireworks night raising £300.

The award winners are:
- Sir Hugh Dundas Volunteer of the Year
- Peter Smith-Nicholls
- Mavis Butler
- Chris Seaward
- Rhoda and Tony Key
- Leslie McAdoo
- Gerald White

Young Macmillan Cancer Champion
- Daniel Savage
- Monty, Freddie, Gus and Ollie Payne
- Elizabeth and Megan O’Shea

Paul O’Shea, father of Megan and Elizabeth, said of the event: ‘It celebrated the hard work and dedication of all your volunteers and was nothing short of a barrage of brilliant and uplifting stories.’

Do you know a fantastic volunteer? There are many ways to thank your volunteers for the amazing work they do. Find out more by contacting volunteering@macmillan.org.uk or go to www.macmillan.org.uk/volunteer

‘It celebrated the hard work and dedication of all your volunteers and was nothing short of a barrage of brilliant and uplifting stories.’
The Late Effects project

Macmillan has been working with the Department of Health (DH), the National Cancer Action Team and a sizeable group of people living with the long-term effects of radiotherapy treatment for breast cancer.

The group, who are in their late 60s or 70s, were treated with radiotherapy in the 1980s and are likely to have developed symptoms within five years of treatment. These symptoms vary, but usually involve several or all of the following:

- fibrosis in any of the irradiated tissue
- pain in the irradiated area
- pain in the hand and/or arm on the side of the body that was treated
- breathing problems
- bone fractures in the collarbone, ribs and/or arm
- severe lymphoedema.

Without early intervention, over the years these symptoms will have progressed to include:

- paralysis in the shoulder, hand and/or arm
- non-healing ulcers in irradiated areas
- tissue necrosis
- severe lung problems
- bone necrosis
- heart problems
- on occasions, radiation-induced sarcoma.

These injuries led to changes in the way radiotherapy was administered and such side effects have all but disappeared from the modern day experience.

The Late Effects project team have worked with RAGE (Radiotherapy Action Group Exposure) to understand what support should be offered to their members, and what lessons can be learned from people living with the late effects of cancer treatment.

The pilot includes four elements:

- a one-off payment to help with daily living
- signposting to other services that may be helpful
- providing access to specialist health services
- raising the awareness of health professionals about the late effects of cancer.

Progress to date – grant payments and signposting

Since October 2008, the team have gathered feedback from over 100 RAGE members. By February 2009, we had received 150 grant application forms and had given out 140 grants. We have gathered evidence on how late effects have affected peoples lives, and what may help to improve the quality of life for this group. RAGE members have already reported changes that they have been able to make since receiving their grants.

‘Your generous cheque will make the difference in helping to meet some of the costs incurred as a result of my radiation damage and also to improve my quality of life.’ RAGE member

This part of the project is currently being evaluated to show the DH:

- ways in which they could support people with the late effects of cancer treatment
- how Macmillan can develop and shape new services that are responsive to the needs of people affected by cancer.

Specialist health checks

One hundred and twenty-six RAGE members have indicated that they are interested in a specialist health check. Invitations have been sent to a number of cancer centres across the country asking them to set up a one-off pilot clinic (for approximately five patients) where RAGE members could come to see an oncologist, pain management specialist and occupational therapist. We are asking the specialists to agree on a personal care plan, which would aim to identify local services that can provide ongoing care and support after the clinic.

It is hoped that these pilot clinics will gather enough information to show the clear benefits of a specialist health check. This would enable RAGE members to get better access to local services and highlight any inequalities of service provision across the UK. If there is enough information to support this, the team will provide evidence to the DH for providing a network of clinics at specialist centres across the UK, which all RAGE members will be able to access.

Further information

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Jo Heath and Occupational Therapist Jill Cooper at a specialist health clinic session at the Royal Marsden

Macmillan Voice summer 2009
Sexual relationships
In May, we launched our sexual relationships campaign targeted at health professionals and people affected by cancer. We aim to raise awareness of how cancer and its treatment affects sexual relationships. We have developed an online toolkit for health professionals which covers topics such as gaining confidence to raise the issue through various communication techniques. This is available on the Learn Zone learnzone.macmillan.org.uk

Our existing patient information and online videos for people affected by cancer are available on our website www.macmillan.org.uk/sex These involve health professionals addressing some of the issues surrounding sexuality and cancer. Themes include body image, medical options, and how to approach clinicians. One of the key messages is to encourage people with cancer to talk to their health professional about the problems they are experiencing. For this reason, we have been working with the Learning and Development team to make sure we can support health professionals to address these issues.

We have a range of patient information booklets on sexuality and cancer which can be ordered from be.macmillan.org.uk

‘Trying to keep our physical relationship active was one of the worst parts of my cancer journey. I had no idea that my body and emotions would be affected in this way. If I’d been spoken to about the effect my cancer and treatment would have on sex and my relationship, I would have been better equipped to cope with it all.’

Personal account from Giette Gudge, Kettering

Hospital car parking charges
Macmillan has been campaigning against hospital car parking charges for people with cancer since 2004. We have had national successes in Wales, Scotland and Northern Ireland. In Wales, hospital parking has been free since April 2008, except where Trusts have external contracts in place. These Trusts will introduce free parking by 2011. In Scotland, free parking came into effect on 31 December 2008, and in Northern Ireland parking is now free for people undergoing chemotherapy and radiotherapy. This just leaves England.

After researching hospital car parking policies in England, we have identified the worst offenders. These are hospitals that are not complying with Department of Health guidance to offer free or reduced parking to patients requiring regular treatment. Our research also shows that hospitals are not telling people about their reduced or free parking policies.

We will be continuing our national campaign asking the government to end hospital car parking charges for people with cancer across England, as per the other nations in the UK.

Travel insurance
People with cancer often find it difficult to obtain adequate and affordable travel insurance.

Some insurers refuse to cover a cancer diagnosis and others are prohibitively expensive. Patients are often forced to shop around extensively and the process can be extremely time-consuming and distressing.

We believe people with cancer should be able to buy fairly-priced travel insurance which covers their cancer diagnosis. We are working with industry bodies and other cancer charities to improve the current situation. By summer 2010, we will be able to signpost people with cancer to insurers who can provide appropriate cover at a fair price.

For more information on Macmillan’s campaigns and how to get involved, please contact us at campaigns@macmillan.org.uk
Stephen Guy
Manager, Macmillan Welfare Rights Service

What is your current role?
I am employed as a Principal Welfare Rights Officer with Durham County Council and I manage the Macmillan Welfare Rights Service in County Durham. I have 16 years’ experience practicing within a welfare rights setting.

Why was the post created?
In September 2006, I secured approval from Durham County Council to explore partnership-working with Macmillan to provide a bespoke welfare rights service for those in the region affected by cancer. I was motivated by the extent of under-claiming of benefits by people affected by cancer, their complex and immediate needs, and the high incidence of cancer in County Durham (where incidence rates have been consistently higher than the national average). A successful bid was made to Macmillan to fund three welfare rights officers and the service was operational by June 2008.

What have you been involved with since you started in post?
Our service has grown very quickly, and we have generated nearly £1.5million in benefits. We have gained some excellent outcomes for clients, largely as a consequence of the commitment, flexibility and skills of the three officers in post.

I have become a member of various steering groups concerned with the provision of cancer services in County Durham, which has provided me with an opportunity to influence priorities. For example, I sit on the Living With and Beyond Cancer/ Specialist Palliative Care Strategic Group. One of our targets is to ‘ensure all people affected by cancer are given information about their rights, what financial help is available (including welfare benefits) and how to access that help’. I am able to help achieve this through increased promotion of our service and staged roll-out to maximise the uptake of benefits.

How does the partnership-working contribute to the service?
Managing this service has facilitated some excellent opportunities for further partnership-working with the acute and primary care trusts. It has created opportunities to provide better-integrated services for people affected by cancer. A key outcome from this has seen patients, their families and carers accessing financial advice at an appropriate time, and in a setting of their choice. I consider this imperative in accordance with the Cancer Reform Strategy.

Do you work with other groups outside your service?
In County Durham, we enjoy effective relationships with the Macmillan cancer information and support centres. Our services complement each other and provide added value to those who access them. The opportunity to engage with staff and volunteers within these centres has proved very enjoyable. The challenge of meeting the urgent and varied needs of our clients often provides the greatest rewards in terms of job satisfaction.

How would you like the role and service to develop?
We have a service delivery plan with defined targets. An integral part is to contribute to Macmillan’s ambition to reach and improve the lives of everyone living with cancer. As our service cannot achieve this alone, we have started to provide training courses on benefit awareness to social care and health professionals, and Macmillan volunteers. The intention is to provide the knowledge necessary to identify potential benefit entitlement and, if appropriate, the skills to help people complete basic benefit application forms. This information can then be passed on to patients, families and carers, maximising the reach of our service. This approach will supplement the provision of advice and information offered directly to people affected by cancer.

Reference

Love your job?
Would you like to share what you do with other Macmillan professionals? Then please email the editor at rrotter@macmillan.org.uk to find out more about being profiled for Macmillan Voice.
Knowledge-sharing exchange to the United States

A trip to the US gave Lead Macmillan Head and Neck CNS Julie Hoole a chance to reflect on the success of her own service

I have given many presentations to voluntary groups as a Macmillan nurse over the last 10 years, but it was following my talk ‘what is head and neck cancer?’ at the Wakefield Rotary Club, that I was invited to apply for the Rotary Foundation’s Group Study Exchange (GSE) programme to Southern California.

What is GSE?
The GSE programme, run by Rotary International, provides the opportunity for a unique cultural and vocational exchange for young professionals aged between 25 and 40. The programme provides travel grants for a team to visit another country and observe how their own professions are practiced abroad. Participants develop leadership abilities and share skills and knowledge, benefiting both professionally and personally. For more information go to www.rotary.org

What I saw
My ‘vocational’ time on the programme was spent looking at the treatment of head and neck cancers and discovering whether the treatment modalities are the same as in the UK. I also looked at whether specific treatment guidelines and pathways exist, and whether they are utilised effectively by clinicians and health providers.

I had the chance to spend time in two oncology centres – City of Hope, a National Cancer Institute-designated Comprehensive Cancer Centre, and the Loma Linda University Cancer Centre. It was interesting to see that non-surgical oncology was delivered in a very similar fashion to the UK. Many aspects of surgery were also similar – although it was gratifying to note that some of my own team’s well-established techniques were still aspirational here.

A major difference was the way in which multidisciplinary teams worked. Essentially the UK model of healthcare doesn’t exist in the US and the treatment decision was often the sole responsibility of the primary healthcare professional (sometimes not even that of the oncology centre). The insurance or HMO-based system of healthcare provision in US was an expected difference. It was very clear that while (arguably) a choice of optimal treatment was available for those with adequate insurance (or huge personal finance), this was not the case for a large ‘underclass’ population.

Comparisons
I found competition rather than cooperation to be a bi-product of the insurance system. While individual areas of excellence can be achieved, there seemed to be little in the way of health promotion and disease prevention. Treatment guidelines suggested by the National Cancer Institute would be overridden by ‘freedom of practice’ for medical staff.

‘While individual areas of excellence can be achieved, there seemed to be little in the way of health promotion and disease prevention.’

Equity of service for all is something of an unknown concept in the areas I visited. Medical and oncology centres do not appear to share their data.

An equivalent role to the Macmillan specialist nurse does not exist in Southern California. The nurse practitioner is their most senior nurse. I identified a massive gap in the patient pathway, particularly in the areas of support and specialist advice on treatment options and symptom control. There is clearly a need for specialist nurses, which interestingly was identified by the teams I met when I explained my role in the UK.

Evaluation
This was a fascinating and unexpected experience. Although flattered by a job offer, I can see clearly how advanced we are in many of the less-publicised cancer services in the UK. I have come home excited by the challenges ahead of me here in the UK, in continuing to develop our first-class head and neck cancer service.

Look out for Julie’s report on her trip to Libya in the next issue of Macmillan Voice.

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Macmillan Voice summer 2009
Study explores the work of Macmillan occupational therapists

I was appointed as a Macmillan occupational therapist (OT) in 2004 and was intrigued to find out about the work of other Macmillan OTs. Whilst previous studies examined the role of Macmillan nurses and Macmillan GP facilitators, none had explored that of Macmillan OTs.

**Developing the study**
As part of my MA in Independent Practice (Health) I conducted an exploratory survey into the role of Macmillan OTs. Three questions formed the basis of this survey:

- what are the working practices and employment profile of Macmillan OTs?
- what support mechanisms are available?
- does working with the charity have any particular bearing on practice?

At the time of the study (completed in August 2008), Macmillan funded 64 OTs, comprising fewer than 2% of Macmillan health professionals. I developed a questionnaire which allowed quantitative and qualitative analysis. A postal survey of 60 Macmillan OTs received a positive 68% return rate.

**Findings: working practices of Macmillan OTs**
The majority of Macmillan OTs provide services to the adult population. Respondents’ employment spans acute and primary care trusts and hospices. Most therapists are employed full-time, 66% work as sole practitioners of OT within multidisciplinary teams, and just over half work without support staff.

Their experience of employment encompasses a broad spectrum in terms of the grading of posts and their location, role and function. Services are provided at patients’ residences, and at inpatient, outpatient, hospital, hospice, community and day care centres.

**Association with Macmillan**
Qualitative data analysis affirmed that the association with Macmillan has a significant influence on their experience and practice. OTs felt the title brought increased recognition at work among staff and patients. They can access funding for their own professional development and patient grants, enhancing the service they are able to provide. The Macmillan role also enabled OTs to work more autonomously and be involved in role-development activities, research, audit and training. They report being able to apply specialist skills and offer a holistic service.

**Recommendations**
- Macmillan should continue to facilitate opportunities for specialist training for Macmillan OTs.
- A formal network of Macmillan OTs would enable practitioners to engage with and support one another. This would be especially helpful for newly-appointed OTs, to help combat feelings of isolation.
- Macmillan OTs should promote their work at every opportunity.
- Macmillan should market the contribution of Macmillan OTs more actively, possibly through collaboration with the College of Occupational Therapists.
- Further studies would extend the knowledge and understanding of Macmillan OTs’ roles and patients’ and carers’ experiences of their services.

**Taking it forward**
I have disseminated the report to Macmillan, the participants, the College of Occupational Therapists, and I am presenting a paper at their national conference in June.

This research has provided Macmillan with evidence to support the learning and development of OTs. A ‘community of practice’ has been offered to OTs, and Macmillan will be exploring ways to further support this group. A copy of the report can be obtained by contacting Debbie Pearson.

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Oncology social work in an acute hospital setting

Macmillan Social Worker Rose Amey explains how social work in an acute hospital setting crosses traditional social work boundaries

People with cancer are not all previously well people who suddenly become unwell. Some have multiple pre-existing medical problems, mental health difficulties, learning difficulties or physical disabilities. As a Macmillan social worker, I offer or facilitate a range of services including practical, psychological, spiritual and financial support to people affected by cancer. I meet with adult patients at all stages of their experience of cancer, from diagnosis, through to treatment, remission and sometimes recurrence of disease, including discharge from inpatient periods and end-of-life care. The acute hospital setting also includes protection of children and vulnerable adults.

My philosophy is that individual responses to cancer require holistic and accurate assessment. This is to maximise the patient’s own strengths and skills at a time when they may feel immobilised by their diagnosis. I believe involving patients in their own responses to the disease enables them to better cope with any outcomes.

The landscape
I am based at the new Fortuneswell Cancer Unit at Dorset County Hospital which is situated in a largely rural area with limited public transport infrastructure. There is a significant amount of unemployment, poverty and homelessness in this area. Although many patients are treated on-site, some have to travel to other hospitals in the region for treatment, tests, or surgery, sometimes involving long distances to major cancer centres.

Issues that commonly precipitate a referral to me are loss or reduction of income, concern about perceived loss of role as a carer, parent or partner, mortgage and debt problems, employment issues and welfare benefit problems. I regularly make applications for Macmillan Grants: sometimes for everyday but necessary things, frequently for travel costs for patients and their visitors, and occasionally for nice things for people dealing with protracted and debilitating therapy. Discharge planning, implementation of care packages and applications for funded care (at home or in a nursing home setting) also take up much of my time. I am also at times a non-medical advocate who understands some of the medical issues involved.

Thankfully there is no typical day or patient, and most patients enjoy accepting responsibility for their ongoing care.

Working with multiple teams
I attend a number of multidisciplinary meetings which help me to understand where the patient is on their cancer pathway and what their treatment plans are. The meetings allow me to access a number of disciplines at one time enabling me to prioritise my interventions. Positive relationships with the local primary care trust and the Joseph Weld Hospice also enable me to respond in an appropriate and timely way to requests for support for end-of-life care in the patient’s place of choice.

Related information
For more information on social care, check out our Social Care Directory and JournalWatch on the Learn Zone learnzone.macmillan.org.uk

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The benefits of dedicated speech and language therapy

Carrie Biddle and Emma Mitchell discuss the development of speech and language therapy services for people with cancer in Cornwall

In July 2005, we trialled a Macmillan-funded project post to investigate the need for designated speech and language therapy (SLT) at an oncology/specialist palliative care service.

We wanted to:

• review the current service provision for people with head and neck cancer
• identify the needs of people with non-head and neck cancer who would benefit from SLT intervention
• explore the role of SLT in specialist palliative care
• establish a designated SLT service for local hospices.

The service was trialled over a 18-month period and evaluated at the end of the project in June 2007. A 16-month extension was funded by the hospital trust to allow for further data collection and evaluation.

Users’ views brought about service revision

A service evaluation highlighted an inequity based on the type of cancer people presented with. Although a specialist speech and language therapist saw people with a diagnosis of head and neck cancer, people with other types of cancer did not have access to this service. Hospices received a piecemeal service as part of the generic community caseload. There was a large variance in the level of knowledge and skills of cancer treatment among community SLTs seeing people with cancer. Therapists could go a long time without seeing anyone with cancer and therefore education and training related to cancer was not viewed as a priority. SLTs felt they ‘did their best’ with the basic knowledge they had.

We surveyed 72 people with head and neck cancer to identify their perceptions of access to the specialist service. Their responses were measured against current national guidelines relating to when patients should be seen.1, 2

The audit identified times when patients felt they needed more support and information. This resulted in a revision of services to people with laryngectomy, weekly telephone reviews for people finishing radiotherapy, and the trial of a patient support group.

The ‘Recovery Club’

With a Macmillan Grant, Emma piloted a support group for people with dysphagia following treatment for head and neck cancer. It took place near the hospital on the day of the follow-up clinic so participants could attend the group before their appointment. Feedback indicated the sessions had helped participants to address many practical and quality-of-life issues they encountered, and reduced their feelings of isolation. Emma secured further funding from the ‘friends of the hospital’ to support the group.

Beyond head and neck cancer

Carrie promoted SLT and forged links with community Macmillan teams, hospices and the hospital palliative care team. Sessions were trialled within a palliative care combined clinic.

Referrals of people with cancer to speech and language therapists increased by 64% in the first year (2005/06), including patients with brain tumours, lung cancer and advanced metastatic cancer.

Outcomes

The post has proved successful having achieved the following to date:

• Head and neck sessions now have permanent funding, allowing Emma to attend all relevant MDT meetings and clinics.
• Carrie is a core member of the hospital palliative care team and continues to work in collaboration with community Macmillan professionals.
• Hospices now have a designated SLT service.
• The ‘Recovery Club’ members have transformed themselves into a self-support group.
• Community speech and language therapists are able to access specialist speech and language therapists for support as required.

We have developed ‘on the job’ research and audit skills and learnt the importance of user involvement in service development. We have demonstrated how dedicated SLT can be of benefit to people living with a range of cancers and can provide a valuable contribution to holistic palliative care.

The full version of this article was published in Bulletin, the official magazine of the Royal College of Speech and Language Therapists, December 2008, Issue 680 pp20–21 (www.rcslt.org).

References


Further information

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Over two million people are living with a cancer diagnosis in the UK. Some will have been recently diagnosed, others will be working through their cancer treatment, or will be coming to terms with how the cancer and its treatment have altered their lives.

In addition to this, about 40% of people living with or beyond cancer tell us that they feel abandoned after they finish their primary treatment. Their issues include the need to be able to fast-track back into treatment if they have concerns about recurrence or the effects of their treatment, and their desire for holistic assessments, which lead to care plans that will be delivered.

We want people to be given the information, confidence and skills they need to self-manage their condition to the extent that they want to. We want them to have the necessary help to ensure they receive all the financial support available, and crucially that they can access advice on returning to work, helping them to remain in employment if that’s what they choose.

Macmillan is working across the four nations to improve care and support for cancer survivors.

**England**
In England, this is through the National Cancer Survivorship Initiative, which Macmillan’s Chief Executive Ciarán Devane is co-chairing with Mike Richards, the National Cancer Director. This initiative aims to optimise the quality and length of life for cancer survivors following primary treatment, by improving the management, care and support they receive. There are currently seven work streams: assessment and care planning, active and advanced disease, long-term effects of treatment, children and young people, self-management, work and finance, and research. Cross-cutting themes identified are commissioning, information and workforce. Recent outcomes include a draft treatment record to be completed by consultants at the end of each phase of primary treatment, a draft assessment framework for adults, and a review of the evidence for self-management support. Test communities across both adult and child services will be used to assess the outcomes of the various workstreams, such as the assessment framework for adults, which will be rolled out after successful testing.

**Scotland**
We are working with the Scottish Cancer Taskforce, through their new ‘Living with Cancer’ group. We were also funded £500,000 by the Scottish Government to increase the provision of financial help services for people affected by cancer.

**Northern Ireland**
We have influenced the draft Cancer Service Framework which will be launched late 2009. We have also campaigned effectively on issues of cancer poverty.

**Wales**
We have influenced the Wales Cancer Rehabilitation Standard, and draft Welsh survivorship recommendations went to the Welsh Health Minister at the end of March.

**Reaching our goal**
To achieve our aim of better cancer care for survivors, we will work with partners like NHS Improvement in England to develop new approaches to care. This will include testing out services that are already in existence, creating innovative approaches to service development and undertaking research to further develop our evidence base. We are ever mindful that the approaches we come up with must demonstrate both an improvement for cancer survivors and be cost-effective.

The following series of articles will give you a feel of some of the exciting work that is happening to support cancer survivors, including self-management, health and lifestyle initiatives and support groups. There is much to do, and we will keep you up-to-date as we progress.

**Related information**
Macmillan’s cancer survivorship agenda, *Two million reasons*, can be ordered through [be.macmillan.org.uk](http://be.macmillan.org.uk)

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Macmillan Voice summer 2009
Group approach offers survivors a valuable form of support

Therapeutic and educational groups offer an important way to support the transition from ‘person with cancer’ to ‘person who has survived cancer’. Group interventions can reduce anxiety and depression, improving mood and aiding adjustment. They also have the dual advantage of peer support and cost-effectiveness, and some studies suggest that groups using a structured psycho-educational framework are more helpful than more open, non-directive ones.1

We have been running two kinds of groups at Torbay Hospital for people who are in the post-treatment transition of their cancer experience.

‘Moving On’ group
The ‘Moving On’ group is led by Christine Ward and a breast care nurse, with visits from a physiotherapist and dietitian. It is for women who have recently finished treatment for breast cancer and incorporates ideas from cognitive behavioural therapy, positive psychology2 and community psychology.3 The group meets every week for six weeks and sessions include:
- post-treatment transition
- managing uncertainty
- breast awareness
- coping with problems of sleep and fatigue
- nutrition and healthy eating
- getting back into activity
- communication with healthcare professionals, family and friends
- lymphoedema risk-reduction and positive outcomes after cancer.

There are three follow-up sessions at three months, six months and one year to refresh everyone on the session topics and for evaluation purposes.

We have run 14 groups since January 2006 and the first five (in year one) were formally evaluated. Group members showed improvements in their levels of well-being and reduced psychological distress, and evaluation found that the groups are highly valued by patients.

‘Stress Reduction through Mindful Awareness’ group
Mindfulness-based approaches to stress management have been offered in various medical and mental health settings. They have been shown to help reduce the distress experienced by people with cancer.4 Mindfulness is an approach to handling emotional stress and physical pain, which focuses on bringing awareness and acceptance to present-moment experience. This skill is learned through various meditation exercises (along with elements of cognitive therapy) practised at home and during the weekly group meetings.

This group is offered to people who have had treatment for any type of cancer. It is led by Jenny Wilks, who has undertaken training in clinical applications of mindfulness meditation.

Since April 2005, we have run eight courses, attended by 52 people. More recently the course was offered to a group of people in a palliative care setting. In response to feedback a monthly follow-up session was started in 2007 for people who had completed the course.

Evaluation of the groups showed improvements in well-being and reduced psychological distress. All participants rated the group meetings as having been useful, and most said the practice of mindfulness had been helpful in their everyday lives.

Summary
Both group interventions have been well-received and continue to be evaluated and developed in response to feedback.

More critical comments from participants were mainly about practical issues such as room size and noise. However, some people found being in a group difficult because of other people’s distress, or meeting people with more advanced disease. Groups are therefore not for everyone, and ideally, as at Torbay Hospital, are offered as part of a service where individual therapeutic support is also available to those who need it.

References
Developing cancer rehabilitation standards in Wales

‘If cancer treatment saves people from drowning, rehabilitation and supportive care makes sure they are not left on the beach to cough and splutter on their own.’

Incorporating rehabilitation into the Welsh cancer standards\(^2\) shows growing recognition of the importance of survivorship. Tumour site and palliative care standards\(^2\) are already used in Wales to define core aspects of the services that should be provided for people with cancer across the nation. Rehabilitation standards, which will complement existing standards, are currently being developed. They aim to continue the process of regular review and modification, ensuring continued relevance and significance to the NHS in Wales.

The inclusion of rehabilitation in the set of standards also reflects the growing importance of non-pharmacological care. Providing holistic care can ensure the best quality of life for people affected by cancer.

In contrast to the existing standards, there are just three objectives in rehabilitation, each described as topics.

**Topic one – Cancer Network Rehabilitation Advisory Group (CNRAG)**

This group will develop, coordinate and deliver all aspects of cancer rehabilitation. This will include formalising any existing services, a process for assessing need, and the delivery of rehabilitation by an appropriate person. The group will have a specified professional membership drawn from the NHS and the third sector, as well as patient representation. It will be recognised as the principal source of opinion across the network on issues relating to rehabilitation in all eight domains of care (physical, practical, spiritual, nutritional, financial, psychological, social and informational).

**Topic two – Cancer Rehabilitation Team**

The standard is quite clear about the need for rehabilitation to be delivered by a competent and capable workforce. It covers details such as the four-level model described in the NICE guidance on supportive and palliative care,\(^3\) as well as the requirement to develop service models for cancer rehabilitation.

**Topic three – referral, assessment and treatment**

This covers the need for referral, screening, assessment and treatment processes to be uniform across a cancer network, thus ensuring equity and quality for all service users. It also refers to waiting times for assessment and interventions.

It has to be stressed that these are non-pharmacological interventions which complement medical treatments. As such, they refer to the work of allied health and nursing professionals, as well as other professions such as psychology and social work. They are designed to be used alongside other standards, recommendations and guidelines that involve patient care, such as health and safety guidelines and those set by NICE, professional bodies and the NHS.

What will be achieved through the standards?

These strategic standards will bring together the people who can advise on rehabilitation. They will conceptualise the development of the rehabilitation workforce to deliver care, and encourage the need to have uniform screening referral and assessment processes.

The development of protocols and pathways will arise from these standards at a local level, but will be based upon a quality agenda across Wales. The consultation process will begin when permission is given by the Welsh Health Minister, and will be followed by a review to make any necessary revisions. The rehabilitation standards will then be launched across Wales.

**References**


Further information

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Focus on survivorship

Lymphoedema and its effects on survivorship

As more patients survive cancer, the issues during their experience of cancer change. Clinical Nurse Specialist Alison Authers recently examined how lymphoedema can affect breast cancer survivors.

The psychosocial changes
Lymphoedema is a chronic and incurable condition which can have a significant impact on people with cancer. Some people with lymphoedema have demonstrated high levels of everyday social dysfunction, and have found it more difficult to come to terms with their cancer diagnosis than those without the condition.

Although it might be assumed that lymphoedema is a small price to pay for reaching the survivorship phase, many patients find the swelling and subsequent comments from others can negatively affect their confidence. Lymphoedema is a visible reminder of their cancer and can make it difficult to forget. People who have had breast cancer in particular, often have a high level of need in relation to their identity and how others see them.

‘You may not have thought about breast cancer for about two days and then someone asks “what’s wrong with your arm?” and it all comes back.’

The physical changes
Lymphoedema can cause physical problems for people. Swelling in the arm can make it feel heavy and very uncomfortable and people can experience difficulty finding suitable clothing to fit the swollen arm. Patients are advised to avoid heavy lifting and to do regular, gentle exercise. Many patients need to wear a compression sleeve, which can draw attention to the swollen limb, and there can be issues with hygiene and keeping the sleeve dry. Patients may have difficulty with the practicalities of managing their lymphoedema when returning to normal activities after cancer treatments.

‘Surviving cancer brings its own set of needs.’

How we can help
It has been found that nurse-led aftercare cancer clinics are valuable to patients. Specialist nurses have adapted to meet the needs of people with chronic illness, and it is rewarding for the nurses to see the endorsement of their practice in the Cancer Reform Strategy.

Patients will often discuss how they are feeling with nurses. They may express difficulty in accepting cancer, adapting to role change in the family, or coping with the many issues associated with returning to a normal routine when surviving cancer. Nurses are in a strong position to network with other local teams and facilitate referrals to help patients through this stage. For example, ‘Look Good...Feel Better’ groups boost women’s confidence at a time when they may be feeling dispirited (go to www.lookgoodfeelbetter.co.uk). At the moment these groups are only offered to people during their cancer treatment, but cancer survivors could also benefit from these sessions.

Conclusion
Surviving cancer brings its own set of needs. Many people affected by cancer have difficulty adapting to the changes survivorship brings. It is hoped sentinel node biopsy, which potentially reduces the number of axillary lymph nodes removed during surgery, will reduce the incidence of breast cancer-related lymphoedema. However, ongoing support for existing patients with lymphoedema is needed. The patient’s own feelings about their support requirements should be kept sharply in focus.

Related information
Our booklet, Understanding lymphoedema, can be ordered on be.macmillan.org.uk

References
Helping survivors take greater control of their lives

Macmillan estimates that there are two million people living with a cancer diagnosis. Given the growing improvements in diagnostic techniques and treatment options, this number is expected to rise. This development is not without consequence. Greater numbers of people surviving cancer has also meant greater numbers of people living with long-term challenges resulting from the disease process and/or its treatments. Because of this, issues relating to quality of life have been brought to the forefront of modern cancer care. Developing skills and confidence in people living with cancer to deal with these issues, and so take greater control of their lives, is the cornerstone of self-management.

What does self-management involve?
So what is self-management? It can be most easily described as what people do for themselves. Examples of this include:
• managing the effects of cancer and its treatments (e.g. tiredness, weight gain, stress, anxiety, fear of recurrence)
• making healthy lifestyle choices (e.g. taking exercise or having a healthy diet)
• adjusting to changes in relationships at home, work or with friends
• learning to monitor themselves and any new changes
• taking prescribed medication and noting its effects.

‘This helps to create an atmosphere of shared experience and acceptance for people who often report feeling isolated by their diagnosis.’

Achieving self-management can be hard without support, particularly if the cancer journey has left the person physically weakened and emotionally vulnerable. Services need to adapt to this growing need and develop information and resources that not only support the person, but also empower them to make the choices that will help them lead an active and fulfilling life. Creating such models of support for self-management is a key strand of work for the National Cancer Survivorship Initiative.

New Perspectives
One way in which Macmillan is helping people to develop their self-management skills is through New Perspectives – a course for people living with cancer. This course (formerly known as Living with Cancer) was recently revised and is now the first specific adaptation of the universally established Chronic Disease Self-Management Programme developed at the Stanford University Patient Education Research Centre. It comprises six sessions, held once a week, focusing on different topics such as handling changes to your body, making decisions and living with uncertainty. However, its main purposes are to encourage problem-solving using the experiences of the group and to support setting goals for the future.

What makes this course unique is that the trainers have had cancer themselves and are able to relate directly with the participants. This helps to create an atmosphere of shared experience and acceptance for people who often report feeling isolated by their diagnosis. What participants feel they accomplish can vary greatly (feedback has included ‘returning to work’, ‘a more healthy eating plan’ and ‘doing a handstand’). But what is commonly reported is a sense that the course has helped participants come to terms with their diagnosis and gain knowledge and skills that help them to cope. Or as one participant succinctly put it: ‘It has made me realise you can still have a life with cancer.’

For more information about New Perspectives, please contact Heather Petty or Sam Poh Voon Hew on 020 7091 2010 or email workshops@macmillan.org.uk

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Macmillan Voice summer 2009
Two pilot sites work to improve the 

Developing a programme to help people cope following a cancer diagnosis

A health and lifestyle coaching programme developed for people with cancer by the North of England Cancer Network will be trialled as a National Cancer Survivorship Initiative pilot site.

Facilitating recovery
The North of England Cancer Network is developing a new intervention to facilitate people’s recovery and adaptation following cancer treatment. The ‘Health and Lifestyle Coaching Programme’ is a project based in South of Tyne and Wear. It will focus on the ways in which people cope following a cancer diagnosis and will develop and evaluate a programme to support self-management during cancer survivorship.

The programme is not intended to replace existing cancer programmes, but will become part of a repertoire of programmes available to meet patients’ supportive care needs. It will not replace standard cancer follow-up but will be an additional resource at this time.

Project lead Dr Karen Roberts and Professor Charlotte Clarke have carried out a number of research studies into the needs of people affected by cancer following treatment. It is exciting as we are moving from exploratory work to actual development work.

Work in progress
Work is currently underway with Dr Sanjay Rao, Consultant Psychiatrist and Director of LOGOS. LOGOS is a mental health centre based at County Hospital in Durham City Centre, which is developing an innovative psycho-oncology intervention. The programme will consist of two ‘Health and Lifestyle Coaching Programmes’, based on a cognitive behaviour therapy model. They will be delivered for two hours each week for 8–10 weeks. A group of men and women who have completed radical cancer treatment for breast, gynaecological or prostate cancer within the last three to six months, will be invited to participate by their key worker (clinical nurse specialist or oncologist).

Upcoming work and evaluation
Recruitment will start in the summer and the first programme will begin in September. The first programme will be evaluated upon completion and its structure, content and outcome will inform the development of the second programme. The ‘Health and Lifestyle Coaching Programme’ will take place at community centres to support the programme philosophy of patients returning to a life before they became a ‘cancer patient’.

The evaluation of the project will include:
• a baseline assessment against current service provision
• a robust cost-benefit analysis of the tested approach to care
• a qualitative research method that elicits the views of participants and feeds back into the programme design.

This programme aims to help people following cancer treatment.
It is hoped that it will facilitate adaptation and prevent mental health problems in the future.

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health and lifestyle of survivors

Cancer survivorship programme pilot aims to improve lifestyle for cancer survivors

The Royal Bournemouth and Christchurch Hospitals (RBCH) NHS Foundation Trust has been accepted as a pilot site for a national survivorship programme. The aim of the pilot is to enable patients to pursue as normal a life as possible, through a rehabilitation programme to improve well-being and promote self care.1

RBCH, which is part of the Dorset Cancer Network, will be working on the pilot with Bournemouth and Poole Teaching Primary Care Trust, and other partner organisations involved in health and social care. These include Dorset Cancer Network, Bournemouth University, Lewis Manning Hospice lymphoedema services and Macmillan. The Littledown Centre and Village Health and Fitness provide all the facilities and trainers for the exercise programme. It is this collaboration that makes the project unique.

Improving the survivorship experience

Cancer survivors may limit their occupational and leisure pursuits due to a fear of physical activity and the possibility of exacerbating lymphoedema or other complications of treatment. However, lifestyle is known to influence survival in breast and bowel cancer, and exercise, weight control and psychological health are therefore hugely important for survivorship. The pilot will move the focus from acute care and treatment of patients, to improving the survivorship experience and integrating people with cancer back into community life.

Assessment

We will assess patients at diagnosis, carry out risk stratification and determine an individualised holistic care plan which includes diet management and exercise. The programme will encompass family and carers to ensure the sustainability of change in lifestyle. A pre-habilitation programme, which includes shoulder exercises, aims to improve function after surgery. A parallel study will examine body mass index (BMI) and fat metabolism in people with cancer.

The project will link with the local sports centres that are already running health referral programmes such as Healthlink 3x30. It also includes a dragon boat team for breast cancer patients called ‘Pink Champagne’, support groups and a buddy scheme. The integration of quantitative and qualitative evaluation tools (such as objective and subjective audit cycles, re-assessment, quality-of-life tools, patient questionnaires, focus groups, and patient experience diaries) will be the linchpin in tying the activity of the work groups together, as many of these will influence all involved projects. We will also evaluate the impact on family, carers and participants.

Data collection

Key to the facilitation will be the development of patient-held records, diaries and care plans. A comprehensive database will be required. This will include national cancer data, psychological, lifestyle, energy and metabolic profiles, and physical parameters such as weight, BMI and exercise tolerances. These records will help coordinate care planning and communication across all care providers.

Moving forward

We aim to make referral to an exercise and lifestyle programme a cost-effective aspect of cancer care and rehabilitation. We anticipate that this will reduce requirements for further support services such as physiotherapy, lymphoedema services, stoma care and specialist psychological support, and have a positive effect on the health and well-being of people with cancer.

Reference


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Focus on survivorship

Money Matters in Scotland

A successful welfare benefits scheme in Scotland shows how working in partnership can achieve great things

Macmillan Money Matters has received 1,346 referrals from across Forth Valley and has generated nearly £5 million in income and benefits since it was launched in March 2007.

Celebrating the achievements of the Macmillan Money Matters Project last June, gave me an opportunity to reflect on setting up the service. A number of events had come together at the time this service was set up. I had seen my friend receive an excellent welfare benefit service following a diagnosis of lung cancer in West Lothian, Scotland. This service was not available in Stirling. Macmillan published a report highlighting that 64% of people in Scotland with a terminal cancer diagnosis were not receiving their appropriate benefit entitlement. Macmillan also contacted Stirling Council offering to meet to discuss funding to set up a service in the Forth Valley area. I had been really frustrated about not having this type of service locally and hoped this would fill the gap.

‘Cancer clinicians soon recognised the value and integrity of the service.’

Meetings between the three local authorities were held and Stirling Council took the lead in the partnership. An operational group with representatives from the three authorities, Macmillan and the newly-appointed project coordinator, worked closely together.

The project coordinator began the rounds of health professionals across the Forth Valley area. Soon everyone knew that there was a new service in town. Referral protocols were set up to be as simple as possible (by telephone, email, letter, from professionals, colleagues or self-referral). IT solutions were developed so that project workers could pick up referrals and access systems from any of the local authority offices. Although at times this was challenging, it helped to build relationships.

‘Everyone worked together to provide the best service to meet the needs of the individual.’

The Department for Work and Pensions joined the project and we were assigned ‘alternative office’ status so that benefits would be paid at an earlier date.

A project worker was located in each authority and had access to, and support from, the welfare benefits team in their respective area. The project worker also had access to the representatives on the operational group to sort out any difficulties that arose in that authority. The operational group met on a regular basis to update and determine the course of the project. Links between the operational group have gone from strength to strength.

Cancer clinicians soon recognised the value and integrity of the service. Patients updated them at appointments with information on how much their income had increased and how helpful the project worker was. Project workers recognised that clinicians had a lot to offer, providing information on cancer types, whether special rules applied to them and providing supportive evidence for claims. Clinicians began referring to the project workers as ‘their team’, so to patients it was all a ‘team effort’. Everyone worked together to provide the best service to meet the needs of the individual.

As Aristotle said: ‘the whole is more than the sum of its parts’. I believe so much has been achieved as a result of partnership working in practice.
GETTING INVOLVED

Diary of 2009 events

June
21–28 June
UK Myeloma Awareness Week
www.myeloma.org.uk

July
6–12 July
Health Information Week
(West Midlands)
www.equip.nhs.uk/custom/healthinfo
6–12 July
Ethnic Minority Cancer Awareness Week
www.emcaw.co.uk

September
14 September
Urology Week
www.urologyweek.org
15 September
World Lymphoma Awareness Day
www.lymphomacoalition.org

October
Breast Cancer Awareness Month
www.breastcancercare.org.uk

Macmillan events

June
Various dates 2009
Walk with us
Raise money for people living with
 canc er and stay fit at the same time
by walking with Macmillan.
www.macmillan.org.uk/walking

July
July–August 2009
Longest Day Golf Challenge
The toughest challenge in golf is back.
Have you got what it takes to play 72
holes, hit 300 shots and walk 20 miles
– all in one day?
020 7840 4614
www.macmillan.org.uk/golf

September
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

20 September 2009
BUPA Great North Run
The world’s biggest half marathon
– if you already have a place in the event
let us know and join Team Macmillan for
a great day in the North East.
020 7840 7887
greatnorthrun@macmillan.org.uk
www.macmillan.org.uk/greatnorthrun

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
1 November 2009
ING New York City Marathon
With more than two million spectators
lining the streets from Staten Island to
Central Park, the New York Marathon
is an incredible event.
020 7840 7875
newyorkmarathon@macmillan.org.uk
www.macmillan.org.uk/newyorkmarathon

5–6 November 2009
Macmillan professionals event
Renaissance Hotel, Heathrow
The theme of this year’s event will be
innovation and improvement. More
information will be available on the
Learn Zone from July.
WE SHARE RESOURCES

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. All resources are available free of charge.

New resources

- **Cancer of unknown primary (CUP)**
  MAC11689
  Written in collaboration with Cancer of Unknown Primary Foundation (CUP) – Jo’s Friends, this new booklet addresses the questions many people have about the diagnosis and treatment of CUP, including the possible reasons why the primary cancer can't be found. It looks at symptoms, tests and surgery, and explores the feelings patients may experience following a cancer diagnosis and treatment.

- **High-dose treatment with stem cell support**
  MAC11691
  This booklet explains why this procedure is used to help treat cancer, and takes you through the four main steps of the process. It contains advice about preparing for treatment and information about how the stem cells are collected. The booklet also covers how the stem cells are given back and the side effects likely to be experienced.

- **Out-of-hours toolkit**
  MAC11367_JAN09 V1
  We are reliant on out-of-hours care for more than 70 per cent of our lives. Our new Out-Of-Hours toolkit is designed to help healthcare professionals provide the highest standard of out-of-hours care by sharing good practice and boosting the quality of care during this potentially problematic period for both cancer and palliative care patients. The toolkit can be downloaded from learnzone.macmillan.org.uk

Updated resource

- **Listen up – cancer information now on audio CD**
  We are passionate about making the cancer information that we provide accessible and of the highest quality. So, over the next few years, we will produce CD versions of lots of the new booklet titles we inherited through our merger with Cancerbackup. These CDs are specifically aimed at people with visual or physical impairment and people whose first language isn't English.

- **Help with the cost of cancer**
  MAC4026.09
  An easy to use guide to benefits and financial help for people affected by cancer. Benefits rates apply from April 2009 to April 2010. Welsh PDF available from be.macmillan.org.uk

  **Northern Ireland version**
  MAC4026.09.NI