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Sue Smith
Macmillan Centre Manager
Mustard Tree Cancer Support Centre

Sharing good practice
Advance care planning

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New be.Macmillan is here
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We welcome feedback!
Let us know your views on Macmillan Voice.
Email macvoice@macmillan.org.uk

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

We’re also looking for new writers to contribute articles. You can write about the issues that matter to you and share your knowledge with other Macmillan professionals. You don’t need to be an experienced writer to get involved in Macmillan Voice. We can help you turn your idea into a news item or feature.

All you have to do is get in touch with our Managing Editor Rosie Cotter at rcotter@macmillan.org.uk or call her on 020 7091 2219.

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

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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Next month sees Macmillan launch a new helpline and web service to provide people affected by cancer with the best cancer information and the extra support they need. Here, Simon Phillips, Head of Direct Services, explains what the service will offer people affected by cancer and how it complements the face-to-face work of Macmillan professionals.

One number
From 1 October callers from anywhere in the UK will be able to get easy access to support by calling one freephone number. To do this, we’re integrating our current telephone helplines – the CancerLine, the Benefits Helpline and the cancer information nurse helpline – into one complete service with one number.

By phoning this number, which is free from both landlines and mobiles, people will be able to ask any question about any cancer, and get emotional and practical support. They can get assistance to deal with the financial impact of cancer, including help with benefit claims, and can find out about different cancers and their treatments. It’s all there at the end of the phone.

More people
We aim to help over 100,000 callers in 2010. To meet this demand, we have made our teams bigger, so there are more trained specialists to provide help to many more callers. And all this is further supported by the constant development of our website, where people can get high-quality information and support, with online communities available 24 hours a day, seven days a week. Together, we can help a wide range of people with questions about cancer.

A better service
We have trained all our staff to provide an even better service to people who contact us. This expanded and improved service builds on the fantastic face-to-face work delivered by Macmillan professionals every day across the UK. We feel passionately that our service should be the first point of contact for people affected by cancer, beyond their face-to-face interaction with professionals.

The service is here for your patients, their carers and families, and the worried well. Whatever questions they may have, or support or help they need, you can tell them to contact us on one phone number or through the website. We can put people in touch with others with similar experiences through our self-help and support groups, and signpost them to appropriate self-referral services within their own communities, maybe like your own.

Working together towards our ambition
By working together, we can make an even bigger difference to the quality of support people receive. We want this service to be a standard-bearer of information and support for people affected by cancer.

This improved service will play an integral part in achieving our ambition of reaching and improving the lives of the two million people living with cancer in the UK today. Help us to help others, by spreading the message that we now have a better service for everyone who needs us. One number, more people, a better service.

Questions about living with cancer? Ask Macmillan on 0808 808 00 00 (freephone, Mon–Fri 9am–8pm) or visit macmillan.org.uk
The wraps are off the new be.Macmillan website. And if you didn’t already know, be.Macmillan is the place to order Macmillan resources for you and your patients, create business cards, and find materials to promote your service in just a couple of clicks. You can also learn lots about how Macmillan’s brand can help your service.

But what’s different this time is that the new site is a lot easier to navigate and you can search by category, material, title and key word.

‘The new look be.Macmillan is a fantastic resource for Macmillan professionals looking to promote their service. With new features such as an improved search facility, the site will be much easier to use.’

Chris Cocroft, be.Macmillan Assistant

Simply, the new be.Macmillan is a lot easier to use: all the feedback we have received has been addressed and it’s easier to find the information you want. So, whether you’re already a registered user of be.Macmillan, you’ve given it a go before, or you’ve never been to the site before, head to be.macmillan.org.uk today. We promise you won’t be disappointed. And if for any reason you can’t access the internet to order your resources, you can call 0800 500 800 to make your order.

Supporting and engaging professionals

UK-wide Macmillan learning and development event 2009

It hardly seems possible that nearly a year has gone by since our very successful 2008 event – Survivorship: Living with or beyond cancer.

We were overwhelmed with the response of those wanting to attend, and judging from the buzz at the event and the evaluations we received, it seems we got it just about right.

One of the things that struck us during conversations with some of you, is the wealth of innovation and good practice that is being led by Macmillan professionals. We are also aware that this innovation and good practice is not always shared or disseminated widely enough, and that the skills required to innovate and improve are often learnt ‘on the job’. Indeed, some of you have suggested that we should provide resources to support you in innovation or service improvement.

That’s why this year our overarching event theme is ‘Innovation and Improvement’. You will hear from experts in this field and we will showcase some of the many excellent examples of innovation and service improvement that we’ve heard about from you in the last year.

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

5–6 November 2009
Macmillan professionals event
Innovation and Improvement
Renaissance Hotel, Heathrow
Helping people with cancer stay warm during the winter months

Over 100 people with cancer are saving money on their fuel bills through an innovative fuel management scheme with energy company npower.

Since the programme was launched in 2007, £7,000 of their debt has been written off and they have saved £18,500.

Patients and carers who are npower customers and suffering from fuel poverty (spending more than 10% of their income on fuel) can access the programme through Macmillan’s Benefits Helpline. Benefits advisers also look into the eligibility of all callers.

If a caller is eligible, the benefits adviser will fill in a financial statement and make recommendations to npower’s First Step team. If the person is accepted by the energy company, it may write off some or all of the customer’s outstanding debt and put them onto the Spreading Warmth tariff, npower’s cheapest enduring tariff in the customer’s region. An affordable payment plan is agreed with the customer, regardless of their energy consumption. This helps them keep warm when they really need to, without worrying about when the bill comes.

An evaluation measuring the programme’s impact is underway. We will use this to help us make it even more effective.

If your patient is an existing npower customer and is in financial hardship, please ask them to call 0808 801 0304. From 1 October patients can call our new helpline on 0808 808 00 00.

See page 9 for more information on our fuel poverty campaign.

Calling all budding writers

Macmillan Voice is for you. It’s your forum to share news, innovative ideas, activities and successes. We’d love to hear what you’ve been up to, so please email us or give us a call. You don’t need to be an experienced writer, just enthusiastic about what you do. We provide full editorial support and can help you turn your idea into a news item or feature. All you need to do is get in touch with Rosie Cotter, Managing Editor, at rcotter@macmillan.org.uk or on 020 7091 2219.

We also want your feedback. We want to ensure that Macmillan Voice is relevant, informative and interesting. You will find a readership survey enclosed in this issue. Please take a few minutes to fill out the survey and post it back, or fill it out online at macmillan.org.uk/learnzone.
Macmillan improves its range of resources for the visually impaired

Cynthia Higgins, a retired nurse, has found reading difficult since she was diagnosed with ocular melanoma in 1997. She has no sight in her right eye, and she has cataracts and glaucoma in her left eye.

To help people like Cynthia access the cancer information they need, Macmillan has expanded its range of cancer information in CD format.

The range of 37 CDs is for people living with cancer who have difficulty reading, or who simply prefer information in audio format.

‘It’s very difficult to ask even a loving relative to continually go over a passage they are reading to you, or to find a section you want to hear again.’

‘Macmillan’s new CDs give people with a visual impairment a degree of independence and a sense of privacy,’ Cynthia said. ‘It’s very difficult to ask even a loving relative to continually go over a passage they are reading to you, or to find a section you want to hear again. Having the information available in audio format also allows people the opportunity to react to the information in private.’

The range of CDs contains information and advice about specific types of cancer, different treatments, possible side effects and the emotional effects of cancer.

‘The choice of speaker on the Macmillan range is superb. It’s important to get this aspect right as it can make or break a recording,’ Cynthia said.

A few years ago, Cynthia signed up to review six audio booklets for people with cancer produced by Cancerbackup (which merged with Macmillan in 2008). She acknowledges that people who are new to the audio format can struggle to get used to it. ‘I recommend that you be patient, because it’s a new technique you’re learning. I was impatient the first time, but I persevered. You need to give it time and learn to navigate your way around the audio cues that mark out chapter headings and different sections.’

Macmillan will continue to produce more audio versions of its cancer information booklets.

To order from Macmillan’s current range of audio CDs, visit be.macmillan.org.uk or call 0800 500 800.

Free cancer and genetics e-learning module proves popular

Over 2,280 professionals have completed the online course ‘Cancer and genetics: an up to date guide’.

‘We are delighted that the course has been so well-received and numbers continue to grow.’

understanding of cancer and genetics. The module emphasises the importance of family history as a risk factor for certain cancers.

The guide is published by BMJ Learning and can be accessed through learning.bmj.com/cancergenetics

For more information about the Macmillan/Department of Health’s Cancer Genetics Partnership, please contact Janice on 02476 575509 or j.koistinen@warwick.ac.uk or visit macmillan.org.uk/genetics-programme
Volunteer wins award for striving to improve cancer services

Dedicated Macmillan volunteer Madeline Mulgrew has been instrumental in improving cancer care for many years. Her hard work and commitment has now been recognised with the Vicky Clement-Jones award.

The award is named in memory of the founder of Cancerbackup. It is awarded to volunteers who have or have had cancer themselves, and make a significant difference to the lives of people affected by cancer.

Madeline became aware of the lack of support and information services for people affected by cancer outside the greater Belfast area following her own cancer diagnosis in 2001. She found out about Macmillan’s Cancer Support Certificate for people affected by cancer and travelled from Dungannon, Northern Ireland, to London 20 times to attend the course days. She was the first person from Northern Ireland to deliver the course and is now part of a team of five tutors delivering courses across the region. She also trained for and ran the pilot of the Living with Cancer course (now called New Perspectives).

‘Being a participant on the programme was a wonderful experience and the key that turned my life from “it’s all over” to “it’s only the beginning”,’ Madeline said.

Madeline also founded ‘Cancer Choices’, an innovative, patient-led service offering cancer information, complementary therapies and financial advice.

Not only does Madeline help people in Northern Ireland to cope with a diagnosis of cancer, but she is a key driver in developing cancer information in eastern European languages. Her work has led to the publication of the first ever cancer information literature in Lithuanian.

‘Madeline lives and breathes the Macmillan brand, and her passion and dedication to improving the lives of people affected by cancer is second to none,’ Nick Pivot, Learning and Development Training Administrator said.

Congratulations to Madeline and all 265 Macmillan volunteer award winners in 2009.

For more information about our volunteer awards, go to macmillan.org.uk/volunteer

Macmillan nurse voted employee of the year

Lorraine Barton has been voted ‘Employee of the Year’ at Hillingdon Hospital NHS Trust, beating 20 colleagues to the title.

Lorraine, who has been a Macmillan cancer and palliative care nurse for eight years, attributes her victory to the work she’s done within patient partnerships – helping people living with cancer and their families to try and improve the services available to them.

Lorraine said: ‘Most people who work in the cancer field aspire to be a Macmillan nurse and really feel they’ve made it when they achieve this. I’m really proud to be part of the organisation – it’s a charity with clear objectives that people know they can trust.’
Highlighting the needs of carers – the UK’s secret service

Three-quarters of carers surveyed during Carers Week 2009 say they have reached breaking point. There are six million carers in the UK and they are often overlooked by themselves, friends, family, professionals and employers. This lack of recognition can impact on their physical and emotional health, employment, finances, and leisure time.

‘The good news is that recognition and signposting to services can make a huge difference,’ said Charlotte Argyle, Macmillan’s Carers Support Manager.

Over 6,000 local events took place during Carers Week, highlighting the needs of carers, promoting services and providing support to ‘hidden’ carers. Here are just a few examples of how Macmillan professionals and services got involved.

A special service for carers
Dr Hazel Barker, who runs the Calderdale Care Scheme, held a service for people of all faiths and none, to reaffirm the community’s support for carers and the cared for.

‘The aim of the service was to celebrate the work of carers and to note publicly how much they are valued by the Calderdale community,’ Hazel said. Around 150 people from the community attended the service. Carers, professionals, people who have been bereaved, and staff from the local hospice gave informal testimonies and spoke from the heart.

‘It was an uplifting event that brought the community together,’ Hazel said. Contact Hazel on 01422 368056 or hazel@calderdalecarescheme.co.uk

Providing a place to talk
The Mulberry Centre, a cancer information and support centre on the grounds of West Middlesex Hospital, held a coffee afternoon open to all carers.

Carers could drop in for information and support and those who attended got a lot out of the session. Most had not met before and were able to share their experiences of being a carer and, in some cases, of having cancer themselves, in a supportive environment.

‘Being in a small group helped people to talk openly and share their feelings,’ Macmillan Cancer Information Manager Caroline Newton said.

The centre has a flexible, fortnightly support group for carers, but also holds other events for carers at a variety of times to make attending easier.

Contact Caroline on 0208 321 6301 or caroline.newton@themulberrycentre.co.uk

Making sure carers have access to the information they need
The Information, Care & Support Service (IC&SS) at St James’s Institute of Oncology ran a promotional event to raise awareness of the services available to carers.

‘The Macmillan social work team were on hand to provide benefits advice and we kept them very busy,’ Macmillan Specialist Radiographer Louise Wem said. ‘The event was also supported by our fantastic, dedicated team of volunteers.’

‘During the week we were joined by Carers Leeds, part of the Princess Royal Trust for Carers, and staff from the Employee Care Service, giving the stand a truly collaborative feel.’

The team had 371 enquiries,138 of which were from carers. Many of the carers came to the stand to ask questions while their relative was receiving treatment.

IC&SS is looking into new ways it can help carers to access the services available to them.

Contact Louise on 0113 206 7616 or louise.wem@leedsth.nhs.uk

Carers Direct
Carers Direct is the government’s advice, information and support service for carers. It was developed as one of the outputs of the National Carers Strategy and is delivered by NHS Choices.

Charlotte Argyle has liaised with Carers Direct regarding Macmillan’s telephone helplines and website. The Carers Direct helpline staff are aware of our services and can signpost carers to them as appropriate.

Telephone advice line 0808 802 0202
Web www.nhs.uk/carersdirect
We are turning up the heat

Macmillan campaigns for a better deal for people affected by cancer. We want everyone with cancer to receive the right level of treatment and support, regardless of who they are or where they live.

Freezing out fuel poverty
Fuel poverty is a growing problem in the UK. Rising energy prices mean that many households are spending over 10% of their income on fuel bills – the official definition of fuel poverty.

Macmillan believes that people affected by cancer should be able to concentrate on recovery and not have to worry about affording their fuel bills.

The Winter Fuel Payment is an annual payment of around £250. It is paid to everyone aged over 60 for their fuel costs. Approximately one in four people diagnosed with cancer each year are under 60-years-old, and therefore do not qualify for the Winter Fuel Payment. The payment could provide immediate relief for households in financial difficulty – crucial for someone who is suddenly facing additional costs on a reduced income.

Macmillan is calling on the government to extend the Winter Fuel Payment to people under 60 with cancer who are in particular need, including people who have undergone treatment in the past year, who are terminally ill, or in receipt of Council Tax Benefit or Housing Benefit.

‘Last winter, I just about kept on top of the monthly gas bills by dipping into savings. I’m still out of work, my savings have dried up, and they’ve written to tell me that my payments are going up 150%. I worry constantly about how I’m going to pay for my heating.’

Julie, 43 from Surrey, was diagnosed with breast cancer in November 2005 and is still being treated with Tamoxifen.

Have you found that coping with fuel bills is an issue for people affected by cancer? Macmillan professionals, particularly benefits advisers, can help the campaign by sharing their experiences with the campaigns team at campaigns@macmillan.org.uk

Help us boot out parking charges in England
An online survey for Macmillan has found that almost 60% of people with cancer are still paying full price to park at hospitals in England. This is despite guidance from the Department of Health telling hospitals they should provide free or reduced-price parking for people with conditions requiring regular treatment.

There are schemes in place to help people with parking costs, but these aren’t always widely publicised. Our survey found that only 15% of people were told about these free or reduced concessions in their appointment letter. We feel this is a clear opportunity to tell patients, and many people have missed out as they didn’t find out about the concessions until after their treatment had finished.

The only way to end this confusion is to scrap hospital parking charges for people affected by cancer in England. We’re not the only people who think something should be done to end this charging lottery – an Aurora national poll for Macmillan found that 9 out of 10 people think that people with cancer shouldn’t have to pay to park at hospital.

You can help Macmillan’s campaign. Simply log on to macmillan.org.uk/parking and sign our petition to show your support and make a difference.

Sex, relationships and cancer
Thank you to all of you who have accessed our sexual relationships toolkit. It has been really well received. If you haven’t accessed the toolkit yet, please go to macmillan.org.uk/learnzone You will find written information, role play videos, an online discussion forum and an archive to the ‘hot seat’ we ran in June, where two experts were on hand to answer any questions on the issue.

Our campaigning video has reached well over 45,000 people, with double the average number of people clicking through to our website for information after watching it. This is fantastic. Our case study video is nearing 2,000 views and there has been a lot of debate on the subject and about people’s experiences of our online forums.

You can find more information about the campaign on our website macmillan.org.uk/sex

Limited uptake of free prescriptions
Following the success of Macmillan’s prescription charges campaign, all people with cancer in England have been entitled to free prescriptions since 1 April. The Department of Health estimates that 150,000 people are eligible. However, they have confirmed that there has been limited uptake of the entitlement to date.

We are therefore asking you to help us with raising awareness of this entitlement. We have produced a simple poster to promote free prescriptions. This can be ordered for free from be.macmillan.org.uk

Reference
[1] CancerStats, Cancer Research UK
Profile

Sue Smith
Macmillan Centre Manager, Mustard Tree Cancer Support Centre

What is your background?
I have been involved in cancer care my entire career. Before helping set up the Mustard Tree Cancer Support Centre, I worked as a superintendent radiographer.

What does the centre offer?
We see over 12,000 people each year. We offer a range of services (benefits advice, counselling, complementary therapies, wig advice) and run support groups, and workshops. We also run several outreach clinics, including one we’ve just started with the Devonport Regeneration Community Partnership, for the community of a deprived inner-city area.

What else are you involved with?
We have been lucky enough to become involved with several projects over the years, including volunteer training and education programmes. We are now focusing on a survivorship project, looking at the needs of patients, their families and carers across health and social care, statutory and voluntary sectors. We are exploring working with local agencies to provide the most effective package.

What are the biggest challenges?
Obtaining funding has been an ongoing challenge. As one of the first cancer support centres in the UK, it was difficult to get recognition for the impact a support centre can make to people affected by cancer. We have been fortunate in recent years, as Macmillan have been able to provide five years of funding for the whole centre through their 15-year partnership with Nationwide, which has raised over £5 million for Macmillan.

What is the most rewarding part of your role?
The diversity and variety of this job holds my interest. I’m involved with such a wide range of projects, in local, network and national schemes. In the end, the reward comes from seeing the difference we can make to our clients and hearing their feedback on the service.

How would you like the role and service to develop?
I hope the service will continue to flourish beyond our current funding. The Cancer Reform Strategy and NICE guidance have given more weight to support services. We hope to receive a staggered pick-up by the local Trust starting in late 2010. Our wish is that everyone who could benefit from the service knows about us and that we continue to link with other agencies to provide as ‘complete’ a service as possible. I don’t want to hear anyone say, ‘I wish we’d heard about you before’ when they visit us after already struggling for six months.

Three quick questions

What is the best thing about being a Macmillan professional?
Working for an organisation that has such a respected name, and in turn attracts so many people that are lovely to work with.

What is the most unusual job you’ve had?
An Alan Whicker ‘stand in’.

If you could invite any four people in the world, past or present, to dinner – who would they be?
Peter Ustinov, Judi Dench, Billy Connolly and Michael Parkinson. Failing that – please ask George Clooney to come four times!

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Macmillan Voice autumn 2009
Surviving cancer for 40 years

Macmillan Palliative Care Specialist Nurse Julie Lamb shares her experience of meeting a woman who has been living with cancer for 40 years

I keep abreast of Macmillan’s work within survivorship, yet until recently I naively felt that this work was not directly related to my role. A large percentage of my patients are very close to the end of their lives and, to me, did not seem to fit into the survivorship agenda. How wrong I was. I was asked to see a 78-year-old woman for symptom management and emotional support. I visited her at her home and after initial introductions she told me about her experience of cancer.

‘Throughout our meetings, I was aware of how Jean viewed cancer as ‘not a death sentence’, but as something that could be lived with.’

Jean was diagnosed with breast cancer in 1968. She was initially treated with a mastectomy and was clear of the disease. But for the last 20 years she has had multiple lumpectomies, radiotherapy and chemotherapies. Jean has had five different chemotherapy treatments within the last seven years and is currently undergoing chemotherapy for chest wall recurrence.

I realised that sitting in front of me was a ‘survivor’. This lovely woman had lived with cancer for 40 years. This is a little bit of her story of how she coped.

Jean’s story

When Jean was diagnosed with breast cancer, her husband worked away from home and she cared for their daughter. Jean was shocked at her diagnosis, but displayed a sense of strength, saying that she ‘just had to get on with it’. Her daughter was her main priority and she was determined that her child would not be badly affected by her illness. Jean had fantastic support from her GP, who visited her weekly for a long period of time after her initial surgery. It was not until many years later that Jean realised her GP was actually providing her with counselling and support. She laughingly described that she just thought he was being friendly.

Jean said that throughout her illness she has always been guided by medical and nursing staff, having ‘great faith’ in their ability to help her cope and make decisions about treatment. Throughout our meetings, I was aware of how Jean viewed cancer as ‘not a death sentence’, but as something that could be lived with. This was a view that she felt was emphasised to her at each medical review.

Jean has made me realise the importance of the cancer survivorship agenda. Jean’s experiences show that, in many ways, healthcare professionals have been independently tackling some of these issues for many years. For Jean, this professional was a proactive GP maintaining regular contact and support visits, along with regular oncology reviews.

This experience has made me more aware that, as healthcare professionals, we will meet ‘survivors’ in many different settings, and not always where we expect. It has also made me realise that there are many more people like Jean. We must strive to ensure they are individually supported and receive the care they need to live a healthy, productive life.

Related information

Macmillan’s cancer survivorship agenda, Two million reasons, is available from macmillan.org.uk/survivorship

Further information

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Closing the gap – palliative care for people with learning disabilities

Dorothy Matthews, Macmillan Learning Disabilities Nurse, charts the progress made to improve palliative care services for people with learning disabilities

My interest in palliative care evolved while caring for people with learning disabilities who suffered from life-limiting and life-threatening conditions. This experience highlighted the many problems faced by clients, families and professionals in accessing appropriate palliative care services.

Our work towards improving palliative care services for people with learning disabilities began back in 1995 when we made contact with our Macmillan adviser, and by 1999 we had established a palliative care service for this client group.

The service was given ‘Beacon status’ in 2000. This award is given to NHS organisations which show the best examples of high quality, modernised patient services. This helped us raise the profile of the palliative care needs of people with learning disabilities. It also provided funding to develop educational materials, and a research project undertaken with St Oswald’s Hospice and Northumbria University, Newcastle. The project led to the creation of a clinical tool to identify and document distress in people with severe communication difficulties – the disability distress assessment tool.

Macmillan became aware of our work and expressed an interest in funding a nursing post specialising in learning disabilities. The postholder has a clinical caseload and works collaboratively with professionals to train and educate carers and other professionals, and to develop and sustain networks across the health and social care community. The role also involves facilitation, research, advocacy, care coordination and providing a support network for others.

The need to increase awareness of palliative and end-of-life issues in learning disabilities was recognised within the regional end-of-life programme in 2005. Several professionals interested in this specialist field were invited to join a strategic health authority sub-group.

The remit of the group was to plan dissemination of work already developed and to raise awareness of the broader aspects of palliative care for people with learning disabilities across North and South of Tyne.

The group organised a very successful conference in 2006 titled ‘Facing the end of life – valuing the experiences of people with learning disabilities and their carers’. Delegates questioned what should be done next in terms of developing learning materials to address a range of issues relating to end-of-life care for people with learning disabilities.

Lynn Gibson, manager of the physiotherapy service for people with learning disabilities, and I were then asked to produce a resource pack for those caring for, or supporting, people with a learning disability at the end of life.

The resource pack is aimed at families, carers and people working within health and social care, who provide vital support to people with learning disabilities at the end of their lives.

‘The role aims to raise awareness of the palliative care needs of people with learning disabilities and to address issues relating to equitable access to services for this group.’

The pack contains targeted, easily accessible and practical information covering the following topics:

• maintaining health – common symptoms, pain medication, eating and drinking, mobility and complementary therapies
• living with dying – relationships, breaking bad news, what is palliative care, spirituality, last days and hours, how do you know someone is dying, and when a friend dies
• challenges and solutions – challenges for carers, consent, complexity, compliance, communication, choice, financial support and people who can help
• useful information – tools in end-of-life care, useful sources of information.

The pack was launched at a second conference in Teesside in 2007, and since then has been disseminated locally, regionally and nationally.

The pack can be downloaded from endoflifecareforadults.nhs.uk/eol/eolcpub or copies of the pack are available free of charge from Dorothy Matthews or Lynn Gibson (but they do require a large SAE).

Further information
Dorothy Matthews, Medical Centre offices or Lynn Gibson, Physiotherapy Department
Northgate Hospital, Morpeth, NE61 3BP
01670 394808/ 01670 39426
dorothy.matthews@ntw.nhs.uk or lynn.gibson@ntw.nhs.uk

Macmillan Voice autumn 2009
Preventing cervical cancer

An overview of the UK’s screening and vaccination programmes for cervical cancer

We now know that the Human Papilloma Virus (HPV) causes 99.7% of cervical cancers worldwide. There are over 70 sub-types of HPV, with sub-types 16 and 18 being responsible for over 70% of cervical cancers. At least 75% of women will have been exposed to HPV by the time they are 50, but their immune systems will protect them.

‘In the UK, cervical screening saves over 1,000 lives every year, and has prevented 8 out of 10 cervical cancers.’

A national screening programme has been in place in the UK since 1964, becoming more structured from 1988 when a recall system was introduced. At present, women in England and Northern Ireland aged 25–50 are screened every three years, and every five years for women aged 50–64. In Scotland, women are offered screening every three years from ages 20–60, and every three years from 20–64 in Wales. In the UK, cervical screening saves over 1,000 lives every year, and has prevented 8 out of 10 cervical cancers.

‘Cervical cancer is a disease that can be prevented if women access the screening programme, and it can be successfully treated if found early.’

A vaccination programme has been running in the UK since September 2008. This is a school-based programme offered to all 12-year-old girls, with a catch-up programme in place up to the age of 18. The vaccine is a bivalent vaccine against sub-types 16 and 18, and was found to be well-tolerated in trials. There is a quadrivalent vaccine against HPV sub-types 16, 18, 6 and 11, with 6 and 11 causing 90% of genital warts. The vaccine consists of three injections at 0, 2 and 6 months, and initial uptake of the vaccine has been good. It is best given to girls who haven’t had sexual intercourse, but trials of the quadrivalent vaccine in women who were sexually active showed protection if they had not been exposed to the 16 and 18 HPV sub-types.

Cervical cancer is a disease that can be prevented if women access the screening programme, and it can be successfully treated if found early.

References

Related information
Our booklets, Understanding cervical cancer and Understanding cervical screening, can be ordered through be.macmillan.org.uk

Further information
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Ensuring palliative and end-of-life care for diverse communities

Diana Murungu, Macmillan Diversity Social Worker, shares how Birmingham St Mary’s Hospice is working to improve access to their services for patients and families from black and minority ethnic (BME) communities

Over 1,200 people from diverse communities are referred to Birmingham St Mary’s Hospice every year. The hospice was established in 1979 to care for people with advanced, progressive illness, and to support families and carers. In its 30th anniversary year, the hospice will have provided direct support to over 100,000 people.

The hospice is committed to providing excellent palliative care to people with the most complex symptoms. It enables people who are using the service to make informed decisions during the planning process. Education and training is also delivered for health and social care professional groups.

However, a perception survey commissioned by the hospice in 2006 found that, apart from those who had first-hand experience of the hospice, a large proportion of the public viewed it as mainly relevant for white, middle-class people from a Christian background, and that the full range of services was hidden. Few were aware that the hospice mainly provides care in people’s own homes and also for people with conditions other than cancer.

People from BME communities didn’t respond to the survey and it was recommended that the hospice establish links with BME community leaders. The findings were in line with the hospice’s own observation that people from BME communities were accessing its services in numbers that were not reflective of the possible need within their communities.

BME communities are often described as ‘hard to reach’. However, the question raised by the hospice management team was whether, in fact, it was the hospice that was hard to reach.

I was employed by the hospice, with Macmillan funding, to address this issue and develop services specifically for people from BME communities. I carried out a study in 2007 to establish what the barriers were and how members of the BME communities felt they could be addressed.

Qualitative research methods were chosen. It was felt that they would provide respondents with the opportunity to describe, in their own words, how they viewed the palliative care services offered by the hospice, what their experiences were in terms of accessing these services, and how they felt access could be facilitated. This information would be vital in informing the hospice about developing services for people from these communities.

‘The findings were in line with the hospice’s own observation that people from BME communities were accessing its services in numbers that were not reflective of the possible need within their communities.’

Because it was assumed that BME community leaders would be knowledgeable about how to reach members of their communities, we decided to make initial contact with community leaders named in the Equality and Diversity Directory (Birmingham City Council, 2006). I assumed that community leaders were best placed to identify members of their communities, and that they would be knowledgeable about factors that would inhibit or encourage access to palliative care for them at the hospice.

I initially identified 55 leaders who I contacted by telephone. Eleven agreed to meet with me. At the initial meeting I explained to the community leaders the two-fold nature of my visit, ie the study and giving information about the hospice. I would then ask the community leader to arrange a meeting for me to meet members of their community. I would also ask the leader if they...
knew of other communities who might like to participate in the exercise. This snowball technique was used to get the initial 11 community leaders to identify other community groups who might like to take part. Twenty-six groups eventually participated in the study and outreach work.

My research showed that there existed:

• little information about palliative/end-of-life care services in these communities and the information that was available was distorted. The hospice was viewed as a nursing home, which most members of the BME communities felt was inappropriate for them to access
• fears of ostracism for accessing services outside one’s community, because of a perceived negation of the duty of care by younger people
• other fears related to end-of-life care, religion and spirituality
• a preference for same gender personal care
• a link between religion, diets and end-of-life care
• fears of being the only one looking different at an inpatient unit.

Recommendations included:

• maintaining existing links between the hospice and the community leaders and continuing to forge new ones
• ongoing awareness work in the communities
• ongoing awareness work with cancer, palliative and primary care teams
• involvement of patients and their named loved ones in care planning and provision of palliative/end-of-life care services, particularly around diets, personal care, family involvement, decision making and spiritual care.

The study continues to inform policies and practice at the hospice, where diversity and equality has been adopted as a priority at all levels. The work has influenced the hospice’s three-year strategic plan which is underpinned by the ‘Reaching People’ campaign theme. Spiritual and cultural awareness courses for health and social care professionals are held at the hospice throughout the year.

The hospice is focused on maintaining engagement of BME communities through meetings with the newly established BME service development team. The ‘Reaching People’ conference, hosted by the hospice in May 2009, provided a platform for dialogue between BME communities, commissioners and providers of health and social care. The conversations highlighted the dilemmas around the acceptability of ‘end-of-life care language’ and how this fits with cultural and spiritual belief. The outcomes from this conference will inform future plans for service development and engaging wider networks of communities and groups.
Creating positive environments through self-help and support groups

There are over 900 cancer support groups in the UK, with many more starting all the time. Every group is different, but they all provide practical and emotional support to people affected by cancer.

Brooke Quinteros, a speech and language therapist, told us about the benefits of starting a support group for people with head and neck cancer in Kent 11 years ago: ‘I could never adequately describe the benefits a support group gives to patients, carers and professionals alike. A friendly, informal, supportive atmosphere really helps to boost confidence, provide insight and establish long-lasting friendships for all involved.’

What are the benefits of self-help and support groups?
Patients, carers and their families who attended a support group said they:
• provide an opportunity to talk to people who are going through a similar experience and who are therefore likely to understand each other’s needs
• can help people regain control of their lives
• help reduce the sense of isolation that many people affected by cancer experience and provide a safe, confidential environment
• create a sense of friendship and togetherness for people dealing with a difficult situation
• look at the person affected by cancer as a whole
• provide an opportunity for people to share their real thoughts, feelings and concerns and express their need for support
• are often a source of information and provide signposting to other organisations and resources
• may provide services such as buddy/befriending, counselling, bereavement support, home visiting, or telephone support.

‘A friendly, informal, supportive atmosphere really helps to boost confidence, provide insight and establish long-lasting friendships for all involved.’

Paula Lawrence, Macmillan Lymphoedema Specialist Nurse at the Nightingale House Hospice said: ‘Setting up the Wrexham Lymphoedema Support Group (WLSG) five years ago was relatively easy. Selecting a proactive group of 15 willing patients meant that patients’ needs could be identified immediately. The initial focus was on afternoon teas and socialising. Later, however, the WLSG successfully organised, and still runs weekly Tai-Chi classes, aqua aerobics and aerobics. The benefits have been two-fold: those affected with lymphoedema have not only formed new social networks, but they have also improved their level of fitness.’

How Macmillan can help
To help you get started, or to further develop your support group, Macmillan provides a range of guidance, advice and resources including:
• a grant of up to £500 to help start a new group
• a grant of up to £3,000 to help develop your group’s existing work and activities
• training to help you start a new support group or maintain, promote, or develop an existing group
• training for your group members, including skills development for listening and responding, how to set up buddying and befriending for people affected by cancer, and new workshops that help you understand how to support people who are bereaved (go to macmillan.org.uk/learnzone for more information and details of the workshops we offer)
• resources to aid shared learning such as Exchange magazine
• grants for your group members to attend training and development events
• advice, guidance and support from your community networks development coordinator (CNDC) – find your local CNDC via macmillan.org.uk/cancersupportgroups

All support, advice, guidance, training and resources are free of charge. You can request an application pack from your local CNDC or contact Kim Levan on 020 7840 4902 or klevan@macmillan.org.uk

Further information
Deepa Masru
Community Networks Development Coordinator
Macmillan Cancer Support
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dmasru@macmillan.org.uk
During a sabbatical to Libya, my ultimate goal was to improve services for people with head and neck cancer. This meant identifying existing patient pathways and attempting to adapt best practice to improve services. As Libya is the fourth largest oil-producing nation, with a state-based national health service, I was surprised to see pathology services and hospitals were of a poor standard.

My first thought was to use the improving outcomes guidance for head and neck cancer as a template for a pathway; this was impossible however as there were no guidelines or pathways within the Libyan health service.

‘I saw two younger patients with terminal cancer. There was no evident knowledge of symptom control.’

I attended a week of clinics, which many people travelled huge distances (up to 1,200km) to attend. I expected to see a significant number of oral cancers, as 75% of head and neck cancers are associated with smoking, which is endemic within Libyan culture. In fact, there were only eight oncology patients (less than 10% of the total). The biggest surprise was that these were not new cancers and that many of the patients did not realise they had cancer. It became evident that cancer was a taboo subject, often being referred to as the ‘secret disease’. Even taking a patient’s medical history was difficult. It appeared not to be culturally acceptable to question a doctor or senior medical professional, and patients presented to us without much knowledge of their previous treatments or investigations.

I saw two younger patients with terminal cancer. There was no evident knowledge of symptom control. I at least had an opportunity to use my skills to advise on palliation for these patients.

The local team recognised that their head and neck cancer service had to improve, but they needed a formal service structure for the patients, carers and the clinical team to work from. It is incredibly hard to start to engage such a process in a culture where cancer is simply not discussed. Patients place absolute authority in senior medical figures, and competition replaces communication and cooperation between hospitals.

The lack of knowledge, training and skills required to effectively diagnose and treat people with head and neck cancer, alongside a significantly depleted hospital service, is hindering development of any head and neck cancer services.

‘Patients place absolute authority in senior medical figures, and competition replaces communication and cooperation between hospitals.’

As a team, we realise we cannot influence the current head and neck cancer service within Sabratha, but we can highlight the plight of developing head and neck services.

From my perspective, perhaps the greatest lesson is appreciation of what we have. Our health service, despite constant political interference, relative under-resourcing and a demand that exceeds supply, delivers something close to excellence and equity in fairly even portions. Sometimes you have to travel to learn ‘there’s no place like home’.

Reference

Further information
Julie Hoole
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julie.hoole@midyorks.nhs.uk

Some Libyan health services were found to be of a poor standard
During implementation of the Liverpool Care Pathway, many staff lacked knowledge and understanding of death and dying. We wanted staff to manage people well in end-of-life care so I applied for a grant to allow nurses within our hospital to complete an Open University (OU) course – Death and Dying.

It is run as a distance-learning course, but we felt using a work-based model, supported by an in-house associate lecturer (myself), was a cost-effective approach to workforce development and would close the theory/practice gap. The £1,000 grant allowed our staff to complete the course at reduced student fees, as there was no funding for this within the hospital.

I was appointed as an associate lecturer with the OU to deliver the course within Milton Keynes Hospital. This enabled me to recruit students directly from clinical areas and gave me direct contact with the students and their managers before the course started. All of the students (11 in total) came in close contact with the care of dying patients and their families as part of their daily work.

I built a close rapport with the students and gave face-to-face feedback and support. The students also formed their own local support group. This seemed to be particularly beneficial when assignments were due. I gave direct support in clinical areas, drawing on practice-based examples as they occurred. This was of great value in supporting many of the ethical and moral dilemmas that arise in respect to death and dying, eg when to stop treatment.

A possible disadvantage to a work-based approach could be the isolation from the wider OU student group, so I will be encouraging greater use of OU resources in the future.

All students successfully completed the course and have reported increased confidence and improved skills in managing death and dying situations. In particular, they have accepted that death does occur in a hospital setting and is not necessarily a failure. All students feel more confident in talking to relatives and the medical teams, and now actively avoid using misleading phrases when talking about death and dying.

An evaluation of the course showed it was a success and we are running the course again this year.

‘I now feel much more confident in dealing with relatives. Before I would have avoided having those difficult conversations.’

Student quote

Further information
Lyn Meehan
Liverpool Care Pathway Lead
Milton Keynes Hospital
Milton Keynes MK5 5LD
01908 660033
Few educational events are available to specialist palliative care staff. I applied for a Macmillan grant to organise a development session in response to a consultation exercise with specialist palliative care staff in South of Tyne and Wear.

The grant was for £4,050 and allowed us to run three half-day master classes. Forty-five palliative care specialists, (Macmillan and non-Macmillan) from three PCTs came together to reflect, share and learn during these sessions.

‘People affected by cancer do not come neatly packaged with a cancer diagnosis; they may also have a range of long-term conditions that require our attention.’

The learning and development needs of our palliative care specialists reflect the changing face of this speciality. There are growing numbers of patients with complex co-morbidities, including other life-limiting illnesses. People affected by cancer do not come neatly packaged with a cancer diagnosis; they may also have a range of long-term conditions that require our attention.

We used the sessions to bring experts to our region, and ensured that as many as possible of the local specialist palliative care workforce could attend. Our speakers had a great opportunity to learn from the experiences of our specialists.

The local teams who organised the 2008 sessions have learnt a great deal about what works and what does not in terms of dates/times/venues and building local knowledge and skill in putting together programmes.

Having a pre-planned set of dates when groups can come together also proved to be mutually beneficial. We have found the model to be financially sustainable and we will continue running the course on a yearly basis. We intend to formally evaluate the impact of the programme at the end of 2009.

For more information on Macmillan learning and development grants, visit macmillan.org.uk/learnzone

Further information
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Further information
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01923 844650
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Raising awareness of how cancer affects men

Men are thought to be less aware than women of health issues, including cancer. Men are less likely to act on signs and symptoms unless these are severe, are generally less ‘body aware’, and may not access information and support when it is available.

We decided to hold a conference targeting men ‘living with and beyond cancer’ and those who are unaware of the risks, signs and symptoms. We aimed to:

• provide information and guidance to people affected by cancer
• increase awareness of the predominant types of cancer affecting men
• raise awareness of the need for early detection of common cancers affecting men
• raise awareness of Macmillan and the breadth of information and support available.

On the day

The conference was held earlier this year in High Wycombe, and included:

• an introductory talk from an oncologist
• talks on some of the rarer male cancers, with presentations from men who have had breast cancer and penile cancer (both men were very willing to share their experiences to support and enlighten others)
• information and discussion in workshops led by health professionals, on tumours that are predominant or common in men, including prostate, bowel, urological, and head and neck cancers
• extensive written information available to delegates, including a large range from Macmillan
• a question and answer session which highlighted the need for awareness and early detection, and the associated improved prognosis.

About half of the 60 delegates were men – some were patients and carers; others were health and social care professionals. Similarly, some of the women had male partners or family members with cancer and others were professionals. They all wanted a better understanding of how cancer affected men. Detailed evaluation forms showed that delegates felt the day was successful. The speakers were excellent and warmly-received. A quiz designed to make delegates think about the effect of diet and lifestyle, and the common cancers affecting men, was very popular. The workshops also received good feedback.

Tips and improvements for next time

We came up with a number of improvements for next time and tips for those organising a similar event:

• Do not organise an event six weeks after Christmas – people are preoccupied.
• An event during half term limits both the number of health professionals and delegates who can attend.

• When publicising to clubs and organisations, start 8–12 weeks in advance, with a reminder in the interim as many only meet every two months.
• For the older generation, Probus (see ukprobus.org) has a huge membership, and is therefore a good target for publicity.
• When health professionals give talks and lead workshops, be very definite about what is wanted – facilitate communication by involving secretaries or personal assistants.
• Quizzes for a mixed audience of health professionals and others need careful management, as health professionals would be expected to gain higher scores.

The conference was organised by two Macmillan professionals from the Thames Valley Cancer Network: Sarah Pyne, Macmillan Facilitator for User Involvement and Patient Information, and Diana Nicol, Macmillan Project Worker for User Involvement and Patient Information. Other Macmillan professionals from around the network were also involved and we were successful in gaining a Macmillan Group Development Grant worth £4,000 to run the event.

This is the first event of this kind we have run, but we will definitely do it again.

Related information

Our booklet, Men and cancer, can be ordered through be.macmillan.org.uk

Further information
Sarah Pyne
Macmillan Facilitator for User Involvement and Patient Information
Thames Valley Cancer Network
01865 225 518 or 07785 341234
sarah.pyne@tvcn.nhs.uk
Spiral – positively shaping children’s futures

Spiral provides support and resources to local professionals involved with children affected by bereavement

A number of professionals came together in 2000 to form a multi-agency group, because they had concerns about the lack of bereavement support for children and young people in Nottinghamshire. A business plan and case of need was formulated, but routes for funding were unsuccessful.

Later, a local bereaved parent was inspired by a Macmillan-funded children’s service in Bury. Within a year Family Care gained funding from Macmillan for three years and established a partnership with Macmillan and Faith in Families. The service was launched in October 2008 and has subsequently grown with the support from children and families.

‘The biggest challenge is responding to the need coming our way.’

First year successes

During our first year of service we have:
• launched an advice and support line which has supported 37 parents and 76 professionals
• run individual emotional support sessions for 90 newly-referred children, in addition to ones referred to Family Care prior to 2008
• provided support to 57 families, in addition to ongoing support to families referred to Family Care prior to 2008
• set up a children’s bereavement group working with children aged between 8 and 10 who have experienced the loss of a parent (running therapeutic groups benefits the children involved and also enables us to reduce the waiting time for support)
• visited families at the earliest convenient time (following a traumatic loss helps children and families longer term)
• continued to develop a quarterly Professionals’ Bereavement Forum (contact us via our website), and developed leaflets and service materials with Macmillan
• built a database of bereavement support agencies
• consulted with professionals who worked with children and young people who have experienced loss.

The biggest challenge is responding to the need coming our way. With only three team members and covering such a wide area, this has to be carefully managed. We need to offer support in varied ways to meet the needs of more bereaved children and their families.

Over the next year we will be working towards this by developing group programmes, recruiting a volunteer coordinator, investigating a memorial space and supporting professionals.

Future funding is a key challenge as we only have Macmillan funding until 2011. We would like to have support from Nottinghamshire Children’s Services and the PCTs to help mainstream this service. We have achieved so much in the first year and it would be devastating for the service to fold after this time.

Further information
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Children’s Bereavement Service Co-ordinator
Warren House, 2 Pelham Court, Pelham Road, Nottingham NG5 1AP
0115 960 3010
angela.cheadle@familycare-nottingham.org.uk
www.familycare-nottingham.org.uk/bereavement_work

Related information
Our booklet, Talking to children when an adult has cancer, can be ordered through be.macmillan.org.uk

Understanding loss: children create a mural at the launch of Spiral

‘I will be forever grateful for how you have helped my children to come to terms with the loss of their beloved dad.’
Influencing healthcare

The Healthcare team at Macmillan helps set the direction of cancer care across the UK. We work closely with the regional teams to ensure consistency, integrate work and establish clear priorities for where donors’ money is spent in healthcare. We are also responsible for keeping up to date with what is going on in healthcare and provide expertise to the organisation so Macmillan can be a force for change for people affected by cancer.

There are similar small, strategic teams for information, social care and financial work within Macmillan which make up, with healthcare, the four main ‘pillars’ of work.

Who are we?
We have a team of five people based at the UK head office, all of whom have a background working in healthcare.

The wider team based across the country consists of six clinical leads, all from a professional background (either AHP or nursing) who lead the development of Macmillan services within their geographical area. We also work closely with our Chief Medical Officer Professor Jane Maher and Chief Clinician Professor Jessica Corner. They act as professional advisers to us on a part-time basis.

What are we currently working on?
There are currently five main areas of our work.

Living with and beyond cancer – ensuring that investment in healthcare supports the national survivorship work and is used as a platform for innovative work that can be translated elsewhere. For example, supporting the development of the emotional support and rehabilitation agenda and providing investment in this where appropriate.

Primary and community services – working with Macmillan GPs to improve primary care for people affected by cancer. We do this by introducing tools such as the Out-of-hours toolkit and championing practical change, such as cancer review templates for all GPs’ computer systems.

Quality – we demonstrate that Macmillan services, developed through partner organisations, are fit for purpose. This includes piloting a clinical patient experience survey across Macmillan services. We plan to roll this out nationally, through you, the professionals, to ensure we enable services to be in tune with what people affected by cancer say they need.

Workforce – we look at the cancer workforce, both Macmillan and non-Macmillan, to see where the gaps are and how we can ensure that the right skills, competencies and roles are available to support the healthcare needs of people affected by cancer. We do this by campaigning for more specialist nurses in areas where there are gaps.

Palliative and end-of-life care – providing support to implement the end-of-life care strategy in England, and ensuring that the palliative care needs of people affected by cancer across the UK are met, eg through education of generalists and lobbying for improved out-of-hours provision.

In order to take our work forward we are fortunate to have access to experts in the field through all of you, and we are keen to ensure that our work is grounded in reality. If you would like to raise an issue with us, share your good practice, or come up with ideas on how we could work better together, please email Philippa Palmer, Head of Healthcare, at healthcare@macmillan.org.uk

Future work
As well as building on the good work already underway, we want to make sure that we respond to the changing health environment across the UK for people affected by cancer. We will be reviewing our work plan for the coming year and subsequent years to ensure that what we work on matches what people affected by cancer tell us is important to them.

Further information
Philippa Palmer
Head of Healthcare
Macmillan Cancer Support
healthcare@macmillan.org.uk
Diary of 2009 events

September
19–27 September
Children’s Hospice Week
www.childhospice.org.uk

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

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

December
Children’s Cancer Month
CLIC Sargent
www.clicsargent.org.uk

World’s Biggest Coffee Morning
Feel Good! Take part in the World’s
Biggest Coffee Morning with your
friends, family and colleagues.
0845 602 1246
coffee@macmillan.org.uk
www.macmillan.org.uk/coffee

November
5–6 November 2009
Macmillan Professionals event,
Renaissance Hotel, Heathrow
This year’s theme is ‘Innovation and
Improvement’. You will hear from experts
in this field and we will showcase some
of the many excellent examples of
innovation and service improvement.

Macmillan events

2009

September
25 September 2009
World’s Biggest Coffee Morning
Feel Good! Take part in the World’s
Biggest Coffee Morning with your
friends, family and colleagues.
0845 602 1246
coffee@macmillan.org.uk
www.macmillan.org.uk/coffee

2010

February
27 February – 7 March 2010
Sahara Hiking Challenge - Morocco
Join our 10th challenge in the Sahara
and trek 100km through one of the
most extreme landscapes on Earth.
020 7840 7887
hiking@macmillan.org.uk
www.macmillan.org.uk/sahara

6–18 February 2010
Trans-Central America Cycling
Challenge
Embark on an epic journey from Panama
City to Lake Nicaragua, taking in the
beautiful Costa Rican coast along the way.
020 7840 7887
biking@macmillan.org.uk
www.macmillan.org.uk/centralamerica

April
25 April 2010
Virgin London Marathon
Be part of one of the world’s most
famous road races by running
26.2 miles with Team Macmillan.
020 7840 7878
londonmarathon@macmillan.org.uk
www.macmillan.org.uk/londonmarathon

May
16 May 2010
Macmillan Cancer Support
Etape Caledonia
Join our team in the UK’s only closed-road
cycle event, which covers an 81 mile
course around Pitlochry.
020 7840 7875
biking@macmillan.org.uk
www.macmillan.org.uk/etapecaledonia
You can view and order from our 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 y fron**
(Understanding breast cancer)
MAC11616_welsh
You can now order a Welsh version of Understanding breast cancer. It covers the causes and symptoms, diagnosis, staging and grading, treatments and clinical trials. It also talks about emotional, practical and financial issues. Keep an eye out for Welsh versions of our booklets on early (localised) prostate cancer, bowel cancer, chemotherapy and radiotherapy over the coming months.

**Understanding diet and cancer**
MAC11625
It’s common for cancer, or cancer treatments, to cause problems with eating and digestion. This booklet gives practical advice about handling specific eating difficulties that can occur during cancer treatment. The booklet is divided into four parts: ‘The building-up diet’, ‘Eating problems’, ‘A healthy eating guide’ and ‘Information on alternative diets’.

**Understanding primary bone cancer**
MAC11614
This booklet addresses the questions many people have about the diagnosis and treatment of primary bone cancer. Several types of primary bone cancer can affect children and young adults, and this booklet has been written for parents of children with bone cancer as well as teenagers and adults who have the disease.

Updated resources

**Understanding cancer of the vulva**
MAC11643
Just over 1,000 women in the UK are diagnosed with this rare cancer each year. New diagrams show the surgery options for cancer of the vulva and the booklet outlines types of vulval cancer, causes and risk factors, and treatment available.

**Macmillan recipes**
MAC11668
Written in conjunction with celebrity chef Brian Turner, the recipes in this booklet have been created or chosen specially for people who are living with cancer, or preparing and cooking meals for someone who has cancer. Many of the recipes have been chosen to be simple and quick to prepare.

Other Macmillan resources

**Managing cancer information materials**
MAC4565
This practical guide helps you identify and meet the cancer information needs of people in your local community. It covers identifying information needs, ensuring accessibility, choosing and managing information materials, providing cancer information and developing new resources.