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**WE ARE
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CANCER SUPPORT**

**ALL
TOGETHER
NOW**

Winter 2009

exchange

The newsletter for cancer self help and Cancer Voices

Editorial

As the nights draw in, what better time to cosy up at home with a hot mug of tea and the winter edition of *Exchange*?



In this issue, we put the spotlight on the recent conferences for Cancer Voices and self-help and support groups. We saw so many familiar faces at the events, which took place in Gatwick, Manchester and Aberdeen. A huge thank you to everyone who turned up and shared their experiences. You've helped to make these conferences some of the best ever.

One exciting announcement you might have heard at our conferences was that we recently launched our new website and freephone number – 0808 808 00 00. This number brings together our CancerLine, benefits helpline, cancer information nurse helpline and YouthLine. And our website combines the best elements of Macmillan's old website and Cancerbackup's former website. Together, these new services will ensure that people affected by cancer have easier access to the information and support they need. To read all about them, turn straight to page 4.

Warm regards and seasons greetings

Carol Gibbons
User Support and Involvement
Projects Manager

■ To submit a story, or to let me know your thoughts on *Exchange*, email me at cancervoices@macmillan.org.uk

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Helping people have more good days

People affected by cancer often tell us that having the right information, in the right way, makes a world of difference to them. That's why we were delighted to launch our new website and free phone service this autumn.

Our new phone service – available on **0808 808 00 00** – brings together our CancerLine, benefits helpline, cancer information nurse helpline and YouthLine. We launched it in October along with our new website. This combines all the best elements of Macmillan's old website and Cancerbackup's website.

Together, our new services will give people affected by cancer easier access to the support they need. More choice over the help they receive. And more control over their lives. Simply, it will help them have more good days.

Get in touch

Everyone who reads *Exchange*, and many of the people they know, are affected by cancer. That's why we want you or anyone else who may need our support to get in touch with us. We can help you in so many ways. We can help you apply for benefits you may be entitled to. We can help you talk to your family and friends about your illness. Or we can simply chat and talk about your day.

■ Call us on **0808 808 00 00**, Monday to Friday, 9am–8pm, or visit macmillan.org.uk

Be part of our new campaign

Over recent weeks, you'll have hopefully caught Macmillan's latest advertising campaign on TV, online and in the press. It centres on our new phone service and website and lets people know that a call to **0808 808 00 00** or a visit to macmillan.org.uk can mean the difference between a good day and a bad day.

Already, we have had an exceptional response to the campaign. But now we need to keep spreading the word about our fantastic new services and reach people

who need our help but haven't contacted us yet – something you can help us with.

All we ask is that you head to our Good Day site at macmillan.org.uk/goodday. There, you can learn more about our new services and campaign, and download items such as posters and email signatures that will help you promote our Good Day message. Also, once you've been to the site, please send a link to it to all your group's members or anyone who may need our help. Thank you.

Merry Christmas



One of the easiest ways you can support Macmillan is to come Christmas shopping with us. Simply order your festive goodies from our catalogue and you'll fund services that help people affected by cancer have more good days.

Just call **0844 579 0001** for a free catalogue, or visit macmillan.org.uk/shop to view all of our products. Highlights include a bargain pack of 25 Christmas cards for only £3.95, timeless digital radios and festive scented candles.



What's new?

We're always looking for new ways to improve the cancer information we provide. That's why, as part of our merger with Cancerbackup, we've redesigned all our patient information booklets. At the same time, we're translating some of our most popular titles into Welsh so we can reach more people with the information they need.

High-quality information

Our patient information booklets certainly look different, but they still contain the same high-quality information.

The booklets are in four series:

- Living with cancer
- Cancer types
- Tests and treatments
- End of life.

The new designs feature:

- the series title in a coloured bar
- the booklet title in green
- the Macmillan and Cancerbackup logos.



Over 1.4 million Macmillan booklets, leaflets and other resources were ordered for people affected by cancer in 2008.

Welsh translations

We've translated three of our booklets into Welsh – *Understanding breast cancer*, *Understanding chemotherapy* and *Understanding radiotherapy*. We're also translating our booklets on localised prostate cancer and cancer of the colon. These will add to our existing range of resources available in Welsh.

■ **You can order any of our booklets at be.macmillan.org.uk or by calling 0808 808 00 00.**

Blooming brilliant

You might remember that we featured the Thyroid Cancer Support Group in Wales in the autumn 2008 issue of *Exchange*. They had transformed rubble and weeds into a scenic garden full of life outside the isolation rooms of the Velindre Cancer Centre in Cardiff.

Well, we're delighted to announce that the group recently won first place in the Cardiff in Bloom category for restricted access gardens. Fantastic recognition of all of the hard work that went into the project and the difference the garden will make to people undergoing radioactive treatment.

■ **Have you or your group helped to improve somewhere people receive treatment? Or have you transformed the place where you meet? Let us know at cancervoices@macmillan.org.uk**

Making our mark

The Macmillan Quality Environment Mark is the first-ever scheme that specifically assesses how well physical environments such as chemotherapy units provide support and care to people affected by cancer.

Macmillan has developed it in partnership with the Department of Health and also involved Cancer Voices in shaping a key element of it. Here, one of those Cancer Voices, Rita Hewitt, talks about her input and why the scheme is so important.

'The room I was in when I was told I had cancer was about six-foot by seven-foot, had a window in the corner of it with the blinds shut, and there was a just a hard chair to sit on. Then, after being told the news, I had to walk back through the reception I'd sat in earlier

and left to head home. It was appalling.

Helped create criteria
'What the quality mark will help to ensure is that far fewer people experience what I experienced. That's because people like me have helped to create the criteria that places must meet if they are to be awarded the mark, which means they're going to have to tick quite a few boxes.

In good hands here
'What's also really super about the scheme is that if a place fails to meet

'What the quality mark will help to ensure is that far fewer people experience what I experienced.'

Rita Hewitt

the standards, Macmillan will help it to reach them. Then, once a building is awarded the mark, they can display it, which I think will be really reassuring to people. They'll see it and think, "I'm getting the best possible treatment at this hospital."

■ **The Macmillan Quality Environment Mark launches in January. If you would like to be a member of the team that assesses cancer environments, head to macmillan.org.uk/opportunities for more information.**



Fuelling the campaign

It's that time of year again when there is a chill in the air and you instinctively reach for the thermostat to turn up the heating. However, for many people with cancer this simply isn't an option because they fear they won't be able to pay their fuel bills.

Our research shows that this winter people with cancer are twice as likely as the general population to face fuel poverty (spending over 10% of their household income on energy bills). At Macmillan, we think that this is totally unacceptable. That's why we've stepped up our fuel poverty campaign

and are calling on the government to extend the Winter Fuel Payment to people with cancer in need. It's simply not fair that everyone over 60 receives a payment of between £125 or £400 to help pay their fuel bills, but if you are under 60, have cancer and are in fuel poverty, you receive no Winter Fuel Payment at all.

'My fuel bill last winter was £700. Now I've taken to wearing long johns, two pairs of trousers, a thermal vest, two jumpers and a bobble hat.'

George, 59, Sussex

Help us secure the Winter Fuel Payment for people with cancer in need

Simply head to macmillan.org.uk/fuelpoverty and email your MP about this issue by following three easy steps. If everyone does this, we'll be able to highlight how important this issue really is and put pressure on the government to act.

Yearly roundup

Macmillan's Campaigns team would like to say a big thank you to all *Exchange* readers for their support in 2009 – your stories, online actions and enthusiasm have really helped to drive our campaigns.



Our **sex, relationships and cancer campaign** was launched this year to raise awareness of how cancer can affect sexual relationships and to get health professionals talking to patients about this issue. So far it has been a great success: 45,000 people have watched our video to promote the campaign; the campaign has received lots of media coverage; and many primary care trusts have told us that they are improving the support they provide to people with cancer whose sexual relationships may have been affected by their illness.

Our ongoing campaign to secure **free hospital car parking** for people with cancer in England is still going strong. A number of hospitals have contacted us to say that they are increasing their efforts to tell people about the concessions they're entitled to, something our campaign calls for.

Looking ahead, we're researching how accessible, available and suitable **wigs, prostheses and lymphoedema sleeves are for black and minority ethnic groups**. If you or someone you know have found that they are not, please tell us your story by emailing campaigns@macmillan.org.uk

■ **For more information on all of our campaigns, and to sign up to become an e-campaigner, please go to macmillan.org.uk/campaigns**

We take action

Many of you have told us that our 'We take action' conference was one of the best Cancer Voices events we've ever organised. So, what was the secret of its success?

Over 250 people attended our two-day conference this October. As ever, it was a great chance for Cancer Voices to get more involved in our work. In response to last year's feedback, we also provided more opportunities for networking. Delegates particularly enjoyed the new welcome group, and a drinks reception on Friday night which featured toe-tapping live jazz.

When it came to workshops, participants were spoilt for choice. There were interactive sessions on challenging inequalities in cancer care, overcoming barriers to financial support, developing communication skills and more besides.

Cancer Voice Jenny Walton did a fantastic job as the conference chair. She had us hanging on her every word when she spoke about the changes she's seen in cancer care over the years. We think Jenny said it all when she announced, 'Now it has improved drastically. And it's down to people like yourselves.'

So, what are our next steps? In 2010, we'll publish a corporate strategy that will be informed by the views of those who attended our conference. Just watch this space for more information.

We'd definitely say that the secret of the event's success was all the Cancer Voices who attended. Thank you for helping to make it extra special.

'A great informative two days – I felt truly inspired and eager to get more involved.'

Conference delegate

We group together

Cancer self-help and support group conferences are a great chance for people to come together, share experiences and gain support. Little wonder, then, that hundreds of you flocked to the conferences that took place in Manchester and Aberdeen this year.

Two hundred and sixty people attended the National Conference of Cancer Self-help Groups and approximately 130 attended the Scottish Conference of Cancer Support Groups. But were they a hit? You bet.

Delegates could choose from a fantastic range of workshops that were designed to help them manage the symptoms and side effects of treatment, and develop practical skills and knowledge to support others affected by cancer. They also heard about advancements in cancer research and how to get involved in improving cancer care.

Despite the busy agenda, there was still plenty of time to unwind. There was evening entertainment of music and dancing at both

conferences and, in Aberdeen, a drumming performance by 100 delegates ended the event on a truly upbeat note.

We look forward to seeing you at the conferences again next year.

'The conference was a tremendous forum for cancer patients, carers and health professionals. It was an inspirational event and I went away feeling that there is life and hope after a diagnosis and treatment of cancer.'

Manchester conference delegate

In memory

We are sad to announce the death of Barry Stables, Treasurer of the National Conference of Cancer Self-help Groups.

Barry was a gentle man who helped make the conference one of the most important fixtures in the calendar for people affected by cancer in the UK. He was at the 25th conference in Manchester when he died.

Here at Macmillan, we will never forget Barry's hard work and dedication. Our thoughts and sincere condolences are with his family and friends in Scarborough.

Ciarán Devane, Macmillan Chief Executive



A tale of two groups

How do you increase your group's membership from a handful to over 100? How do you keep your members enthused and recruit new ones after your group's been going for many years? Here, the recent histories of two very different groups help to answer these questions.

The rising star

'Back in December 2005, it was a urology cancer nurse specialist and six patients who got together and formed The North Staffs Prostate Cancer Support Group,' reveals Ron Hillman, the group's fundraising and awareness manager. 'Today we have over 160 members.'

'Foremost, this has been down to a dedicated committee and investing in the right equipment. Printers and laptops have been invaluable in helping us promote ourselves, and our PA system is essential for meetings.'

'Of course, you do need the money to fund all of this, so we've also concentrated on fundraising and asking local businesses and the council for support and donations. Finally, raising awareness plays a massive part in growing your group. We've distributed leaflets at Port Vale FC, outside supermarkets, and we've got close links with hospitals and other voluntary groups. You need to get yourself noticed.'

The rejuvenated veteran

'Cancer Action Rotherham [formerly Rotherham Cancer Service Users Forum] was one of the first user involvement groups and has been in existence for 14 years,' says a proud Shirley Harvey, the group's chair. 'As the demand for user involvement has increased so has the need to maintain the group's momentum and sustainability.'

'That's why we decided to take stock of what we were doing and consider how we could be more successful in achieving our aims. To do this, we invited an outside facilitator to help us as we felt she would be able to take a more objective view.'

'We decided to take stock of what we were doing and consider how we could be more successful.'

Shirley Harvey

'What came out of this is that we needed to raise awareness of the group's aim to influence the development of services and that we're not a support group. So now we've changed our name, redefined our identity and we're promoting ourselves around hospitals, GP surgeries, support groups and to clinical professionals.'

Three top tips for groups

- Keep revisiting the original aims and objectives of your group and don't be afraid to change them.
- Have a treasurer and make finance an agenda item in each meeting.
- Plan any communication – define your target audience and what you want them to do.

■ For more top tips, visit be.macmillan.org.uk or call 0808 808 00 00 and order our good practice resources for cancer support groups.

Be inspired. be.Macmillan

However you get involved with Macmillan, there's lots of help available on our revamped be.Macmillan website.

be.macmillan.org.uk has everything you need to promote and support your activities. For those affected by cancer, all our cancer information is free to order, including booklets and audio CDs. For self-help and support groups, there are Macmillan posters and flyers to promote your activities. Plus we also have hundreds of posters you can personalise for your own fundraising events and details of all the T-shirts, banners and other merchandise available from your local fundraising office. Finally there are promotional posters and other resources that can be downloaded or ordered to help you spread the word about our work.

Search away

One of the best things about the revamped be.macmillan is our vastly improved search engine. Simply type in a word like 'Christmas' and all our Christmassy items will pop up, including our 2009 Christmas catalogue. You can do the same to search for anything from information on specific cancers to ways to say 'thank you.'

■ **Inspired? Then visit be.macmillan.org.uk today and see what it can do for you. And if you have any questions, simply ask your local Macmillan contact or call 020 7840 4921. We'll be happy to help.**



DISCOVER
WHAT
BE.MACMILLAN
HAS TO
OFFER
YOU

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We rally round

Dave Phillips, Patient Advocate of the Gut Digestive Tract Cancer Support Group, had a few nerves when he helped to organise the group's first rally in June. But he needn't have worried.

The event, which brought together more than 60 patients, clinicians, volunteers and carers from Coventry and Warwickshire, was a resounding success.

'Finding a venue was one of the main challenges for the group,' says Dave, 'especially because we were operating on a shoestring. But Macmillan's Marilyn Meade-Brown [community network development coordinator] offered helpful advice which we followed and things got off the ground.'

A laughter workshop

The rally was dedicated to Becky Kingston, a specialist nurse who

helped to found the support group and who has since sadly died from breast cancer. In the morning, consultants Dr Sheldon Cooper and Dr Ling Wong gave a lecture on cancer research. This was followed by a talk from Marilyn Meade-Brown on how Macmillan can work with support groups, and finally there was a presentation by the Oesophageal Patients Association. After lunch, delegates enjoyed an informative laughter workshop with Matt Hudson, a neuro-linguistic programming trainer.

Just go for it

Looking back at the day, Dave says, 'It gave the group the chance to say

what we wanted to say and the professionals the opportunity to share some useful knowledge. It was a good balance – with the laughter workshop being an ideal finish to the rally.'

Asked if the end result justified the pre-rally jitters, Dave adds, 'It was definitely worth it. I'd say to any group thinking about organising a similar event, "Just go for it!"'

■ **If your group would like to organise a rally or similar event, please speak to your local Macmillan community network development coordinator for advice. See back page for details.**



A big benefit

Filling out benefits forms can be a bewildering experience. Going to meet a benefits adviser can be extremely daunting. That's why Macmillan has launched an online benefits guide this autumn that's been tested and shaped by people affected by cancer so these problems can be overcome.

'The online guide is interactive and easy to use, educates people about the benefits system in a really simplistic way and helps to prepare them before they speak with benefits advisers in person or over the phone', says Neal Southwick.

They saw things we couldn't see
Asked about the input people affected by cancer had in shaping the guide, Neal adds, 'Their comments about the feel and look of the guide and the content that's on it were so helpful. 'What they picked out were things that me, IT developers and benefits advisers just couldn't see. For example, they told us when questions weren't explicit enough,

that some areas weren't easy to navigate and, for the most part, the male-voiced narrator was preferable to the female one.

A big thank you
'Overall, I'm really happy with the guide and what it will offer. So a big thank you to everyone who helped to create the finished product.'

■ **You can visit the online benefits guide at macmillan.org.uk/financial-support. Or if you'd like to speak to someone about the benefits you may be entitled to, or find out about local benefits services in your area, call 0808 808 00 00.**

Grants for groups

When you're running a cancer support group, the costs can mount up fast. Whether you need to pay for refreshments, promotional leaflets or anything else that your group needs, a grant from Macmillan can be a big help. Something that Kim Levan, our new User Support Coordinator, knows all about.

Kim says, 'There are already over 900 cancer self-help and support groups across the UK and this number continues to rise as people identify gaps in support in their area. Whatever their needs, my team is here to support the fantastic work they do.'

'A key part of my job is managing the grants that are available to groups. Right now, I'm reviewing the grants programmes to ensure that more people affected by cancer can access the funding we offer. We've awarded over 154 grants to groups so far this year and applications continue to flood in, so keep them coming.'

Apply today
Applying for a grant is easy. All you need to do is email resources@macmillan.org.uk or call **020 7840 4936** to request an application pack.

- The three grants available to groups are:**
- Start-up grants – you can apply for up to £500 to fund initial set-up costs, such as venue hire and publicity.
 - Developing grants – established groups can apply for up to £3,000 to develop their activities.
 - Training and development costs grants – to cover the costs of attending or hosting training courses, events and conferences.

'We've awarded over 154 grants to groups so far this year and applications continue to flood in, so keep them coming.'
Kim Levan

What could you do with a Macmillan Grant?
Grants we have awarded to groups include:

£160
for publicity materials to attract new group members

£185
for website development software

£275
for a group trip to the seaside

£650
to spend on a quarterly group newsletter

£1,525
to deliver creative writing sessions

£2,443
to hold a networking event within the local community

Knowledge is power

Macmillan offers a range of free workshops and courses to support people affected by cancer so they can rise up to the challenges they face or help other people living with the illness.

The courses and workshops are broadly divided into three categories:

Self management focuses on developing the skills and confidence of participants to help them to help themselves. An example is New Perspectives (formerly known as Living with Cancer), a six-week course available to anyone who has had cancer. This course has been recently revised to specifically address the unique issues associated with cancer, such as the fear of uncertainty.

Supporting others concentrates on developing the knowledge and skills of those supporting people living with cancer, to help them fulfil their responsibilities. Courses range from day workshops that aim to build up personal skills and offer guidance on running self-help and support groups,

to the Open College Network accredited Cancer Support course, a year-long course for those working to support people affected by cancer.

Getting involved courses centre on supporting the work of Cancer Voices and giving training on a range of topics, such as research training, making a

'I gained an enormous amount of knowledge from attending the Listening and responding workshop. I think Macmillan's courses are vital to anyone who wants to get involved with a support group.'

Ron Hillman, North Staffs Prostate Cancer Support Group

difference and charring meetings. The courses aim to better equip participants so they can effectively take part in activities that strive to benefit others at both a local and national level.

Where it all happens
All of the courses take place in a variety of local settings, with some using conference calling or e-learning to reach a wider audience. The courses rely on using the knowledge and experience of the group, and also offer an important opportunity to meet and connect with people with similar issues and concerns.

Improve your knowledge
For up-to-date information about all of the learning opportunities available to people affected by cancer, visit macmillan.org.uk/learnzone. You never know what you might find.

THE
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BEST THINGS IN LIFE ARE FREE

Would you like to learn some tips and techniques to help you improve your quality of life after having cancer? If you would, Macmillan is looking for people to sign up to a free online self-management course called **Cancer – Surviving and Thriving**.

For further information, visit the Learn Zone at macmillan.org.uk/learnzone, enter the 'Members of the public' section and then click on the banner 'Free online cancer course'.

Your community network development coordinators

Contact your Macmillan community network development coordinators to talk about:

- self help and support
- getting involved in improving cancer care through Cancer Voices
- financial help for setting up or developing your group
- training opportunities.

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Things to look out for

December

4 December
Carers Rights Day
www.carersuk.org

Childhood Cancers
Awareness Month
www.clicsargent.org.uk

January 2010

25-31 January
Be loud be clear – Beating Bowel
Cancer Awareness Week
www.beatingbowelcancer.org

Dates for your diary

We are currently finalising
our training dates for 2010.
For information on future courses
call **020 7091 2010** or email
workshops@macmillan.org.uk.



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