

Cancer Matters

Macmillan Cancer Support Parliamentary Update **Winter 2007**



**WE ARE
MACMILLAN.
CANCER SUPPORT**

**GETTING
YOUR
LIFE
BACK**

Cancer Reform Strategy must focus on life after treatment

Due to the success of the first National Cancer Plan, more and more people diagnosed with cancer are living longer. The 10-year relative survival rates for all cancers combined have increased from 24% thirty years ago to 46% now – and this trend is set to increase further over the next decade.

As more people live longer after their initial cancer treatment, a range of new and difficult challenges are becoming evident. People are facing numerous physical, psychological, social, spiritual and financial issues for the rest of their lives.

Macmillan wants the government to start tackling these issues now by announcing a major new 'survivorship' programme as part of the soon-to-be published Cancer Reform Strategy (CRS). The term 'survivorship', from the US, means those people who are living with cancer and its consequences.

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Getting your life back

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‘Coming to terms with living with cancer and not knowing where to go for help. You know your GP is a very busy individual and you feel a burden when you want to know things. Aftercare was virtually non-existent.’

‘My marriage ending, my job ending (I went back to work but couldn’t cope with the pressures), feeling a burden on society and feeling weak in the head for not being able to get on with life. I am a big bloke who used to play rugby and for four years after treatment, not being able to talk to people and spending time crying was and still is unbelievable.’

Among the key challenges we want the survivorship programme to address are:

- **More appropriate and effective post-treatment support programmes**

– the current way in which patients are followed up after their initial treatment is expensive and too heavily focused on assessments that take place in hospital, despite the fact that few recurrences are spotted in this way. Twenty-five percent of people with cancer also feel abandoned by the health system when they leave hospital. We believe there is a need to extend supportive care packages beyond the initial treatment phase so people can manage the long-term consequences of cancer more effectively.

- **Better emotional and psychological support**

– there is now substantial evidence that cancer affects people emotionally and psychologically long after treatment finishes. Over 40% of people with cancer say the emotional aspects of cancer are more difficult to cope with than the practical and physical effects. People need better access to peer support programmes and psychological support to deal with these problems.

- **Helping people to help themselves**

– giving people living with cancer the skills and tools to manage their own care improves their quality of life and reduces their reliance on health and social care services. We want to see people provided with better information and support. We also want them to have more access to Expert Patient Programmes – self-management courses that give people the confidence, skills and knowledge to manage their condition better and be more in control of their lives.

- **Tackling financial hardship**

– far too many people are struggling to make ends meet while dealing with the consequences of cancer. A National Audit Office report found that 77% of cancer patients are not given financial support information at any point during their cancer treatment. This is despite 91% of cancer households suffering a loss of income and/or increased costs as a direct result of cancer. Better access to financial support information and advice is vital.

- **Getting people back to work**

– improvements in policy and practice are needed to help people get back into employment in the most appropriate way as soon as they feel ready. One way to do this might be by improving vocational rehabilitation provided by the NHS.

- **Tackling the side effects of treatment**

– some side effects of cancer treatments can emerge soon after treatment, eg fatigue. Other side effects may not become apparent until some years after initial treatment, but they can still have a debilitating impact. For example, late effects of pelvic radiotherapy can include a change in continence habits, while chemotherapy can affect a person’s capacity to concentrate and process information. Currently, there are no systems in place to ensure the appropriate management of long-term effects of treatment when patients are under the care of GPs. We need to improve how we prevent, minimise and manage these side effects.

A lot of things need to change if people living with cancer are to get the long-term support they need. You can help us by pressing Ministers to support our call for a new survivorship programme as part of the Cancer Reform Strategy.

End the scandal of unaffordable prescriptions



Nearly one in 10 cancer patients aged 55 and under who have to pay prescription charges can't afford them. That's why we're delighted to hear that the Department of Health is about to launch a public consultation to make prescription charges fairer.

We believe the government should follow the example set in Scotland, Wales and Northern Ireland and provide free prescriptions for people with cancer in England. But the government's most urgent priority must be to make sure that no patient has to choose which prescription they can afford from week to week.

We want to see:

- more people on low incomes becoming eligible for free prescriptions
- much more action to raise patients' awareness of Prescription Prepayment Certificates, which limit the amount they have to pay.

You can help us by asking Ministers to use the forthcoming consultation on prescription charges to ensure no cancer patient is unable to afford their prescriptions.

Barbara, a single parent with noble sarcoma, spent at least £1,000 on prescription charges during the first few years of her cancer treatment. When she couldn't afford them any more, she ticked the box on the back of the prescription saying she was entitled to free prescriptions and worked when she had been told by her doctor to rest. No one told her about Prescription Prepayment Certificates.

David, a bowel cancer patient, had to pay £25 a week for prescriptions to treat side effects. He told Macmillan that some weeks he could not afford his prescriptions, which led to his side effects getting worse.

Hospitals still not acting on parking costs



On average, cancer patients travel 53 times to hospital during the course of their treatment, paying out £325 in travel and parking costs.

It is now nearly a year since the government published revised guidance strongly recommending that hospitals provide car parking concessions for patients travelling regularly for treatment.

Macmillan and our supporters have spent the summer urging hospitals to follow the new guidance. This has resulted in some successes, for example the Gateshead NHS Foundation Trust now issues parking permits to patients and visitors entitling them to free car parking. But the reality is that far too many hospitals are continuing to ignore the guidance.

We need your help as we make one

final big push to tackle what is a major issue for people fighting a life-threatening disease.

We would like MPs to write to their local hospital chief executive and ask them if they are following the government's guidance on parking concessions. To help you do this, we have written a draft letter that is available from www.macmillan.org.uk/hospitalparking. Please let us know when you get a response.

And for those MPs who have already written to their hospital, a big thank you. Your help – alongside the campaigning efforts of your constituents – is really helping to make a difference.

Help us shout about our services

Macmillan launched a major awareness campaign recently to tell more people living with cancer about how we can help them. We now need your help to spread the word even further.

We're most famous for our Macmillan nurses but we want your constituents to know that:

- We can help them deal with the financial impact of cancer by providing Macmillan Grants and benefits advice.
- We can answer their questions about cancer face-to-face at our information centres.
- We can help them find a cancer support group that is local to them.
- We can help them share their feelings and concerns with other people affected by cancer through the Share section of our website.

If your constituents need support dealing with cancer, please tell them to call Macmillan on 08000 898 500 or to visit www.macmillan.org.uk



Contact us

If you have any questions about Macmillan Cancer Support's work, please get in touch with us.

Gus Baldwin

Public Affairs Manager
tel 020 7840 4625
email abaldwin@macmillan.org.uk

Kate Ravenscroft

Public Affairs Officer
tel 020 7840 4946
email kravenscroft@macmillan.org.uk

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