

cancer matters



Parliamentary
Update
Winter 2010

A
CHANCE
TO
TRANSFORM

**WE ARE
MACMILLAN.
CANCER SUPPORT**

The Government has a once-in-a-Parliament opportunity to transform the lives of cancer survivors when it publishes the Cancer Reform Strategy (CRS) refresh.

Andrew Lansley, Health Secretary, is expected to launch the updated Cancer Reform Strategy in the next couple of weeks. The CRS is the strategy for cancer services in England.

Macmillan hopes care plans for cancer survivors will be front and centre in the strategy.

Over a quarter of all MPs supported our call for care plans for cancer survivors during the General Election.

Care plans are the key to help unlock access to vital services that support cancer survivors to get their lives back after a life-threatening illness.

We know that only one in 10 cancer survivors (11%) receives an assessment of their on-going

physical, emotional, social, practical, financial and spiritual needs at the end of initial treatment which is then written up into a care plan.

Care plans enable more patients to self-manage their condition, improve survival rates and quality of life, and reduce avoidable and costly hospital admissions.

‘Only 11% of cancer survivors receive a written care plan.’

Macmillan thinks cancer needs to be included in the long term conditions outcome measure in the new NHS Outcomes Framework and in new proposals for every person with a long term condition to be offered a care plan.

This will encourage Primary Care Trusts and GP consortia to commission new post treatment assessment and care planning services for cancer survivors.

Please ask Andrew Lansley to support care plans in the CRS refresh.

For more information, please visit the *Vote cancer support* section at macmillan.org.uk/parliament

What is a care plan?

A post treatment care plan is a written agreement between the cancer patient and a health professional (and/or social services) about how to manage the patient’s day-to-day care and support their needs after initial cancer treatment ends.

It follows a personalised assessment of the person’s physical, emotional, social, practical, financial and spiritual needs.

Help us improve end of life care

Macmillan is calling on the Government to make sure every person with cancer nearing the end of their life is supported by a community nurse, whenever they need one, so that they can die at home if they so wish.

Macmillan believes access to 24/7 community nursing is the key to helping more people nearing the end of life to die at home.

As such, we warmly welcome the Government's recent commitment to round-the-clock community nursing for terminally ill patients in its Patient Choice consultation.

As well as being better for the patient and their family and loved ones, a joint report by

Healthcare at Home and Dr Foster estimates that delivering end of life services in the home could also save the NHS £160 million.

However, our recent end of life report, *Always There?*, identified that nearly half of Primary Care Trusts (PCTs) are not currently providing this vital service.

To make sure 24/7 community nursing actually happens on the ground, we want the Government to:

- Ensure patients' preferred place of death is recorded and that patients' wishes are met
- Ensure new funding arrangements, developed through the Palliative Care Funding Review, incentivise 24/7 community nursing.

For more information about our campaign and to read *Always There?* visit macmillan.org.uk/parliament



An 'Information Revolution' for cancer patients

Macmillan is calling for every cancer patient to be offered a cancer Information Prescription (IP) by the end of 2012.

Macmillan was very pleased to see IPs mentioned in the Department of Health consultations on the 'Information Revolution' and 'Greater Choice and Control'.

Macmillan research shows that 93% of cancer patients want to be 'very or fairly involved' in decisions about their treatment and care. That's why we are pleased the Government has made '*no decision about me without me*' the central theme of its health reforms.

To make informed decisions, people living with cancer need information about their condition, the different treatment options available to them, and the performance and quality of different health services.

But we also know that many cancer patients aren't getting vital information that could improve their quality of life. For example, 75% of cancer patients aren't given any financial information and 68% feel their emotional needs are not adequately met.

Patients need to know about benefits, return to work, local support groups and much more to feel fully supported throughout their cancer journey.

IPs are an innovative mechanism for ensuring that people affected by cancer get all the high-quality personalised information they need at key points in their cancer journey. They are delivered with face-to-face support from a healthcare professional.

Please ask Paul Burstow, the Minister for Care Services, to guarantee that the 'Information Revolution' will ensure cancer patients are offered an Information Prescription to give them the right information at the right time delivered with the right support.



Fair for rare

The Government's Cancer Drug Fund must focus help on people with rarer cancers.

Drug treatments for people with rarer cancers are often not approved by the National Institute for Health and Clinical Excellence (NICE) because these medicines can have high development costs and are only suitable for small patient populations.

We are delighted that since May the Government has not only announced the creation of a new £200 million Cancer Drug Fund by April 2011, but has also launched an interim £50 million fund available from October to make sure more cancer patients can access treatments straight away.

The Government is now consulting on how the Cancer Drug Fund will be delivered and Macmillan will be responding to say:

- The fund must help people affected by rarer cancers
- It should also be patient-centred and patients must be supported to

make informed decisions about their drug treatment options

- Funding decisions must be made in a timely and transparent way
- The fund must be monitored and audited.

Please write to the Minister of State for Care Services, Paul Burstow, to ask him to make sure the Cancer Drug Fund meets the needs of people with rarer cancers.



Fuel poverty review must help more cancer patients

The independent fuel poverty review announced in the Comprehensive Spending Review must lead to a better deal for vulnerable cancer patients.

Macmillan research shows that cancer patients feel the cold more, spend more time at home and are often on reduced incomes. The cold also affects patients' mental well-being and can make pain worse.

Yet far too many cancer patients are currently excluded from the financial help available – for example, 93% of people with cancer in fuel poverty are not on a social tariff and around a quarter do not qualify for the Winter Fuel Payment, which is being cut anyway.

Macmillan has been campaigning for more help for three groups of particularly vulnerable cancer patients – the terminally ill, those who have had treatment in the last year and those on particular benefits.

Latest research shows that among these groups up to half are currently in fuel poverty – 47% of cancer patients in receipt of housing benefit are in fuel poverty.



Macmillan is also awaiting the launch of the Department of Energy and Climate Change consultation on the new social price support scheme. The scheme, to be funded by energy companies, will replace voluntary social tariffs. We want particularly vulnerable cancer patients to be included in the new scheme.

Ministers have the chance to transform the lives of cancer patients in fuel poverty over the next few months. Please write to Gregory Barker, Fuel Poverty Minister, to show your support.

Government parks plans to remove charges

Britain Against Cancer 2010

14 December, Church House,
Westminster

Macmillan has long argued that all cancer patients should receive free hospital car parking.

Sadly that was not what was recommended when the Government recently published its response to a public consultation on NHS car parking. Naturally we are disappointed with this result.

We know that the current guidance just isn't working. Around 60% of cancer patients still have to pay the full price for parking during their treatment, even though guidance from the Department of Health recommends that hospitals in England offer free or concessionary rates.

However, we are not giving up. We will be focusing our campaign at a local level to see what changes we can make.

If you think hospital parking for cancer patients is an issue in your constituency please visit **macmillan.org.uk/parking**

The All Party Parliamentary Group on Cancer, supported by Macmillan, is bringing together MPs, Ministers, patients and members of the cancer community for the annual Britain Against Cancer conference on 14 December.

Conference delegates will hear from the key decision makers behind the Government's health reforms – including Secretary of State for Health, Andrew Lansley – about how proposed changes will impact upon cancer services, care and research.

MPs and Peers can register for free for this year's Britain Against Cancer by visiting **appg-cancer.org.uk**

Work, cancer and the Equality Act 2010

Are employers in your constituency getting it right?



Please support Macmillan's Working through cancer campaign to ensure that more cancer survivors can remain in, or return to, work if they so wish.

We've created an online guide on how the Equality Act affects

constituents and employers in your area. We want you to write to local employers to make sure they know their responsibilities under the Act.

Many people diagnosed with cancer want to remain in work and a supportive employer can be vital. However, we know that less than half of employers are aware that cancer was included in the Disability Discrimination Act (now superseded by the Equality Act).

Macmillan has developed a package of support which helps employers to support any staff affected by cancer.

Visit macmillan.org.uk/parliament to promote this campaign.

Contact us

If you have any questions about Macmillan Cancer Support's campaigns, please visit macmillan.org.uk/parliament or follow us on twitter @[macmillanPA](https://twitter.com/macmillanPA)

If any of your constituents have been affected by cancer and need support, please tell them to call our helpline on **0808 808 0000** or visit macmillan.org.uk

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