

# Macmillan Cancer Support's Manifesto Calls



Briefing for: **People with an interest in better cancer care**  
Purpose: **To outline Macmillan's manifesto calls**  
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## Why is Macmillan Cancer Support worth listening to?

- We represent the two million people living with and after cancer in the UK today.
- Cancer is regularly voted the public's most important health priority.
- In the past decade Macmillan has invested £320 million (in today's values) in the NHS and we plan to invest a similar amount over the next 10 years.
- We have over 4,700 Macmillan nurses and other specialist professionals working in the health and social care system across the UK today.
- Macmillan has a track record of championing health innovations which dramatically improve patient experience, outcomes and value for money.
- We warmly welcome the growing focus on better patient centred care and service transformation and are keen to actively support this agenda.
- We are confident that two of our three cancer care priorities will save the NHS significant amounts of money and that all three will dramatically improve the lives of cancer patients.

## What are Macmillan's top three health and social care priorities?

1. **Survivorship** – Macmillan would like the next Government to demonstrate a clear commitment to the cancer survivorship agenda over the next decade based on the principles of post-treatment care management and appropriate support to get people back to work.
2. **Equalities** – Macmillan would like the next Government to improve access to drug treatments for people with rarer cancers by reforming NICE.
3. **End of Life** – Macmillan would like the next Government to ensure that people with cancer nearing the end of their life have 24/7 access to community nursing.

### 1. Supporting the survivorship agenda

Macmillan would like the next Government to demonstrate a clear commitment to the cancer survivorship agenda over the next decade based on the principles of post-treatment care management and appropriate support to get people back to work.

In the UK there are already two million people living with or after cancer and this figure will increase by 3.2% per year. This is placing an ever growing demand on the capacity of the NHS 'follow up' system with an associated spiralling cost.

## The 'follow up' system is no longer fit for purpose

Cancer patients who survive initial treatment currently enter what is called the 'follow up' system. This involves regular surveillance to check that the cancer has not returned. Macmillan believes this system is costly, ineffective and fails to meet the needs of cancer survivors:

- **Costly and ineffective** – follow-up fails to spot recurrence. One study found that between 70 and 75% of breast cancer patient recurrences are detected *between* routine hospital appointments.
- **Failing cancer survivors** – approximately one in five people living after treatment for cancer will develop significant long term emotional, psychological and physical problems that seriously affect their quality of life (e.g. depression, incontinence, psychosexual problems, heart disease, new cancers). There are few, if any, NHS services specifically for cancer survivors and little coordination with generic services for people with other long term conditions. As a result, many patients do not receive the help needed to effectively manage their condition which both significantly affects their quality of life but also leads to unnecessary illness escalation and admittance to A&E.

## The benefits of the survivorship model

Since 2007, Macmillan has been championing the 'cancer survivorship agenda' by co-chairing and co-funding the National Cancer Survivorship Initiative (NCSI) with the Department of Health. The survivorship agenda or 'aftercare' model is about improving the quality of care provided for cancer survivors to help them get their lives back on track after a life-threatening disease. It also acts as an effective prevention and early detection model of care management. It is based on the principles of:

- Post-treatment assessment from an appropriately trained professional, such as a specialist doctor or nurse, to identify likely ongoing or long-term consequences of cancer and its treatment
- Care planning and proactive management of these identified consequences to reduce their likelihood or escalation

Following initial treatment, a cancer patient would be assessed and assigned into one of three categories (see below) – rather than everyone going through the same system as happens now. A care plan would then be devised with the aim of minimising risks and supporting the patient to manage any ongoing conditions.

Level of need	Estimated number of patients involved
<b>Level 1</b> – supported self-care with quick access back into the system if and when needed to improve early detection	c75%
<b>Level 2</b> – high risk patients involving proactive care management by the Multi Disciplinary Team	c20%

<b>Level 3</b> – highly complex patients requiring case management by an assigned key worker (often a CNS) actively managing and joining up care for the patient	c5%
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There is growing evidence, based on the findings of similar models for other long term conditions, that as well as significantly improving the quality of life of cancer survivors, such a model of managed care would lead to a reduction in consultations and admission rates and hence significant cost savings to the NHS.

A recent Macmillan poll of the general public also found that 94% would expect a full assessment of their on-going needs after the end of treatment, 92% would expect to discuss potential side-effects and how to manage them, 91% would expect to have a named contact and 89% would expect a personalised care plan.

The NCSI is undertaking a number of pilots to provide greater evidence of the benefits to both cancer survivors and to NHS budgets. The results are expected by November 2010.

### **The importance of getting cancer patients back to work**

As well as improving the quality of life of cancer survivors and reducing the costs to the NHS and social services, survivorship services also provide a significant benefit to 'UK plc'.

Approximately 90,000 people of working age are diagnosed with cancer each year in the UK and there are 774,000 people of working age in the UK who have had a cancer diagnosis.

International evidence suggests around 60% of people diagnosed with cancer return to work. Return to work support for cancer patients is currently very limited across the UK for the simple reason that cancer patients didn't used to go back to work after treatment – instead they died. For example, we know that less than half of cancer patients are advised by their clinicians about the likely impact of cancer treatment on their working lives. As a result, many struggle to cope and currently 40,000 receive incapacity benefits.

By 'return to work support' we mean a range of services from basic information about appropriate workplace adjustments through to case managed support from a specialist. This specialist might help the employee to produce a return to work plan or negotiate flexible working or provide occupational therapy, physiotherapy, or counselling.

Economic analysis by Monitor for Macmillan has concluded that a 4-6% increase in the numbers of patients getting back to, and staying in, work after cancer each year would result in an overall net value to the UK economy (saved benefits and income tax paid etc) of £102-£113 million per year.

The NCSI will be running a number of pilots in 2010 to develop a best practice model for return to work support for cancer patients with the results expected by the middle of 2011.

## **2. Equalities – fairer access to drugs for people with rarer cancers**

Macmillan would like the next Government to provide fairer access to drugs for people with rarer cancers. In order to do this we would like to see:

- NICE adopt a more flexible approach to evaluating new cancer drugs which takes into account the severity of the disease and whether there are alternative treatments available
- New drugs for very rare cancers, which affect 1 in 50,000 people, should no longer be appraised by NICE but instead be funded and evaluated through the National Specialised Commissioning Group
- A new process to fund and evaluate drugs for extremely rare cancers where there are currently no licensed treatments available.

### **Why does access to rarer drug treatments on the NHS need to improve?**

The UK uses significantly fewer new cancer drugs than other European countries and is slower to provide access through the NHS. English patients are losing out on what are deemed 'gold standard' treatments throughout the rest of Europe.

The challenge is that drug treatments for rarer cancers have high development costs but are only suitable for small patient populations. This means they are expensive in comparison to drugs for more common cancers and have difficulty passing the current 'cost effectiveness' appraisal process used by NICE.

NICE has itself acknowledged that the standard NICE appraisal process is not suitable for evaluating drugs for a number of rarer cancers. For example, it has estimated it would need to use a cost-effectiveness threshold up to ten times the current limit to allow kidney drugs like Temsirolimus, which is only effective for around 465 people in the UK, to be paid for on the NHS.

The debate on 'top-ups' last year led to the creation of a new set of guidelines for end of life drugs. However, in practice, recent NICE decisions to reject the use of Bevacizumab and Sorafenib, as well as Temsirolimus, for the treatment of kidney cancer, and Sorafenib for liver cancer, suggest it is unlikely to enable many new and innovative treatments to be approved.

For people affected by extremely rare cancers the situation is often even worse because the majority of drugs they receive are not licensed for their particular condition. NICE is not allowed to appraise the use of drugs outside their licensed indication, which means that national guidance is unlikely to ever be developed.

Despite the complicated nature of the NICE appraisal process, for Macmillan the issue is simple. Cancer patients do not choose which cancer they get. The current five-year survival rate for women diagnosed with kidney cancer is half that for breast cancer (43% in comparison to 79%). We feel passionately that the NHS has a

choice about whether to treat people with different cancers equitably to ensure more people live with and beyond rarer cancers. Approving more drug treatments is part of the solution to improving cancer survival rates among people with rarer cancers.

### **How should the current process be changed?**

In the short term we would like to see greater flexibility in the application of the End of Life guidelines created in response to the debate on top-ups last year (the 'Richards Review'). In the longer term we see an argument for a move to a new system of Value Based Pricing which uses definitions of value that better reflect the overall benefits to patients and society of these new drugs.

We would also like to see new drugs for very rare cancers evaluated and funded by the National Specialised Commissioning Group instead of going through NICE. The use of this process would mean that drugs could be commissioned based on their overall affordability rather than just their individual cost-effectiveness. It would also reduce the funding burden on individual Primary Care Trusts by allowing for pooled budgets. Key issues that would need to be considered are how to ensure nationwide access and how to moderate the price of drugs.

We would also like to see a new national process and fund for the commissioning of 'near label' drugs for extremely rare cancers to deliver nationwide access for all who need them. This process should be underpinned by a national audit to build up evidence on the effectiveness of these treatments.

### **3. End of Life – helping people to die at home**

Macmillan would like the next Government to ensure that people with cancer nearing the end of their life have 24/7 access to community nursing.

#### **People want to die at home but most of the time they don't**

Half a million people die in England each year. Over a quarter (27%) of these deaths are caused by cancer. The government predicts that the number of deaths will continue to fall until 2012 and will then steadily increase to 590,000 by 2030. If current trends continue, less than one in ten people will die at home by 2030 and institutional deaths will increase by over 20%.

Yet most people would prefer to die at home. A recent poll of the general public found that 54% would want a sick relative to be cared for at home, 22% in a hospice, 14% in a hospital and 7% in a care home (4% didn't know).

Despite this, in 2009 the National Association for End of Life Care 'national snapshot of end of life care in primary care' found that only 56% of those on an end of life care register had a preferred place of care recorded. Of those on the register who had a preferred place recorded, only 42% had died in their preferred place of care. Almost no one said they would prefer to die in hospital but about one third of those on a register had died in hospital.

In practice, most cancer patients die in hospitals (48%) or hospices (18%) and less than a quarter (24%) die at home. For many people, place of death is by default

rather than by choice, due to a lack of planning or service provision, problems with symptom control or carer support. Inadequacies in district nursing and home help provision discourage relatives from caring for dying patients.

There is growing evidence that this lack of support at home also leads to unnecessary emergency hospital admissions and prolonged stays.

### **The importance of 24/7 nursing care**

Macmillan believes that people with cancer nearing the end of their life require access to 24/7 coordinated, community nursing. This is strongly supported by the general public – in a recent poll, 89% said the government should provide access to support day and night so people with cancer can die at home.

By community nursing we mean a person or team of people who are able to:

- Assess the patient
- Provide medical support which would otherwise have to be provided within hospital – for example taking a blood sample or managing a syringe driver
- Manage symptoms
- Provide supportive care
- Prescribe medication
- Stay in the house for extended periods of time during the day and night
- Be linked to the primary care team
- Provide emotional support

In the past this type of support has been provided by a district nurse but increasingly this role is played by a team of people with varied skills (including specialist palliative nurses and health care assistants).

Both the NICE Improving Supportive and Palliative Care for Adults with Cancer Guidance (2004) and the End of Life Care Strategy (2008) have stressed the need for 24/7 nursing and personal care support services.

The King's Fund also recommended that commissioners and services "ensure timely access to care 24 hours a day" in its January 2010 report, *Delivering better care at end of life*, which followed a summit held with key experts in the field.

However, a National Audit Office (NAO) census of PCTs in November 2008 found that only half (53.2%) provided access to district nursing 24/7 at home for all patients, 17.7% provided this for some patients and nearly a third (29.1%) for no patients.

### **The excessive cost of wasted NHS bed days**

As well as contrasting with the majority of patients' wishes, institutional deaths are far more expensive than home deaths. If the trend for fewer home deaths continues it will prove extremely costly for the NHS.

The NAO has estimated that the average cost of keeping someone in hospital for their last year of life is £222 per day. In comparison the average cost of home/community care per day is £28.

An NAO analysis of patient records in one PCT found that 40% of patients who died in hospital over a one-month period did not have medical needs which required them to be treated in hospital. Nearly a quarter had been in hospital for over a month.

The NAO concluded that £104 million could be used to meet people's preferences for place of care by reducing emergency hospital admissions for cancer patients by ten per cent and the average length of stay following admission by three days.

This evidence is supported by a recent joint report by Healthcare at Home and Dr Foster, Hospital Care at Home, which estimated £160 million savings for the NHS if end of life care was delivered in the home.

#### **About Macmillan Cancer Support**

Macmillan's role is to improve the lives of people affected by cancer (cancer patients, cancer survivors and their families, friends and carers).

You can find out more about what we do at [www.macmillan.org.uk](http://www.macmillan.org.uk)