

# What can MPs do to improve cancer care in the new NHS?



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MACMILLAN.  
CANCER SUPPORT**

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# A GROWING PROBLEM

**By 2020 almost half of the people living in the UK will be diagnosed with cancer during their lifetime.**

This huge number of people poses a significant challenge to an NHS with scarce resources and tightening budgets. It also means, as an MP, you are more likely to come into contact with constituents living with cancer who need the right information and support at such a difficult time in their life.

We have developed this guide to help you understand the four stages of the 'cancer journey' these people are likely to go through (diagnosis, treatment, end of life and survivorship) and the bodies in the new NHS that play an important role during each stage.

The guide also explains what you can do to help make sure people diagnosed with cancer in your constituency have the best chance of survival and receive high-quality care.

A woman with long dark hair, wearing a black dress and dark tights, is sitting in a light-colored wooden chair with a light blue cushion. She is holding an open magazine or newspaper, looking down at it. The background shows other similar chairs in a row.

'I did have symptoms, but I wasn't aware of them at the time. Unfortunately, I didn't think these symptoms were important enough to bother the doctor with, so I didn't mention them.'

**A person diagnosed with late ovarian cancer**

# DIAGNOSIS

## Stage one of the cancer journey

People often go to their GP after showing signs and symptoms that may be caused by cancer. The GP then refers a patient for tests to find out more. Screening aims to detect cancer at an early stage or find cells that could become cancerous if not treated.

### Who is responsible for early cancer diagnosis?

Early diagnosis often relies upon people being aware of the signs and symptoms of cancer. To promote early diagnosis, **Public Health England**, working in partnership with the **Department of Health** and **NHS England**, runs national campaigns such as Be Clear on Cancer. These aim to raise the public's awareness of cancer symptoms.<sup>1</sup>

Simultaneously, **local authorities** are responsible for promoting health in the community by providing information, services and facilities.<sup>2</sup> This could include leaflets about local cancer support groups, stop smoking services or free dental check-ups for mouth cancer.

Local authorities are also members of **Health and Wellbeing Boards**, which assess local priorities and develop strategies for health, including how to increase the number of early cancer diagnoses.<sup>3</sup>

Services that invite people to be screened for cancer are vital to making sure cancer is caught early. NHS England selects and purchases (i.e. commissions) the screening services that are used. Public Health England coordinates screening programmes for breast, cervical and bowel cancer and local authorities support and review its delivery.

## How are bodies held to account for improving early cancer diagnosis and survival rates?

Early diagnosis is essential to improving cancer survival rates. NHS England is held to account by the Department of Health to improve one and five-year survival rates for all cancers (through the 2013/14 NHS Outcomes Framework).

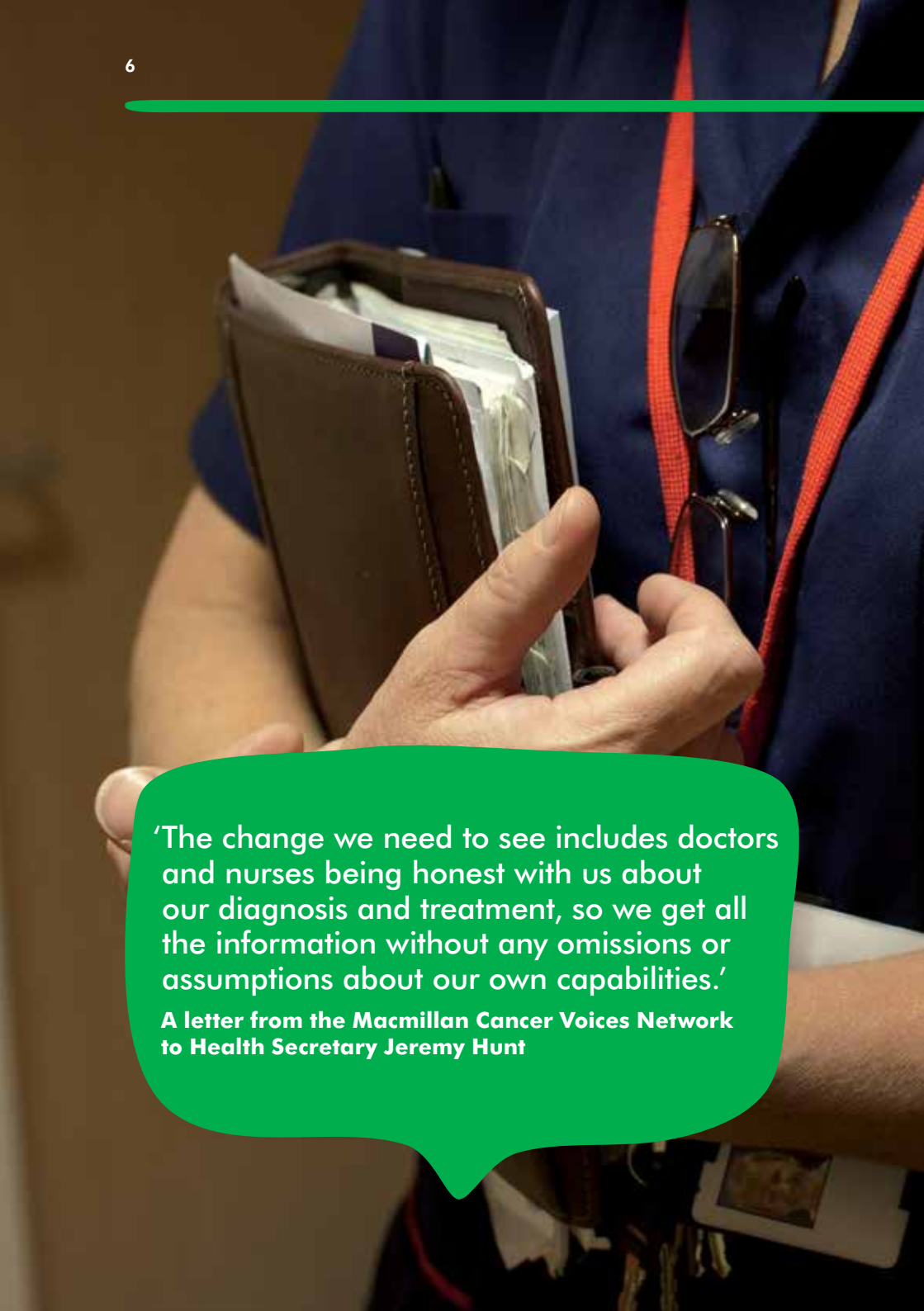
Similarly, **Clinical Commissioning Groups (CCGs)** are accountable to NHS England for improving survival rates locally (through the CCG Outcomes Indicator Set 2013/14).

**Macmillan is calling for NHS England and CCGs to be held accountable for improving survival rates for all cancers and delivering better outcomes for people living with cancer. Further clarity is needed about how NHS England will ensure CCGs make these improvements and how they will deal with any underperforming CCGs.**



### How can MPs help to increase early cancer diagnosis rates?

- You can call on NHS England to hold Clinical Commissioning Groups to account for collecting and using one and five-year cancer survival rate data for all cancers to improve early diagnosis and overall survival rates in their local area.
- You can urge local Health and Wellbeing Boards to prioritise cancer awareness and screening in their joint strategic needs assessments and joint health and wellbeing strategies.



'The change we need to see includes doctors and nurses being honest with us about our diagnosis and treatment, so we get all the information without any omissions or assumptions about our own capabilities.'

**A letter from the Macmillan Cancer Voices Network to Health Secretary Jeremy Hunt**



# TREATMENT

## Stage two of the cancer journey

Cancer can be treated in different ways depending on its type, where it is located in the body and whether it has spread. Treatments for cancer include chemotherapy, radiotherapy, surgery, hormonal therapies and biological therapies. The treatment a person receives will depend on their own individual circumstances.

## Who is responsible for commissioning cancer treatment services?

**NHS England** is responsible for the procurement and administration of specialised services such as chemotherapy, radiotherapy, services for rarer cancers and specialist surgery.

Simultaneously, **CCGs** commission the majority of treatments for cancer, which includes non-specialised surgery and hormone therapy.

NHS England and CCGs are supported and advised by **Clinical Senates**<sup>4</sup> and **Strategic Clinical Networks** that provide advice on commissioning and help to address variations of care.

**Macmillan is calling for Cancer Strategic Clinical Networks to have a key role at the heart of the new NHS, driving forward improvements in the quality of cancer services and outcomes.**

**Macmillan wants NHS England and CCGs to deliver a better cancer patient experience and work together in their commissioning roles to provide cancer patients with a seamless service.**




### **How can MPs help make sure their constituents receive effective cancer treatment?**

Macmillan is concerned that there is a risk that the split in commissioning of cancer services could potentially lead to poorer care being delivered to patients, if the parts of a person's care journey are not effectively joined up.

To change this:

- ➔ You can urge NHS England to promote effective integration of specialised and non-specialised cancer services.
- ➔ You can call on NHS England to provide Strategic Clinical Networks with adequate resources to help them be as effective as possible.



'After being discharged from hospital following my operation, I felt deserted. There was no check-up to see how my wound was healing or how I was coping psychologically with my diagnosis. My keyworker has not contacted me at all, other than to return my calls, so I have felt deserted by her too.'

**Person treated for breast cancer**

# SURVIVORSHIP

## Stage three of the cancer journey

Encouragingly, an increasing number of people are surviving cancer. However, this is producing a large population of people living for years with debilitating health conditions caused by their cancer or treatment. Currently, many of these people do not receive the support they need to have a fulfilling and active life.

## Who is responsible for supporting cancer survivors?

**NHS England** is held accountable by the Government via the Secretary of State for Health, for helping people to recover from episodes of ill health, and manage their long term conditions, (which can include either ongoing cancer or conditions brought on by their cancer or treatment) through the NHS Outcomes Framework. It is responsible for commissioning primary care, specialist cancer services, including long-term follow up and survivorship, such as for children and young people.

**CCGs** are also responsible for commissioning care pathways for cancer survivors, which include help to prepare people for the transition at the end of treatment, and whatever support may be needed afterwards, such as routine monitoring.


The **National Cancer Survivorship Initiative**, a partnership between NHS England and Macmillan, aims to ensure that people living with and beyond cancer get the care and support they need to lead as healthy and active a life as possible, for as long as possible.

Macmillan is pushing for more effective back to work support for people with cancer who want to stay in or return to work. This includes vocational rehabilitation services. We also believe more could be done to help people affected by cancer who are unable to work, claim the benefits they're entitled to. They must also be protected from future cuts to the welfare budget.



### What can MPs do to make sure cancer survivors receive the support they need?

- ➔ You can urge NHS England to continue supporting the National Cancer Survivorship Initiative call for the 'Recovery Package': routine assessment and care planning for all cancer patients, a treatment summary at the end of each treatment from hospital to the GP and patient, a patient education event at the end of treatment, and a cancer care review with their GP.
- ➔ You can ask CCGs and local authority public health teams, which are tasked with assessing the needs of the population, to take into account the long-term consequences of cancer and its treatment, and particularly to promote suitable opportunities for physical activity and healthy lifestyle for cancer survivors.



'My Dad wasn't given the option to think about where he wanted to be when he died. We didn't know that it was possible to get social care support. If someone had talked through the options with us, we would have asked for more help. We all would have liked for him to have died at home or in a hospice. They were the two places he felt safe and looked after.'

**Lacey, whose dad died of cancer**



# PALLIATIVE AND END OF LIFE CARE

## Stage four of the cancer journey

Palliative care focuses on relieving and preventing the suffering of patients. End of life care generally focuses on the care provided to patients who are in the last year of life. The patient's needs, and those of their family and carers, often increase as the person moves closer to death.

## Who is responsible for palliative and end of life care?

**NHS England** is responsible for commissioning specialist palliative care services and is accountable to the **Department of Health** for improving patient experience of care at the end of life.

**CCGs** administrate end of life care services. On the ground, GPs, hospital staff and hospices are responsible for palliative care.

**Cancer Strategic Clinical Networks, local authorities** and **Health and Wellbeing Boards** also play a key role in identifying local priorities and integrating services so the best support is provided at the end of life.

## Is care in the community delivered effectively at the end of life?

Most people with cancer at the end of their life want to spend their last weeks and days at home. Right now, only 29% of people are able to do so.

We know that free social care at the end of life can help people die in their own home, surrounded by friends and family. Furthermore, 24/7 community nursing has been identified as being key to avoiding unnecessary hospital admissions.

Even more important, and even less widely available, are electronic palliative care registers (EPaCCS). They record and share the care preferences of people who are approaching the end of life between all the services that are providing their care. Where EPaCCS are used, death in the preferred place of care is as high as 80%.

Macmillan wants people at the end of life to have access to free social care, 24/7 community nursing and for their preferred place of death to be recorded, allowing more people to die at home and reducing unnecessary and expensive stays in hospital.



### How can MPs help to improve end of life care?

- During the passage of the Care Bill, you can ask the Government to reconfirm that by the end of this parliament it intends to make a decision on the implementation of free social care at the end of life.
- You can ask the Government if it is still committed to a review of choice in end of life care, which it promised to deliver in 2013 but hasn't yet.

# INDEX OF BODIES

**NHS England:** an executive non-departmental public body of the Department of Health. Commissions primary care and specialised services, as well as oversees the planning, delivery and day-to-day operation of the NHS in England, as set out in the Health and Social Care Act 2012. It also holds clinical commissioning groups to account and allocates their resources.

**Public Health England:** an executive agency of the Department of Health. Aside from running health awareness campaigns and cancer screening programmes they also prepare for public emergencies and conduct research.

**Clinical Commissioning Groups:** clinically led groups consisting of GPs in geographical areas. They organise the delivery of NHS services in England, as set out by the Health and Health and Social Care Act. There are currently 211 CCGs in England, which are overseen by NHS England.

**Health and Wellbeing Boards:** groups consisting of health and social care local bodies, local authorities and patients. They promote integration and reduce inequalities, as set out in the Health Act. They also produce joint strategic needs assessments and joint health and wellbeing strategies.

**Clinical Senates:** bodies that bring together clinicians from across different professions, who work together with patients to provide leadership and advice in a local and wider geographical area. Senates are hosted by NHS England.

**Cancer Strategic Clinical Networks:** groups that brings together a wide range of professionals responsible for cancer care, as well as patients and the public. SCNs improve the way care is delivered by focusing on local healthcare strategies and driving the integration of services. Hosted by NHS England, SCNs were previously known as cancer networks.

## REFERENCES

- <sup>1</sup> [www.gov.uk/government/organisations/public-health-england](http://www.gov.uk/government/organisations/public-health-england);  
[nhs.uk/beclearoncancer](http://nhs.uk/beclearoncancer)
- <sup>2</sup> [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213009/Public-health-role-of-local-authorities-factsheet.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213009/Public-health-role-of-local-authorities-factsheet.pdf)
- <sup>3</sup> [www.ncat.nhs.uk/our-work/diagnosing-cancer-earlier/public-health-and-commissioning](http://www.ncat.nhs.uk/our-work/diagnosing-cancer-earlier/public-health-and-commissioning)
- <sup>4</sup> [www.kingsfund.org.uk/projects/nhs-65/alternative-guide-new-nhs-england](http://www.kingsfund.org.uk/projects/nhs-65/alternative-guide-new-nhs-england)

# DO YOU HAVE ANY QUESTIONS?

We have produced this guide to give you an overview of the new NHS, what the four stages of the cancer journey are and who is responsible for providing care at each stage.

If you have a question or need more information after reading this guide, please don't hesitate to get in touch.

Also, please remember that we are here to help you make a difference to the lives of people affected by cancer in your constituency and further afield.

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Cancer is increasing. Your action is urgently needed to ensure that cancer remains a priority for this and the next Government. Start making change now. Visit us at [macmillan.org.uk/parliament](https://www.macmillan.org.uk/parliament)

Cancer is the toughest fight most of us will ever face. But no one should go through it alone. The Macmillan team is there every step of the way, from the nurses and therapists helping people through treatment, to the campaigners improving cancer care.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way  
call Macmillan on **0808 808 00 00**  
(Monday to Friday, 9am to 8pm)  
or visit **macmillan.org.uk**