

A short guide to supporting a constituent with cancer



Briefing for: **New Members of Parliament**
Purpose: **To outline how you can talk to and support someone with cancer**
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Introduction

There are over two million people living with and after cancer in the UK today. One in three people will get cancer at some point in their lifetime. So it is highly likely that you will regularly meet constituents who have direct experience of cancer, or who have family members or friends with direct experience of cancer. Macmillan recognises that many Members of Parliament are also affected by cancer themselves. This guide aims to give basic advice on how to talk to someone with cancer, and the kind of support you can offer.

How should you describe someone with cancer?

You might be concerned about the language you use when representing your constituents in Westminster. There is no one right way to use language around cancer; what one person finds helpful, another may not.

At Macmillan we generally say **cancer patient** when we are explicitly referring to someone who is currently receiving treatment for cancer in the healthcare system. We say someone is **living with cancer** if they have had a cancer diagnosis but may not currently be receiving active treatment. We say **cancer survivor** when we mean someone who is living with or after a cancer diagnosis. A **person affected by cancer** is anyone who is directly affected by a cancer diagnosis – usually the patient themselves or their family and carers. We use the expression **cancer journey** to describe the whole pathway of someone's experience from diagnosis onwards.

We **do not use** terms such as cancer victim or cancer sufferer which can often make the person with cancer become an object of pity. The key is to listen to your constituent and find out what they personally prefer.

“Through Macmillan’s Cancer Voices I work directly with people living with and beyond cancer. People have different stories and different backgrounds, and this can really affect the language that they want to use to talk about their experience of cancer. For example, one woman from Cancer Voices didn’t want to be called a ‘Cancer Survivor’; she explained that she didn’t identify herself solely in terms of her survival against cancer and she felt that term didn’t acknowledge the more important things in her life that she built her identity on. After talking it through she chose to use the term ‘Cancer Patient’ to describe herself”.

Carol Gibbons, Macmillan’s Cancer Voices team

How should you ensure you are easy to approach?

Physical access to your surgery – some constituents receiving treatment for cancer may not be able to meet you at your surgery. Some people aren't comfortable speaking on the telephone so be flexible about meeting somewhere else that is easier for them, like their home, as needed. NB – it is likely that MPs, as service providers, are legally required to make reasonable adjustments to ensure equal treatment for constituents who fall under the Disability Discrimination Act.

Confidentiality – if you hold your surgery in an open area make sure there is an option for constituents to request a private space to talk to you in confidence.

How should you talk to someone with cancer?

The key to communicating with someone with cancer is simple – be open and willing to listen. Below are five tips to being a good listener:

1. *Get the setting right:* get comfortable and be relaxed; switch your phone off to show you won't be interrupted; be sensitive to how the other person responds to eye contact and adjust accordingly.
2. *Listen and show that you're listening:* don't get distracted thinking about what you're going to say next; don't interrupt; don't be afraid of silences.
3. *Make sure that you haven't misunderstood:* don't assume you know how people are feeling; be confident to check if you don't understand the issue.
4. *Allow for them to use humour, or be sad or upset:* some people may use humour to deal with their situation and feel more in control, and you can help by going along with it. Others will feel emotionally low, and it can be helpful for you to acknowledge this and not try to force a more positive mood.
5. *Don't give advice early:* ideally, wait until you're asked for advice before you offer it and make sure your advice is in response to their specific problem.

For more information download Macmillan's guide *Lost for Words – how to talk to someone with cancer* from <http://be.macmillan.org.uk> .

What support can you offer constituents with cancer?

It is most likely your constituent will be looking for advice or help to deal with the various challenges someone with cancer or their family can face on a regular basis. They might also be looking for you to champion the rights of people affected by cancer in your constituency or in Parliament.

1. **Help people affected by cancer to know their rights** – often cancer patients and their carers receive very little support from healthcare professionals beyond medical guidance. Macmillan is currently working with the Department of Health to improve information and support to people living with and beyond cancer, but you may find constituents coming to you for all sorts of help. For example:
 - **Employment and services** – cancer patients are covered by the DDA, which puts duties on service providers and employers (and others) to promote the rights of disabled people. The DDA has also been used to defend the rights of carers. Only one in five employers consider cancer to be a disability, a situation likely to result in employers not knowing to what their employees with

cancer are entitled. Every public body – central or local government, schools, health trusts or emergency services – is subject to the Disability Equality Duty (DED) and must pay 'due regard' to the promotion of equality for disabled people in every area of their work. It is possible that your constituents may be being discriminated against.

- **Access to drugs** – you may have some constituents who have been denied access to drug treatments. This may be due to a decision by NICE, the UK drugs commissioning service, or a decision by your local Primary Care Trust. You may like to refer your constituent to the Macmillan helpline, where they can discuss their problem with cancer support specialists. Macmillan is campaigning on fair access to drugs, so contact us if you want to get involved.
2. **Cancer information** – your constituents will want to find out more information about how to cope with a cancer diagnosis. Macmillan has a range of information booklets available free of charge including:
- a. Cancer type
 - b. Living with and after cancer
 - c. Tests and treatments
 - d. Self help and support
 - e. Young people and children
 - f. End of life support
 - g. Financial support: benefits, insurance, savings and borrowings
 - h. Directory of Information Materials for People Affected by Cancer
 - i. Hospice and Palliative Care Directory
 - j. Self management of long term health conditions

For these and a whole range of other information booklets on cancer and cancer care simply go to our Be Macmillan website: <http://be.macmillan.org.uk> .

3. **Signposting to useful services** – your constituents may want to know where they can access further cancer specific information and support in their local area. If so, Macmillan can help link you to the cancer services that are available in your constituency:
<http://www.macmillan.org.uk/GetInvolved/MPs/InYourLocalArea.aspx>
4. **Putting constituents in touch with Macmillan's helpline** – the Macmillan helpline offers practical, medical, emotional and financial support from cancer support specialists. The number is **0808 808 00 00** (or textphone - 0808 808 0121). If your constituents prefer, they can email a question from our website.
5. **Being a champion for people affected by cancer** – individuals or groups may ask for you to support them to challenge poor treatment or care either in your constituency or nationwide. You can find out more about Macmillan's campaigning activities at:
<http://www.macmillan.org.uk/campaigns>

What if you need more advice or guidance?

Please do not hesitate to contact the Public Affairs Team at Macmillan about any queries. If we don't know the answer we will put you in touch with someone who

does. Beth Capper, Public Affairs Officer, BCapper@macmillan.org.uk, 020 7091 2068.