

CANCER AND CORONAVIRUS

Know your rights in England



MACMILLAN
CANCER SUPPORT

We know that the coronavirus pandemic has had to be the main priority for the NHS since the outbreak began. But we also know that there are millions of people living with cancer who still need the right care, treatment and support.

NHS workers are doing their absolute best to deal with coronavirus under very difficult circumstances, but it's vital that cancer diagnosis and treatment continues as much as possible.

The government have told local NHS leaders that they have certain duties towards people living with cancer during this time. **This guide is designed to help you to understand and act on your rights**, as part of Macmillan Cancer Support's Forgotten 'C' campaign.

'Each of us has gone through our own difficulties because of coronavirus. We urge you to speak up if you aren't getting the treatment you need. People living with cancer must not be forgotten.'

Carole, Martin, Cheryl,
members of the
Forgotten 'C' Campaign
advisory group

This guide includes:

- Your rights - government guidelines on the care you should expect
- Take action - what to do if you think you are not receiving the right care
- Discussion guide for support groups
- Where to find further support

For information, support or just someone to talk to,
call 0808 808 00 00 or visit [macmillan.org.uk](https://www.macmillan.org.uk)

Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). Also operating in Northern Ireland. A company limited by guarantee, registered in England and Wales company number 2400969. Isle of Man company number 4694F. Registered office: 89 Albert Embankment, London SE1 7UQ. VAT no: 668265007



YOUR RIGHTS

What have the government said about continuing cancer treatment during the coronavirus pandemic?

While the government have said that NHS Trusts must do all they can to respond to coronavirus, they are clear that where services or treatment are changed for people with cancer, they still need to comply with national requirements. **They are also clear that wherever possible, cancer treatments should continue.**

A [letter](#) was sent out by NHS England to all local NHS Trusts on 30 March 2020, which gave clear advice about maintaining cancer treatment during the coronavirus pandemic.

This means certain factors must be considered when local Trusts make decisions about carrying out treatments and surgeries during the pandemic, as well as what they have to consider if they decide to delay or cancel cancer treatments.

'We are clear that the NHS must ensure that cancer diagnosis, treatment and care continues during the response to the COVID-19 emergency. This means:

- Essential and urgent cancer treatments must continue. Cancer specialists should discuss with their patients whether it is riskier for them to undergo or to delay treatment at this time.'

Letter from NHS England sent to all NHS Trusts in England, 30 March 2020

Underlying principles for NHS Trusts around cancer services and treatments:

- Delivery of essential and urgent cancer treatments must continue during the coronavirus outbreak.
- When cancer specialists are making decisions about whether to carry out or cancel cancer treatments, **they should include the patient (and family members if appropriate) in those discussions.**
- Cancer specialists should clearly explain to patients what the risks are both of delaying treatment or of going ahead with treatment so that the patient is fully aware of whether it is riskier for them to undergo or to delay treatment due to coronavirus.
- NHS Trusts must ensure every patient is considered on an individual basis. This means their particular situation has to be considered when making any decisions about their treatment and that decision must be fully explained and recorded. They must not make generalised decisions like 'all cancer treatments have been cancelled for all patients'.
- GPs need to make considered decisions about sending people for a suspected cancer referral and diagnostic tests (where the person may be sent to a hospital for these tests) and must assess the risk to the individual. If they decide not to send the person for further tests, they must keep them on a list to follow-up and monitor if their symptoms worsen or do not resolve. Patients should be fully involved in reaching this decision and given advice on how to report worsening or new symptoms.
- Each area is developing a 'covid-light' service where cancer surgery can take place. A 'covid-light' service is one where every effort is made to keep it free from coronavirus. In order to provide this, some hospitals may have to use different buildings or send patients to a different location so their treatment can be carried out more safely.

TAKE ACTION

What to do if you think you are not receiving the right care

If you have experienced changes, delays or cancellations to your cancer treatment or appointments since the coronavirus pandemic began, you are not alone. It is understandable that during a national emergency there will be changes to existing health and care services. NHS services – from GPs to hospitals – are doing their best to provide for patients during this difficult time.

While it may have been necessary to cancel or postpone your appointments, tests or treatments since the outbreak began, it is important to ensure that you understand exactly why and how these changes were made, and what they mean for you and your cancer treatment in the future.

The following questions should help you to think about whether you have all the information you need to feel comfortable with the decision to postpone/cancel your treatment, or if you need more information to feel clear about what's happening next.

- If you were due to have an appointment with a cancer specialist and it was cancelled, was it clearly communicated to you and your family members/carers (if appropriate) why it was necessary to cancel and were you given a new date?
- If there were changes to your treatment, were you involved in a discussion with the cancer specialist/other health professionals to agree the decision on your treatment being cancelled or changed?
- If the decision to change/delay your treatment was made without you, has any health professional explained to you how they reached the decision to cancel/postpone your appointment/ treatment?
- Was an alternative appointment date or start date for treatment discussed with you and are you clear on dates and timings for when your treatment will start?

Writing a letter about delays to your cancer treatment

If you have looked at the questions above and decided that you are not clear on how decisions about your treatment were made, and you aren't sure what the plan is for your treatment, then you may want to write a letter to the doctor in charge of your cancer treatment. This might be an oncologist (cancer specialist) at your local hospital or you may have been given the name of a cancer nurse specialist to contact.

If you had been seeing your GP about your cancer treatment and don't have the name of your cancer specialist or nurse, then you could write to your GP. If you have other letters from the hospital or from your cancer specialist, then please address your letter to them.

Below is a template that you may find helpful for writing your own letter. If you decide to use this template as a guide, please make sure you go through and fill in details and information about your own situation.

Template letter

Oncology Department

Hospital Name

Hospital Address

Your Name

Your address

Date

To the Oncology Team/Dr name/cancer nurse specialist,

Re: Postponement of appointment/ treatment for YOUR NAME AND HOSPITAL NUMBER

I am writing to enquire about the cancellation/postponement of my appointment/cancer treatment/chemotherapy/radiotherapy/scan that was due to take place on DATE

Background information on your situation

I was diagnosed with advanced prostate cancer on 20th February 2020. I had been undergoing monthly hormone treatment (injections) and was told that in April I would see the oncologist prior to starting radiotherapy. I had an appointment booked for 12th April to see the oncologist (Dr X). I was expecting to discuss the hormone treatment ending and when my radiotherapy would start. In late March I received a letter cancelling my 12th April appointment and rescheduling it for July 2020. The letter did not mention anything about my radiotherapy, whether it had been cancelled or just postponed, or the impact it would have on my cancer. There were no details of how the decision was made to postpone my treatment and no alternative treatment plan was offered.

Suggested standard wording

I understand that coronavirus will have an impact on how cancer services and treatment are delivered at this time and that, during the height of the virus, hospitals had to prioritise coronavirus patients. While I appreciate that all health professionals across the NHS are currently under immense pressure and that you must be very busy dealing with the pandemic, I am still very concerned about the impact of delaying my cancer treatment, and would appreciate the opportunity to discuss and understand the reasons for cancelling/postponing my appointment/treatment.

This paragraph is a made-up example of someone with advanced prostate cancer to give you an idea of how to write a summary of your own situation.

You may wish to give a brief summary of any tests, diagnosis or treatment you had received prior to the coronavirus pandemic. It is important to highlight any abrupt cancellation of treatment or postponement of appointments with specialists/oncologists.

If you are at a stage where you had already received a cancer diagnosis and you know the details of your diagnosis (what type of cancer, what stage etc), then it is worth mentioning here.

I am aware that NHS England wrote to all local Trusts at the beginning of the pandemic giving 'advice on maintaining cancer treatment during the COVID19 response'. In that letter, NHS England state that:

We are clear that the NHS must ensure that cancer diagnosis, treatment and care continues during the response to the COVID-19 emergency. This means:

- **Essential and urgent cancer treatments must continue. Cancer specialists should discuss with their patients whether it is riskier for them to undergo or to delay treatment at this time.**

In line with this, I am keen to understand the reasons behind the postponement of my appointment/treatment and would therefore like to request:

- A conversation with **Dr X/my oncologist/ Cancer Nurse Specialist** to discuss the decision to cancel/postpone my treatment, how this decision was reached and who was involved.
- I would like to fully understand what the risks and benefits are of postponing/cancelling my appointment/treatment and if there are any alternative treatments on offer.
- To understand and agree what the plan is for managing my cancer and what the timelines are for it?

Please feel free to amend these points with details of your own case – so for example, if you were due to have chemotherapy or radiotherapy and it was cancelled, you could ask if there is any alternative treatment you could have in the meantime.

Similarly, if you were due to have surgery but it has been cancelled, you could ask more detailed questions about other treatment options which may be less risky that can be administered away from a hospital?

Suggested standard wording

Again, I would like to state that I understand the immense pressure all NHS professionals are currently under but I hope you can also appreciate my current concerns and need for clarification on how and when my cancer treatment will continue.

I would really appreciate you contacting me as soon as you are able using any of the below contact details so that we can set up a meeting. I am happy to hold a meeting on the **telephone/Zoom/Skype.**

Yours sincerely,

YOUR NAME (Mobile: NUMBER, Email: ADDRESS)

If you are not able to use the telephone or digital methods, then you could ask if it is safe to come in for a meeting, although it is safer to avoid face-to-face contact wherever possible.

DISCUSSION GUIDE FOR SUPPORT GROUPS

Are you a member of a cancer support group? If so, you have probably heard from a range of different people about the ways the coronavirus outbreak has affected them.

If your group is able to meet online, you may find this discussion guide useful to help you have a conversation about your experiences and how you could take action together. If group members would like to share their own experience with us to help inform our Forgotten 'C' campaign, these can be submitted through our [cancer and coronavirus survey](#).

Introduction:

- Explain that this discussion is about the issues Macmillan is highlighting through our Forgotten 'C' campaign on cancer and coronavirus
- Explain that the topics covered may be upsetting for group members and sensitivity may be required
- The following questions are here as a guide, but the group should use the time to discuss issues that are affecting them most

Discussion prompts:

Question 1: What are the biggest concerns currently for group members about the coronavirus outbreak? How have these changed since the outbreak began?

Question 2: Has anyone's treatment or care been affected?

Question 3: Has anyone made contact with their cancer team, local NHS Trust or MP to raise concerns? If so, what was the response?

Question 4: Were you able to fully comply with guidelines around shielding? If so, are you continuing to shield, and what has the long-term impact of shielding been?

Question 5: Do group members think that decision makers in England have given enough attention to the needs and concerns of people living with cancer and those who are shielding? Is there anything you think decision makers could do differently?

Close:

Please let group members know that they can sign up to [join as a Macmillan campaigner](#) if they are interested in campaign action to stop cancer becoming the forgotten 'C'.

GET SUPPORT

If you need information, advice or support about cancer and coronavirus:

- You can find information on [cancer and coronavirus](http://www.macmillan.org.uk/coronavirus) on the Macmillan website (www.macmillan.org.uk/coronavirus)
- You can call the Macmillan Helpline on **0808 808 00 00**, 7 days a week, 8am - 8pm
- You can speak to others in our [online community](#)
- Sign up to our [Macmillan Telephone Buddy](#) service so that you don't have to face cancer alone
- Contact your local Macmillan Information and Support Centre by phone or email. Find yours by entering your postcode [here](#) (www.macmillan.org.uk/in-your-area)

**For information, support or just someone to talk to,
call 0808 808 00 00 or visit macmillan.org.uk**

Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). Also operating in Northern Ireland. A company limited by guarantee, registered in England and Wales company number 2400969. Isle of Man company number 4694F. Registered office: 89 Albert Embankment, London SE1 7UQ. VAT no: 668265007

