

CANCER AND CORONAVIRUS

Know your rights in Northern Ireland



MACMILLAN
CANCER SUPPORT

We know that the coronavirus pandemic has had to be the main priority for the health service since the outbreak began. But we also know that there are many people living with cancer in Northern Ireland who still need the right care, treatment and support during this time.

The Health Service is doing its absolute best to deal with coronavirus and are working under very difficult circumstances, but now more than ever people living with cancer must be able to get the right treatment and care, with the right support, at the right time.

This guide is designed to help you to 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:

- 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



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. During the pandemic there has been some disruption to health and care services across the UK. However, the NHS is still open and there for you so we urge anyone with cancer or possible cancer symptoms to come forward - you are not a burden.

You should be involved in making choices about your care. It is important to ensure that you understand exactly why and how these changes to your treatment were made, and what they mean for you and your cancer treatment in the future.

Each NHS Trust must have a 'clean' environment, free of coronavirus, where cancer treatments and surgeries can take place. If your treatment is continuing and you are concerned about your safety, you should speak with your oncology team, doctor or cancer nurse specialist.

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?

If a family member, friend or carer is unable to attend an appointment with you because of restrictions on visitors, ask your healthcare professional if you can call them on loudspeaker or video call them so they can listen to and speak with your healthcare professional.

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. 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 keen to understand the reasons behind the postponement of my appointment/treatment and would therefore like to request:

- A meeting 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 surgery but it has been cancelled, you could ask 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 [Macmillan Storybook](#).

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 Health and Social Care Trust or MLA 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 local decision makers have given enough attention to the needs and concerns of people living with cancer and those who were 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](https://www.macmillan.org.uk/cancer-and-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

