Raising Your Voice Toolkit

I SEE THE FORGOTTEN 'C'

Everyone should get the very best cancer care and treatment, no matter what. If you're worried about the care you're receiving, or feel you're being treated unfairly, we can help.

Our toolkit is here to support you if you have concerns about your care or how you're being treated. Read on to learn about your rights and who to contact.

Please note this toolkit applies to **England only**.

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CANCER SUPPORT

What is the Raising Your Voice toolkit?

This toolkit was formed from a partnership project between Well Versed Ink (CIC) and Macmillan Cancer Support's London Engagement Team. It is a development from Macmillan's 'Mind the Gap: Cancer inequalities in London' report and conference in December 2019 at London City Hall and the ethnography stories gathered from seldom-heard groups living with cancer. Over the course of ten weeks, the two organisations hosted 'Poetry, Storytelling and Campaigning' sessions with a group of people affected by cancer based in London.

The first half of the sessions were focused on using poetry as a form of self-expression to create a safe space to share experiences and the second half of the sessions were focused on using those shared experiences to co-produce this toolkit.

The participants were mainly from a BAME background and therefore this toolkit has been designed to ensure BAME communities and other seldom-heard groups are able to create a change in their treatment or care without facing discrimination or inequality. While this toolkit was co-produced by a group of mainly Black, Asian and minority ethnic people experiencing issues accessing healthcare, it will be useful for anyone going through similar challenges.

If you have experienced changes, delays or cancellations to your cancer treatment or you are not receiving the care that you are entitled to, this toolkit is for you. If you need assistance using this toolkit or have any feedback for us, we'd love to hear from you at campaigns@macmillan.org.uk.

Contents Page

Understanding your cancer care rights

We have information about your rights as an NHS patient. If you feel like some of your rights aren't being met, then our toolkit is here to support you. Please note, this content applies to the English healthcare system.

What are my rights as an NHS patient?

We know that being treated for cancer can be an overwhelming and confusing experience.

This section is designed to make things clearer and help you to understand what you can expect from your cancer care and NHS staff.

It contains some common questions you might have during your cancer journey. If you feel like some of your rights aren't being met, then you can follow this toolkit to empower you to change this.

What is the NHS constitution?

The NHS Constitution sets out your rights and responsibilities as a patient. These include:

- free access to health services, except in some situations such as if you're not a UK resident
- not being unlawfully discriminated against, and being treated with dignity and respect
- being treated by appropriately qualified and experienced staff
- being protected from abuse, neglect, and care and treatment that is degrading
- choosing your GP practice and expressing a preference of doctor within your GP practice
- receiving care and treatment that is appropriate to you
- accessing NHS services within the maximum waiting times
- not having to share sleeping accommodation with patients of the opposite sex when you are admitted to hospital
- receiving suitable and nutritious food and hydration to sustain good health and wellbeing
- receiving information about the test and treatment options available to you, what they involve and their risks and benefits
- being given access to your own health records and to have any factual inaccuracies corrected

- being involved in planning and making decisions about your health and care
- being able to accept or refuse treatment that is offered to you
- having access to drugs and treatments that have been recommended by NICE (National Institute for Health and Care Excellence) if your doctor says they are clinically appropriate for you.
- receiving care and treatment that is appropriate to you, meets your needs and reflects your preferences
- being able to complain if you're unhappy or if things go wrong.

What should I expect from the NHS?

As an NHS patient, you should be:

- treated with dignity and respect and not be abused or neglected.
- cared for in a clean, safe, secure, and suitable environment.
- treated professionally by qualified and experienced staff and not be unfairly discriminated against.

You can read your full set of rights in the NHS Constitution.

See also:
Your treatment options
Making treatment decisions

What are my rights to GP services?

You have the right to choose your GP practice, and they will accept you unless there are reasonable grounds to refuse you. This usually includes living outside of their catchment area.

If the GP practice refuses to accept you, they must write to tell you their reasons. You can find a local GP on the NHS website. You can change GP practice at any time.

Please note there are many reasons why it might be important to register with your local practice, including emergency appointments when you are sick and your GP having knowledge of what services are available in your local area.

It is important to register with a GP as they are the main point of access to NHS care.

You have the right to ask to see a GP of your choice, and the practice will try to comply with your wishes. This may not always be possible if your GP works part-time or is on annual leave when you book an appointment.

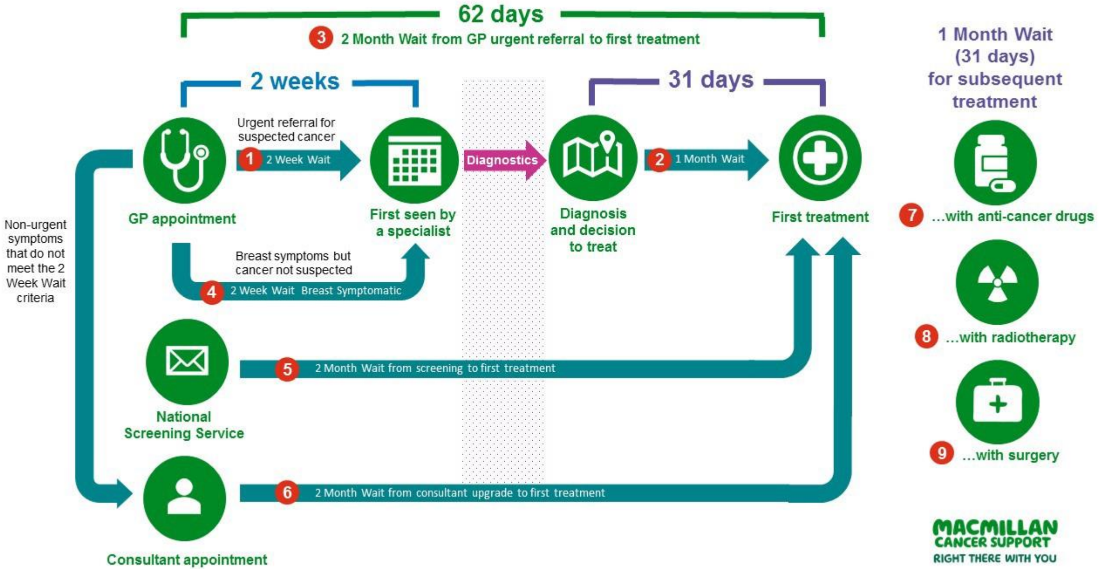
How long should I have to wait to start cancer treatment?

If you have a new cancer diagnosis

If your GP sends you for an urgent referral for suspected cancer, you should be seen by a specialist within a maximum of 2 weeks of the referral date.

If you are referred to a specialist, you should not have to wait longer than 62 days from the referral before starting treatment. If you are diagnosed with cancer, you should not have to wait more than 31 days from the diagnosis and a decision to start treatment before you have treatment.

Please note that it is important for your healthcare team to make a fully informed decision and cancer waiting times are in place to ensure treatment happens as soon as possible before the cancer progresses.



1: A diagram illustrating NHS cancer waiting times

NHS England has set a new target of 28 days from referral to finding out whether you have cancer. This target will apply to you if you were urgently referred to see a specialist through the 2-week urgent referral or the urgent screening programme pathway (this is for breast, bowel or cervical cancer) after April 2020.

If you received a non-urgent referral as your GP did not originally suspect cancer, your wait time should be no more than 18 weeks from the day your appointment was booked, or when the hospital or service received your referral letter.

However, if your GP has any suspicions about cancer symptoms they would usually make an urgent referral.

If you have a recurrence of cancer

NHS England has a waiting-time target for cancer that has come back (a recurrence). They say that you should start treatment within 31 days. This time starts from the meeting in which you and your doctor have agreed on your treatment plan.

If you have a new primary cancer

If your doctor has diagnosed a new primary cancer rather than a recurrence, you should wait no more than 2 months (62 days) to start treatment. This time starts on the date that the hospital has received an urgent referral for suspected cancer.

You might have to wait longer if you need extra tests to diagnose your cancer. Waiting times can vary depending on the type of cancer you have and the type of treatment you are going to have.

Can I choose which hospital I am referred to?

You have the right to make choices about your NHS care. This can include choosing the hospital that provides your care when you're referred for your first appointment with a consultant. You can speak to your GP about where and when you would like to see a specialist.

However, when you are being referred for cancer services you cannot choose which hospital you are referred to as you must be seen within the 2-week maximum waiting time. You can ask to be referred to a different hospital if you have to wait more than 2 weeks before seeing a specialist for suspected cancer.

The waiting time starts from the day the hospital receives the referral letter, or when you book your first appointment through the NHS e-Referral Service.

How should I be involved in decisions about my health?

You have the right to be involved in planning and making decisions about your health and care with your healthcare team.

You can speak to your healthcare team about being involved in any decisions about your health. This is often referred to as 'shared decision making'. You should have a conversation about all your concerns and needs, and what matters to you. This can help you to think about what's important to you when making decisions about your treatment. A tool called a Holistic Needs Assessment or a Concerns Checklist may be used.

You can ask your healthcare team for information and support about the tests and treatments that are available to you, including what they involve and their risks and benefits to you and any side effects on your health. When making these decisions remember you can involve your family and carers.

You can also request to access your medical records to help you better understand your condition, treatments and cancer care. Doctors write to each other about your care. They should aim to send you a copy of their letters or emails. If you do not get a copy, you can ask for one. This can help you make decisions about your care. Please note that you should only request this if absolutely necessary, accessing records can take a long time.

Your doctors will not be able to give you any treatment until you have given your consent.

We have further information about talking to your healthcare team and making decisions about treatment.

Do I have the right to the treatment I want?

You have the right to receive care and treatment that is appropriate to you, meets your needs and reflects your preferences.

Speak to your healthcare team about the treatment you want, and you can make decisions about your care together. They will be able to give you more information about your care and they should support you to fully understand any decisions and choices you make.

What can I do if I can't access the treatment I want?

You might feel disappointed if you can't have the treatment you would like. You may find it helpful to talk to your healthcare team. Ask them whether there are other treatments you can have or if you can take part in a clinical trial. You can read more about clinical trials.

It is worth remembering that treatment decisions are complex and are based on the evidence as to what is best for you at your stage of cancer. They also take into account other issues such as separate medical problems you may have. This may limit your treatment options.

You might be able to talk with other people who have tried to get the same treatment. It can be helpful to share experiences. Ask your specialist whether they can arrange this for you.

Alternatively, the Macmillan Online Community is a place to share your experiences, get and provide emotional support to other people who may have a similar experience. If you would like advice and support about not receiving the treatment you want, speak to a Macmillan Support Line advisor on 0808 808 00 00, 7 days a week, 8am to 8pm.

Can I get a second opinion?

A second opinion is when you ask a doctor if they agree with your diagnosis or treatment. You can ask your doctor to be referred for a second opinion if you do not agree with them, but you do not have a right to a second opinion.

GP

If you want a second opinion from a GP, you can ask to see another GP at your surgery. Or you could consider changing your GP practice. You can ask your GP to arrange a second opinion either from a specialist or another GP. However, the GP does not have to do this if they do not think it necessary.

If a GP refers you for a second opinion, you cannot insist on seeing a particular doctor. However, you should not be referred to someone you do not wish to see. If the GP refuses to arrange a second opinion, you may wish to change your GP.

Specialist or consultant

There are several ways of getting a second opinion from a hospital consultant or specialist.

Before asking for a second opinion, it's worth asking your consultant team to go over your diagnosis and explain anything you don't understand. If you're unhappy with your diagnosis or would like to consider a different course of treatment, discuss this with them. Your healthcare team will be happy to explain things, and, in many cases, there may be no need for a second opinion.

If you are still unhappy, speak to your GP. They will be able to refer you for a second opinion, either on the NHS or privately. This can allow you to get an independent second opinion. Some people do their own research to find the name of a consultant they think they would like to see.

For funding reasons, your current consultant may not be able to refer you to some specialists. They may recommend talking to your GP about getting a second opinion from another specialist. You may worry that asking for a second opinion will upset your consultant. But this is unlikely to happen. Doctors often ask for the opinion of a colleague, especially for complex cases.

People who are referred for a second opinion are treated as a new patient referral and are assessed appropriately. A second opinion with a different healthcare team may be at a different hospital which could, in some cases, involve additional travelling. Whilst waiting for your second opinion, you may wish to discuss or inform your initial healthcare team about this. If you have a serious medical condition requiring urgent treatment, we advise that you discuss this with the team and ask whether any delay in starting treatment could affect your wellbeing.

For more information about getting a second opinion, please contact our Support Line on 0808 808 00 00, open 7 days a week, 8am–8pm.

Can complain about NHS services or staff?

You have the right to be treated with respect and receive good-quality service from the NHS. If you feel you have been treated unfairly, are unhappy with the care or treatment, or something has gone wrong you can make a complaint.

Holistic Needs Assessment

A Holistic Needs Assessment (HNA) identifies any physical, emotional, practical, financial and spiritual concerns you may have from your cancer diagnosis.

An HNA is an assessment and discussion you may have with someone from your healthcare team. Together, you talk through your needs and concerns. HNAs are often done electronically, but there is also the option of a paper form. You will need to speak with your healthcare team for an electronic Holistic Needs Assessment.

You then agree on a plan for your care and support needs, which should lead to referrals to support and services to help meet the needs you have identified. It is called holistic because you can discuss any needs or concerns you have about any area of your life. It is not only about the physical symptoms of cancer or the side effects of treatment.

HNAs may not be standard practice in all hospitals and they may be more informal. However, there is a national government commitment that **everyone diagnosed with cancer in England should be offered an HNA**. If you are not offered an HNA and would like one, you can ask someone from your healthcare team about it.

For more information about HNAs, see our Holistic Needs Assessment leaflet, and the video Holistic Needs Assessment: why should I use it?

If you would like more information about your patient rights, please contact our free Macmillan Support Line on 0808 808 00 00, open 7 days a week, 8am to 8pm.

Challenging conversations about your cancer care

Having a difficult conversation with your healthcare professional

If you feel that your healthcare or treatment needs have not been met, the next step is to have a conversation with your healthcare professional to highlight the gap in your care. This could be with your cancer nurse.

This conversation will hopefully go well, and your healthcare professional will note down and take forward your concerns. However, there may be some instances where the conversation could be a challenging one.

Unconscious bias

You might worry about being labelled 'difficult'. You may also feel there is a power imbalance because you lack specialist knowledge, or you might feel that unconscious bias is present.

Unconscious bias is when people hold stereotypes about certain groups of people that are formed outside their own conscious awareness. Unconscious bias might affect the way someone communicates with or treats another person.

Making the most out of a consultation

If it goes well, you will leave a consultation with your healthcare professional feeling satisfied with the care you've received, but there may be occasions when you don't feel happy with how it went. These reasons can include:

- You haven't fully understood the information that has been given to you
- You don't feel you have been properly heard
- You don't feel your questions have been answered
- You have concerns that your worries weren't taken seriously
- You have concerns that the doctor or nurse didn't communicate effectively, or even politely.

Understandably, if you experience any of these feelings and concerns it can be an upsetting situation to find yourself in, but there are ways to address this. The first step is understanding how you can make the most out of each consultation you have.

Preparing for your consultation

Here are some tips to help you make the most of each consultation.

1. **Preparation can be helpful** – do you have specific questions you want answered? If so, write them down so you don't forget.

2. **Be aware that an appointment may be time-limited** - the doctor or nurse may feel the pressure of that as much as you do. If you don't feel you have had long enough, flag this and ask if a follow-up appointment or call can be organised.

3. **If you haven't had all your questions answered, raise this concern** - ask if there's another way to ask questions that's easier for you to understand. For example, could you agree with your doctor to email the questions in?

4. **If you feel that you aren't being heard, try to voice this** - the doctor may not be aware of how you are feeling.

You may feel that your doctor or nurse is not giving you the chance to explain how you feel or they have been dismissive of your concerns. If so, it's okay to move on to the next steps outlined in this toolkit.

However, do remember that we all have pressures affecting our day and there could be a number of reasons why a consultation has not gone well.

Feedback is always helpful for healthcare professionals and you can feedback both positive and negative issues via PALS or Primary Care.

The NHS has more information on giving feedback on your care.

See also: Questions to ask your healthcare team

Top tips for challenging conversations

Before the conversation

- Prepare yourself by finding out as much information as you can. This will help you play an active role in decision-making and feel empowered.
- Be clear about what you want to achieve from the conversation.
- Talk through what you want to say with a friend, family member or carer beforehand, until you feel confident.
- Think about the assumptions you are making about the practitioners' intentions. You may worry about feeling intimidated, ignored, disrespected, or marginalized, but be cautious about assuming that this is their intention.
- Consider if your attitude towards the conversation is influencing how it might go. If you think this is going to be horribly difficult, it probably will be. If you believe that whatever happens, some good will come of it, that will likely be the case.

During the conversation

- Be confident and believe in your ability to bring about change – this is about you and your health.
- Take someone with you if it helps, but not to speak for you unless you have agreed this beforehand.
- See yourself as an equal. Remember the person across the desk from you is human too and try to understand their perspective. Acknowledge the expertise of the practitioner, but remember you are an expert in your own experience.
- Make notes or ask the person with you to do so and always ask 'why' until you understand.
- Check out Macmillan's top tips for talking to your healthcare professional team.

After the conversation

- Follow up the conversation with an email or letter setting out your understanding of what was decided, if you are able.
- If you did not achieve what you wanted to, there are other options on what to do next in the next stages of this toolkit.

TOP TIP: If English is not your first language, you can ask for an interpreter to attend appointments with you.

Macmillan also offers cancer information in languages other than English.

Letters to healthcare professionals

We recognise that it may be tough to have these challenging conversations with healthcare professionals, or you may find they are not open to having a conversation.

Writing a letter to your healthcare professional detailing your concerns could be a next step if the conversation doesn't go well, as a way to escalate your voice further and have a formal record of your concerns which will go on your file.

Additional options and next steps

After the conversation, you may not feel you achieved what you wanted to. You might feel you are still being treated unfairly on the basis of your identity. If so, there is more you can do.

Patient Advice and Liaison Services (PALS)

Your local Patient Advice and Liaison Services (PALS) will help you to informally resolve issues with a hospital before making complaints. PALS can be very effective if your issue is urgent and about your treatment. If they can't help you, they will explain the hospital's or trust's complaints process to you and who can help you with your complaint.

NHS Complaints Advocacy

You might find it helpful to have someone to help you make your complaint. This person is called an advocate. Find out more about the independent NHS complaints advocacy service by VoiceAbility.

Healthwatch

Find your local Healthwatch to share your experiences of health and social care. They use the recommendations they receive to shape future services in the area. They can also help you make a complaint about the NHS.

Three stories about challenging conversations

Hear from participants to contributed to the making of this toolkit below.

> 'I always remind myself that I have a responsibility to know as much as possible. I try not to forget that the practitioner I am meeting with is also a person too who might be busy, stressed or unsure and not intentionally being difficult.' – **David**

> 'In so many areas of my life, I feel confident to assert myself and put my own views forward. Unfortunately, when it comes to meetings with my GP, I feel cowed and uncertain even before I enter the consultation room. Even though I know much about my condition and the range of treatments, I feel that as a Black woman this will be perceived as my being aggressive and pushy and therefore, I feel silenced.' – **Judith**

> 'There is no doubt that as a young person I have often felt patronised and not taken seriously when dealing with health professionals – being talked at rather than with. I know a lot of people who feel the same way as me. It takes a lot of effort for me to ask questions and question someone's opinion and I don't feel I do it well and it leaves me feeling anxious and tired afterwards.'– **Tawanda**

Cancer support groups

When campaigning or advocating for yourself or someone else, it can help to share your experiences and connect with others. Cancer support groups can help.

Creating a safe space with others

When advocating for yourself or a loved one, it can often be helpful to reach out to people who are going through a similar experience, so that you know you're not in it alone. By sharing experiences, you may be able to find out about different services that are available to you or you might even find yourself joining forces to campaign together. Teaming up with other people in the community can be a powerful way to get the attention of those in power, for example healthcare professionals and politicians.

Creating a safe space could be as simple as having a conversation with someone on social media or joining a support group.

Finding cancer support groups

You can find out about the different support groups in your area.

If you don't feel like your experiences or your identity are represented in an existing support group, you could try setting up your own. For inspiration for setting up your own support group, you can read Judith's story below.

You can also join a cancer patient representative group. Every cancer alliance and many hospitals have one. They can call for action and try to improve future patient experiences. These groups are a good place to take concerns, including:

- poor experiences
- problems with information
- problems with communication from healthcare professionals that have affected you.

Our Online Community is a digital forum where people affected by cancer can connect with others for support 24/7. Users can ask questions, discuss experiences, and even share poetry.

See also: local support groups

Judith's Story

My name is Judith and I am 49 years old. I was brought up in East London and my mother was part of the Windrush generation. I have two brothers and a 22-year-old daughter.

On the 31st of July 2018, I was diagnosed with terminal cancer and given under a year to live. I thus commenced the fight of my life to live.

Shortly after my diagnosis, I felt the need to start a support group that would prevent others from having the same lonely and negative experience that I did. This was because of the challenging experiences I had at the beginning of this journey.

FROM ME TO YOU is an organisation that provides support to people with a cancer experience, specifically those from within marginalised and often disenfranchised communities.

FROM ME TO YOU was formulated in response to my personal experience, which I found to be replicated within the wider BAME community. I passionately believe in aiding the personal self-development and empowerment of anyone who is living with cancer.

The aim of the group is to help others, specifically those from the BAME community, to navigate their way through a cancer diagnosis and to not waste time looking for answers in all the wrong places.

Time is a huge issue when fighting cancer. We need all the help we can get to navigate a clear and beneficial pathway through the minefield of cancer.

We offer support in our group no matter what pathway the individual chooses, albeit a medical or holistic framework. The group is currently growing rapidly and one of our aims is to secure funding to facilitate advocacy for our members.

Today I stand proud knowing that FROM ME TO YOU has achieved a great deal, but there is so much more to achieve.

Contacting your MP about your cancer care

How can my MP help?

If you need to escalate the situation further, meeting with or writing to your local MP (Member of Parliament) could be a great way to get further support. MPs have a duty to their constituents to make sure their voices are heard and represented in parliament.

Your MP could help in a range of different ways, including writing to the CEO of a hospital trust, raising an issue with the relevant government department, or asking questions at Prime Minister's Questions. It's worth noting that they cannot get involved in any legal proceedings.

MPs are elected by people in their local area to represent their interests and concerns in the House of Commons in Westminster. If you're unsure who your MP is, visit www.theyworkforyou.com.

Tips for contacting your MP

Writing to your MP

- Include your postcode in your letter to show that you have the relevant constituency area. It may take a while to get a response. If this is the case, you may have to chase a response by letter, email or telephone.
- Make sure it is personal to you. It's important to MPs to hear about what specifically is going on in your case as their constituent.
- Write about what you would like your MP to do, whether this is writing a letter to your hospital trust on your behalf or raising your concerns directly with the health minister. If you are unsure, suggest a follow-up meeting to discuss your options.
- You can send a message to your local MP online from www.writetothem.com.

Template letter to your MP

[INSERT NAME OF MP] MP
[Their constituency address]

[Your Name]
[Your address]

[Date]

Dear [INSERT NAME OF MP] MP,

I am writing as your constituent to ask for help with an issue within my cancer care/treatment. My cancer treatment has been postponed and I have no alternative treatment plan or updated timescale for when my treatment will resume.

Explain the background information on your situation:
I was diagnosed with advanced prostate cancer on [insert date]. I had been undergoing monthly hormone treatment (injections) and was told that in [insert date] I would see the oncologist prior to starting radiotherapy. I had an appointment booked for [insert date] to see the oncologist (Dr X). I was expecting to discuss the hormone treatment ending and when my radiotherapy would start. In [insert date] I received a letter cancelling my [enter date] appointment and rescheduling it for [insert date]. 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.

Describe what you have already done:
I wrote to my cancer care team at Example Hospital on [insert date] asking for them to meet with me to discuss my treatment options and to update my cancer care plan. I spoke to them on the phone last week and they were unable to offer me an alternative treatment plan or arrange to see me earlier than [insert date].

Ask what you would like them to do:

I am very worried about my cancer treatment and the effect this delay could have on my health and quality of life. I would like to ask for your help to resolve this matter. As my MP, I would like you to write to my hospital to ask why my treatment has been postponed and request for me to restart treatment. Are there other ways you could help me with this matter?

I look forward to your response. If you wish to discuss this further with me, you can contact me on the telephone or by email. I would be happy to discuss this in a meeting.

Yours sincerely,

[Your name]

[Email, telephone number]

Top tip: Writing your letter by hand and sending it in to your MP's office, rather than typing it out and emailing it, is an easy way to grab an MP's attention.

Meeting with your MP

Meeting with your MP, whether in person or virtually, can be a powerful way to share your story and experiences. By telling your story face to face in your MP session, you're able to communicate the seriousness of the issue and the effect it had on your healthcare experience.

Each MP has a preferred way of setting up meetings with their constituents – you can check what this is by visiting your MP's website or calling their constituency office. Normally they run drop-in constituency surgery sessions – you can find times and locations of these on your MP's website or advertised in places like your local library. Alternatively, you can contact them to set up a meeting.

Please note that it may not be easy to secure a meeting with your MP, and some are more receptive to meeting than others.

Preparing for a meeting with your MP

Here are some tips to help you prepare for a meeting with your local MP.

- Think about what you want to say and what you'd like your MP to know by the end of your chat. It's definitely a good idea to write down your key points.
- If you are having a virtual meeting make sure your computer/device is fully charged or plugged in. Make sure you have a comfortable place to sit, and anything you might want during the meeting such as a glass of water and tissues.
- If you are meeting your MP in person, make sure you leave plenty of time to travel to your meeting so you are not late.
- Re-read your notes and go over what you want to say to your MP to refresh your points in your mind.
- Relax and remember that your MP works for you and so it is important to leave the meeting feeling that you've both agreed on the next steps, including timelines.

During the meeting with your MP

- Share your personal story. Think about what you want to tell your MP and what you want them to take away from your meeting.
- Don't worry about meeting an MP. You might have seen your MP on television and feel a little anxious when you first meet them. Remember their job is to represent you, so they want to hear your story.
- Try to avoid being confrontational. If you do not support their political party or party leader, don't mention that during the meeting. MPs have often been given the party position, which most will stick to. Yet your story could lead to them thinking differently.
- Be clear and concise. Most MPs won't know that much about cancer treatment, so try to avoid using too many technical terms.
- Remember that they might ask questions. They're also used to being asked questions, so don't hold back with yours!

After the meeting with your MP

Send your MP a follow-up email to thank them for meeting with you. In the email, include key action points that you discussed in the meeting that you would like your MP to take (eg asking a question in Parliament on your behalf).

Top tip: MPs love to hear how they have directly had an impact on their constituents' lives. If the meeting goes well, consider recording a short film thanking your MP and posting it on social media, tagging your MP. This ensures your MP will publicly be held accountable, but also the issue will remain at the top of their agenda.

If you would like to contact your MP and need assistance, please email the Campaigns and Public Affairs team on campaigns@macmillan.org.uk.

Empowering ways to drive change in your cancer care

At Macmillan Cancer Support, we work with Governments and politicians across the UK to improve care and support at every stage of the cancer journey.

We encourage people living with cancer to share their experiences to help drive that change. Here are some of the ways you may be able to resolve issues you are facing in your cancer care or treatment or help others in the future.

Engage with your local politicians

The relevant decision makers will be different depending on which area you live in.

For example, in London, the Greater London Authority is made up of the Mayor of London, the London Assembly and City Hall. The Assembly investigates issues of importance to Londoners such as health, publishes its findings and recommendations, and makes proposals to the Mayor.

You could write to an Assembly Member to tell them about the issues you are facing in your cancer care and treatment and to ask them for help or to investigate your issues.

Some Assembly Members represent all of London, while others represent specific areas.

Use social media

Social media accounts have the potential to reach a wide audience.

You can use Instagram to connect with people through photos, videos and captions to share your story and raise awareness of the issues you are facing.

Twitter allows you to connect with key people such as MPs and hospital board members. You can use the platform to share text, photos and videos.

Write a blog

Free blogging sites like WordPress are great tools for you to share your cancer journey with other people. Sharing your story through blogs can help raise awareness of the issues you are facing and help you escalate the situation further.

Kris Chadwick, one of the co-creators of this toolkit and founder of Chadders Cancer Club, shares some advice about blogging and how it empowers her when facing challenges in her cancer care and as a carer.

Kris's top tips for writing blogs

- Blogger and WordPress are both free blogging sites. WordPress has more functionality than Blogger.
- Blog regularly. Set a routine to post on the same day at the same time.
- A good length for a blog post is around 750 words.
- Blog posts should include an image and links to previous posts from your blog as well as external links.
- If you have a story or experience to share but you're not sure about starting your own blog, then you could write a guest blog for an existing charity or cancer support group.
- Quote reputable sites, those based on science and research like Macmillan or Cancer Research UK.

> 'Traditional blogs are relatively low in reach – people have to Google keywords or have the link to come across your blog. But as my blog reached more people, opportunities arose to get my message to people with whom it could resonate.
>
> In 2020, I was approached to speak at a palliative care conference as a result of someone reading my blog. Through this, I was able to share a patient and carer's perspective of uncertainty in cancer directly to the doctors who are on the frontline of providing cancer care.' – **Kris Chadwick**

You can watch Kris's video Uncertainty, Another Symptom of Cancer on YouTube.

Contact local newspapers

MPs and local decision-makers such as NHS leaders will often read local newspapers to see what is happening in the local area. Sharing your story with a local paper might help you escalate your situation and resolve your issue.

If you are a blogger you could repurpose a popular blog post about your cancer journey to include the issue you are facing and send this to a local newspaper. If you do not want to write an article or press release yourself, you can contact Macmillan to possibly share your experience with the media team.

Find support in your community

Support networks within your local community can be used to help you resolve issues you are facing in your cancer care or treatment.

If you are involved with any local groups or communities, such as a religious group or sports team, you can ask to speak at one of their meetings about your cancer journey and the issues you are facing to raise awareness with the public.

You can include some information about the issues you are facing in any messaging that goes out to the group, for example in a newsletter.

If people wish to support you, you can ask them to write to their MP to ask them to support your requests, such as writing letters to your hospital about your treatment.

If you find other people in your local community who are experiencing similar issues in their cancer treatment or care to yourself, then you could unite to start community organising. The more voices that speak about an issue, the more likely it is to change.

Get involved with craftivism

Craftivism is a type of activism that uses different forms of craft, such as knitting or crochet, to influence decision-makers. The crafts encourage people to engage thoughtfully with issues to reflect on the key problem statements and to converse with other campaigners.

The crafts can then be put up in people's home windows and shop fronts, or even sent to decision-makers directly. Using social media and a hashtag will help you to promote your craftivism more widely.

If your craftivism is popular in your local community, your local radio station or newspaper might want to do a piece on you.

Campaigning with Macmillan

Macmillan Cancer Support campaigns to help people living with cancer live life as fully as they can. Find out more about how our work makes a difference.

Sign up to become a Macmillan Campaigner

As a campaigner, you will be joining a network of people across the UK campaigning for people living with cancer. By signing up we'll keep you up to date with opportunities to take action and the latest news from our campaigns.

Sign up as a campaigner

Sharing your story on Macmillan's Storybook

Macmillan's Storybook is a place for people living with cancer and affected by cancer to share their stories as part of The Forgotten 'C' campaign. If you feel empowered by this toolkit and want to share your story, you can add your story to our Storybook.

Share your story

Macmillan Digital Storytelling Project

This is a series of online workshops supporting people affected by cancer to share their stories online. These stories are then turned into a video format, to create a powerful visual representation of people's stories.

Find out more

Contacting the Campaigns team

Contact the Campaigns team to share your experiences, issues or concerns regarding the toolkit.

Email us