

# Q&A for cancer charity support lines: UPDATE 4 June 2020

## 1. Summary of Government Advice

The Government is advising everybody to:

- Stay alert
- Stay at home as much as possible
- Work from home if you can
- Limit contact with other people
- Keep your distance if you go out (2 metres apart where possible)
- Wash your hands regularly

**Do not leave home if you or anyone in household has symptoms of coronavirus.**

In the first instance, please refer to wider Government guidance on:

- [Staying at home if you think you have coronavirus \(self-isolating\)](#)
- [Staying alert and safe \(social distancing\)](#)
- [Staying alert: what you can and cannot do](#)
- [Staying safe outside your home](#)
- [How to protect clinically extremely vulnerable people \(shielding\)](#)

The Government have a wide range of information to help people at this time, including on employment, financial support, and childcare. See: <https://www.gov.uk/coronavirus>

## 2. Summary of Key Lines for Patients

### **Cancer services during the restoration and recovery from COVID-19**

The NHS is currently moving into the next phase of its response to the COVID-19 outbreak: to restore and recover all services for patients. If you need to access care or treatment for suspected or diagnosed cancer, arrangements have been put in place to keep you safe from COVID-19.

If you have a worrying symptom, and you think it might be cancer, please contact your GP surgery straightaway. GP surgeries are offering online consultations and/or remote triage so that people do not have to attend in person unnecessarily.

If you have been asked to go to hospital for further investigation or for treatment if you are diagnosed with cancer, it is important that you attend. The NHS is reorganising the way that it delivers services to keep you safe:

- COVID protected hubs have been established for cancer surgery across the country to keep patients safe. These are in COVID protected areas of a hospital or on separate hospital sites. The model is now being expanded to cover diagnostics too.
- Wider measures are also being taken by all hospitals treating COVID patients to ensure that COVID and non-COVID patients are kept separate. This may include using separate entrances for COVID and non-COVID patients, ensuring staff and patients do not move between different parts of the hospital, and making sure that, as far as possible, staff are social distancing both inside and outside clinical areas.
- The staff caring for cancer patients will be vigilant for any symptoms that they or their families are showing and are required to self-isolate in line with government guidance. Staff will be tested for the virus if they are displaying symptoms. Hospitals are also introducing testing for staff not displaying symptoms where there is testing capacity to do so.

- All patients can support NHS staff to maintain COVID-protected environments by being aware of any symptoms they or their family may be displaying, and by following the advice of the clinical teams working with them. If a patient is uncertain whether they should come into the hospital, they should discuss this with their clinical team.

The NHS is here for you if you need it: help us to help you.

# Q&A

## For people worried they have cancer

### Q1 I am worried that I have symptoms of cancer. Should I still go to my GP?

It is important that you seek clinical advice if you have a worrying symptom. GP surgeries have been advised to offer online consultations and remote triage so that people do not have to attend in person unnecessarily. Please do contact your GP surgery directly if you are worried about a possible cancer symptom, for example if you have any of the following symptoms for no explainable reason:

- Bleeding that doesn't come from an obvious injury
- A lump
- Weight loss
- Or any type of pain that won't go away.

You can find a fuller list of the symptoms to look out for on the [Be Clear on Cancer](#) website.

### Q2 I have just been referred by my GP with suspected cancer. Should I attend my diagnostic appointment?

If you have been asked to go to the hospital for further investigation, it is important that you attend. The NHS is reorganising the way that cancer diagnosis is delivered so that you can undergo diagnostic tests in places protected from the coronavirus. Because of that, you may be asked to self-isolate for seven days before any diagnostic procedures, even if you do not have coronavirus symptoms. You should discuss with the clinical team at the hospital if you have any concerns about attending.

Most people who go to their GP with symptoms do not have cancer. However, if you do have cancer, earlier diagnosis can mean more effective treatment and improved chances of survival.

If you have been asked to attend hospital, the only reason you should not go is if you have any symptoms of coronavirus. In this case, you should tell the hospital, cancel your appointment and self-isolate. The clinical team will discuss with you about when your appointment can be safely rescheduled.

## People living with cancer now

### Q3 Do I need to do anything differently as someone who is being treated / in remission from cancer/living with a chronic cancer?

People with certain cancers and those who have received or are receiving certain treatments are at risk of severe illness if they catch coronavirus (Covid-19). This includes:

- people with cancer who are undergoing active chemotherapy

- people with cancer who are undergoing radical radiotherapy for lung cancer
- people with cancers of the blood or bone marrow such as leukaemia, lymphoma or myeloma who are at any stage of treatment<sup>1</sup>
- people having immunotherapy or other continuing antibody treatments for cancer
- people having other targeted cancer treatments which can affect the immune system, such as protein kinase inhibitors or PARP inhibitors
- people who have had bone marrow or stem cell transplants in the last 6 months, or who are still taking immunosuppression drugs<sup>2</sup>

The Government updated their [guidance](#) for these people on 31 May, and advises them to continue to take precautions in order to keep themselves safe:

1. If you wish to spend time outdoors (though not in other buildings, households, or enclosed spaces) you should take extra care to minimise contact with others by keeping 2 metres apart.
2. If you choose to spend time outdoors, this can be with members of your own household. If you live alone, you can spend time outdoors with one person from another household (ideally the same person each time).
3. You should stay alert when leaving home: washing your hands regularly, maintaining social distance and avoiding gatherings of any size.
4. You should not attend any gatherings, including gatherings of friends and families in private spaces, for example, parties, weddings and religious services.
5. You should strictly avoid contact with anyone who is displaying symptoms of COVID-19 (a new continuous cough, a high temperature, or a loss of, or change in, your sense of taste or smell).

The NHS has written to people in these groups with advice and information about what to do during this time, and where to access support. This advice will be in place until at least the end of June.

Please visit the [Government website](#) for more information regarding shielding advice.

If you are affected, and have a scheduled hospital or other medical appointment during this period, talk to your clinical team to ensure you continue to receive the care you need and determine which of these are absolutely essential.

#### **Q4 Why has the shielding guidance been updated now?**

The government has updated its guidance for people who are shielding taking into account that COVID-19 disease levels are substantially lower now than when shielding was first introduced. The number of cases is falling and the average rate of incidence of the virus has fallen from around 1/40 to 1/1000 cases per week, delivering greater reassurance that it is safe to cautiously reflect this in the guidance for those who have been advised to shield.

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<sup>1</sup> This means before, during or after treatment, including those being managed expectantly

<sup>2</sup> When applying these criteria locally, clinicians should take into account the new Covid-19 NICE guidance on haematopoietic stem cell transplantation which states that patients should follow shielding advice:

- if they had an autologous HSCT within the last year
- if they had an allogeneic HSCT within the last 2 years, or they are having continuous immunosuppressive therapy, they have chronic graft versus host disease (GvHD) or there is evidence of ongoing immunodeficiency (or for other extremely vulnerable groups based on clinical assessment).

### **Q5 What support is available to me if I have been advised to shield?**

Everyone who has received a letter advising that they are clinically extremely vulnerable should [register online](#) if you need any extra support. This may include having essential groceries delivered to your home or setting up regular calls with an NHS volunteer if you are experiencing feelings of isolation.

Information on the support available to people who are shielding can be found [here](#).

### **Q6 I think I should be considered as clinically extremely vulnerable, but I haven't received a letter. What should I do?**

The criteria for cancer patients were carefully defined, based on those with greatest clinical risk.

**If you are unsure of your risk and what measures you should be taking, you should speak with your hospital specialist. If this is not possible, you should contact your GP.**

### **Q7 Why have I been told by my clinical team that I no longer need to shield?**

Your clinical team may inform you that you no longer need to shield if you are no longer considered to be 'clinically extremely vulnerable'. Your clinical team should discuss this with you. If you have any questions regarding this, you should contact your clinical team.

### **Q8 Why have I received a text saying that I no longer need to shield?**

You may have received a text saying that you no longer need to shield if your GP or clinical team feels that you are no longer considered to be 'clinically extremely vulnerable'. Your clinical team should discuss this with you, but you may receive a text from the Government about this before this conversation has taken place. If you are not sure why you have received this text, you should contact your clinical team.

### **Q9 I don't think I should be considered as clinically extremely vulnerable, but I have received a letter saying I am. What should I do? / I have received a letter saying I am considered as clinically extremely vulnerable but I do not want to follow the guidance.**

The criteria for cancer patients were carefully defined, based on those with greatest clinical risk. Some cancer patients may receive a letter because they have other conditions that place them in the highest risk cohort.

We understand that the restrictions imposed by shielding are difficult, both for you and for your family members and/or carers. The Government has issued shielding guidance, strongly advising you to stay at home as much as possible and keep visits outside to a minimum (for instance once per day) until at least the end of June. This is the safest thing to do to protect you from illness/ complications of COVID-19.

However, this is guidance and whether you follow the guidance or not is a personal decision for you to make. You may decide, having weighed up the risks and the implications of shielding, that you do not want to follow the guidance.

You may also choose to remain in your own home at all times if you do not feel comfortable with any form of contact with others.

Before deciding, we would ask you to discuss the matter with your GP or hospital specialist and those that may provide care for you. This may be particularly relevant for patients who are receiving end of life care. Please do talk to somebody before you decide what to do.

If you are unsure of your risk and what measures you should be taking, you should speak with your hospital specialist. If this is not possible, you should contact your GP.

#### **Q10 I have received the letter more than once. Why?**

Some people may receive the letter more than once because they have more than one condition that places them in the highest risk cohort.

Some people may receive a letter from the central NHS point and their local clinical team or GP, as both have identified them as clinically extremely vulnerable.

#### **Q11 Will this categorisation of people be used to determine prioritisation for treatment?**

Absolutely not. This is about identifying those people most at risk so they can take measures to protect themselves from developing serious illness from Covid-19. It is also about making sure they can access care and support during this time, including social care and help with practical needs such as getting medicines.

If you fall ill from COVID-19, or any other condition, and require treatment in hospital, you will still be treated as normal and will not be denied any medical intervention because you are in the shielding group.

#### **Q12 What will happen to my cancer treatment? For example:**

- **Will it be postponed?**
- **Should I still go to hospital appointments?**
- **How will my hospital decide whether I am a priority for treatment? Will there be national rules?**
- **If treatment, including stem cell transplants, are deferred and I begin to relapse will this limit my eligibility for future lines of treatment?**
- **Should I start chemotherapy treatment (particularly if it is a 2nd/3rd line for "mop up" ) or postpone?**
- **As a stage 4 patient will I be given life support if I have breathing difficulties due to the virus?**
- **If I get the virus and recover, will this affect my cancer treatment and outlook?**

The NHS is currently moving into the next phase of its response to the COVID-19 outbreak: to restore and recover NHS services so that they start to operate as they did before the pandemic. This means that cancer diagnosis, treatment and care are continuing, and the NHS is working to ensure that these services return to operating as they did before.

Changes are being made to the way services are delivered to keep patients and staff safe. For example:

- COVID-protected hubs have been established across the country to ensure that cancer treatment continues. The hubs support hospitals across the NHS and independent sector to work together to maximise capacity and ensure that people receive the treatment that they need. Some patients may start to see their treatment move to a different hospital as these hubs are set up. You will remain under the care of your treating hospital and clinical specialist team and should contact them with any questions about your treatment and care.
- Most hospitals have started to use more telephone consultations as a way of helping people to avoid long waits in clinics and for treatment. You may be called to arrange your treatments in this way, and planned treatments may need to be moved to help with running a smooth service.
- Some patients may have their chemotherapy at home or have fewer radiotherapy appointments, to reduce visits to hospital while continuing with their treatment.
- For some people, it may be safer to delay surgery. Your doctor may suggest a different treatment in the meantime, such as chemotherapy or hormonal therapy.

Wider measures are also being taken by all hospitals that are treating COVID patients to ensure that COVID and non-COVID patients are kept separate. For example, there may be separate entrances for COVID and non-COVID patients, all patients admitted to hospital as an emergency will be tested for COVID, and patients going into hospital for surgery or another elective procedure will be asked to isolate for 14 days and be offered a COVID test wherever possible.

Your clinical team are best placed to talk with you about your treatment and appointments. They will work with you to determine the best course of action in each individual situation. If you have any concerns or questions about your treatment, please speak to your clinical team.

**Q13 I am on chemotherapy. If I experience sweats/ cough/ shivering should I call NHS 111 or the chemotherapy care line?**

You should call the chemotherapy care line. If the chemotherapy care line is not available in your area, please speak to your clinical team about who you should call in this situation.

**Q14 If I need to shield/self-isolate for more than seven days, what will happen in relation to treatment that has to be done weekly?**

Your clinical team are best placed to talk with you about the effect on your treatment and appointments. They will work with you to determine the best course of action in each individual situation.

There is guidance if you think you or someone in your household have coronavirus:  
<https://www.gov.uk/government/publications/covid-19-stay-at-home-guidance/stay-at-home-guidance-for-households-with-possible-coronavirus-covid-19-infection>

### **Q15 How can I maintain my mental health during this time?**

We understand that this may be a worrying time and you may find staying at home and having limited contact frustrating. At times like these, it can be easy to fall into unhealthy patterns of behaviour, which can make you feel worse. Simple things you can do to stay mentally and physically active during this time include:

- look for ideas for exercises to do at home on the NHS website
- spend time doing things you enjoy – reading, cooking and other indoor hobbies
- try to eat healthy, well-balanced meals, drink enough water, exercise regularly, and try to avoid smoking, alcohol and recreational drugs
- try spending time with the windows open to let in fresh air, arranging space to sit and see a nice view (if possible) and get some natural sunlight. Get out into the garden or sit on your doorstep if you can, keeping a distance of at least 2 metres from others.

You can find additional advice and support from [Every Mind Matters](#) and the [NHS mental health and wellbeing advice website](#).

### **Q16 What are the symptoms likely to be?/Will the symptoms be different because I have cancer?/What should I look out for? / What should I do?**

The NHS outlines the common symptoms of coronavirus on its [website](#).

If you are experiencing symptoms of any infection or illness, including coronavirus, you should contact your cancer team know as you would normally. You can do this as well as calling 111 for advice about coronavirus symptoms.

### **Q17 Can you catch this virus more than once?**

It is not yet known whether reinfection is possible, although many experts think it is unlikely.

### **Q18 What should I do if my clinician is diagnosed with coronavirus?**

If your clinician is diagnosed with coronavirus and you have not seen them recently, then you are unlikely to have been exposed to coronavirus.

Health professionals are working to contact anyone who has been in close contact with people who have coronavirus. If you are concerned about the impact this will have on your treatment, contact your hospital for advice.

### **Q19 Should I go to work / see friends?**

Please refer to the Government advice:

- [Staying at home if you think you have coronavirus \(self-isolating\)](#)
- [Staying alert and safe \(social distancing\)](#)
- [Staying alert: what you can and cannot do](#)
- [Staying safe outside your home](#)
- [How to protect clinically extremely vulnerable people \(shielding\)](#)

## **Q20 Will my clinical trial continue? / Why has my trial been stopped?**

You should contact your clinical team with questions about your individual treatment including any trials you are part of.

The National Institute for Health Research (NIHR) issued guidance earlier during the pandemic response which recognised that much research would need to pause, not least because many clinical research teams were asked to redeploy to help with providing patient care. The NIHR has now published a framework to support work towards the restoration of research that they fund and/or support.

## **People who have had cancer in the past**

### **Q21 Does having had cancer treatment in the past (for example, stem cell transplants, chemotherapy, radiotherapy) in the past – even if I am now in remission – increase my risk if I get the virus?**

This depends on the type of cancer and the treatment you have had. Most people make a full recovery after cancer treatment and their immune system either recovers fully or is not affected. See [Q3](#) for further information.

## **Family/friends/carers of people living with cancer**

Please refer to the wider Government advice to protect yourselves and family/friends:

- [Full guidance on staying alert and safe \(social distancing\)](#)
- [Staying at home if you think you have coronavirus \(self-isolating\)](#)
- [How to protect clinically extremely vulnerable people \(shielding\)](#)

### **Q22 Should my child return to school if they/someone in our household has been asked to shield?**

If your child with cancer falls into any of the clinically extremely vulnerable groups outlined in [Q3](#), they and others in the household should follow the measures to ‘shield’ them.

The government has set out the following advice on attending school for children and young people who fall into any of the clinically extremely vulnerable groups outlined in [Q3](#) or who live with someone who is clinically extremely vulnerable:

- Children and young people in eligible year groups are strongly encouraged to attend (where there are no shielding concerns for the child or their household).
- Children, young people and staff who have been classed as [clinically extremely vulnerable due to pre-existing medical conditions](#) have been advised to shield. We do not expect people in this category to be attending school or college, and they should continue to be supported to learn or work at home as much as possible.
- If a child/young person or staff member lives in a household with someone who is extremely clinically vulnerable, as set out in the [guidance on shielding](#), it is advised they only attend an education or childcare setting if stringent social distancing can be adhered to and, in the case of children, if they are able to understand and follow those instructions. This may not be possible for very young children and older children without the capacity to adhere to the instructions on social distancing. If stringent social distancing cannot be adhered to, we do not expect those individuals to attend. They should be supported to learn or work at home.

Please refer to the wider guidance on [which pupils can attend school](#) on the Government website for more information.

## The future

### **Q23 Will cancer patients be a priority for the vaccine if/when it is developed?**

There is currently no vaccine for this form of coronavirus. Research is being done to develop a vaccine, but this will take many months.

### **Q24 If the pressure on the NHS grows, will my treatment be delayed?**

See [Q12](#).

### **Q25 Will there be problems accessing my cancer drugs?**

There are currently no medicine shortages as a result of COVID-19. The country is well prepared to deal with any impacts of the coronavirus and we have stockpiles of generic drugs like paracetamol in the event of any supply issues.

The Department of Health and Social Care is working closely with industry, the NHS and others in the supply chain to ensure patients can access the medicines they need and precautions are in place to prevent future shortages.

There is no need for patients to change the way they order prescriptions or take their medicines. Patients should always follow the advice of doctors, pharmacists or other

prescribers who prescribe and dispense their medicines and medical products. The NHS has tried-and-tested ways of making sure patients receive their medicines and medical products, even under difficult circumstances. If patients order extra prescriptions, or stockpile, it will put pressure on stocks, meaning that some patients may not get the medicines or medical products they need.

## Detailed questions about the categorisation of clinically extremely vulnerable people

Please look at the [Government guidance](#) on shielding in the first instance for more information, including the process for contacting people who are highest risk, how to access support, and what to do if you are living with someone who is shielding.

### Q26 Does the clinically extremely vulnerable people category include:

- **Only patients undergoing active chemotherapy for lung cancer?**  
No. Everyone undergoing active chemotherapy is included.
- **Patients who have received chemotherapy in the past three months?**  
People's immunity remains compromised for some time after finishing chemotherapy and clinical teams will be aware of this when considering their highest clinical risk patient lists.

If you have completed chemotherapy in the last 3 months, please contact your care team to discuss your specific circumstances. In the meantime, you should follow the Public Health England guidance on 'shielding' - in summary, stay at home and avoid face-to-face contact until at least the end of June.

- **Patients with blood disorders who are immunocompromised but not receiving chemotherapy?**  
Yes. These patients are included within 'people with cancers of the blood or bone marrow such as leukaemia, lymphoma or myeloma who are at any stage of treatment'.
- **Patients having radiotherapy for metastatic lung tumours?**  
Yes. These patients are included within 'people with cancer who are undergoing radical radiotherapy for lung cancer'.
- **Patients with metastatic cancer in the lungs who are not currently receiving treatment?**  
People with metastatic cancer in the lungs could be more vulnerable and therefore at highest clinical risk from Covid-19. Vulnerability will depend on the type of cancer and treatments that you have had.

If you have not received a letter, please contact your care team to discuss your specific circumstances. In the meantime, you should follow the Public Health England guidance on 'shielding' – in summary, stay at home and avoid face-to-face contact until at least the end of June.

- **Patients having any targeted treatments (more than just antibody treatments)?  
Would anti-angiogenesis targeted drugs fit into that?**

Yes, all these treatments carry excess risk and therefore people receiving these treatments would be included. These patients are included within 'people having other targeted cancer treatments which can affect the immune system, such as protein kinase inhibitors or PARP inhibitors'.

- **Transplant patients?**

Yes, if they have had a transplant within the last 6 months, and if they are taking any immunosuppression. These patients are included within 'people who have had bone marrow or stem cell transplants in the last 6 months, or who are still taking immunosuppression drugs'.

- **Patients autologous as well as allogeneic transplants in the last 6 months?**

Yes.

- **All patients with rare diseases?**

No, how rare the disease is not relevant. The issue is whether the disease significantly increases the risk of infection. If a patient has a rare disease **and** that disease significantly increases their risk of infection, they will be included in the category of clinically extremely vulnerable people.