Q&A from cancer charities – UPDATE: 18 May 2020

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

This document contains:

- Cancer patient specific Q&A's:
  - For people worried they have cancer
  - People living with cancer now
  - People who have had cancer in the past
  - Family/friends/carers of people living with cancer
  - The future
- Detailed questions about the categorisation of clinically extremely vulnerable people

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 exampleif 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.
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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[1]
- 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[2]

The Government has published guidance for these people, and strongly advises them to rigorously follow shielding measures in order to keep themselves safe:

1. Strictly avoid contact with someone who is displaying symptoms of coronavirus (COVID-19). These symptoms include high temperature and/or new and continuous cough.
2. Do not leave your house, except to attend essential medical appointments (please speak to your hospital team to determine which appointments are absolutely essential).
3. Do not attend any gatherings. This includes gatherings of friends and families in private spaces for example family homes, weddings and religious services.
4. Do not go out for shopping, leisure or travel and, when arranging food or medication deliveries, these should be left at the door to minimise contact.
5. Keep in touch using remote technology such as phone, internet, and social media.

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 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.

[1] This means before, during or after treatment, including those being managed expectantly

[2] When applying these criteria locally, clinicians should take into account the new Covid-19 NICE guidance on haemotopoietic 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).

Information on the support available to people who are shielding can be found here.

Q5 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.

Q6 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 and avoid face-to-face contact 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. 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.

Q7 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.

Q8 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.

Q9 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?**

Essential and urgent cancer diagnosis, treatment and care are continuing, and the NHS is planning now for the restoration of all services. NHS staff are working hard to make sure cancer treatments can continue in the safest and best possible way. To do this during the pandemic, there may need to be some changes to how treatments are delivered.

Cancer treatments, especially operations and chemotherapy, are riskier now than before. Cancer and its treatment can weaken the immune system, making a person more vulnerable to the virus. In some cases, it may be safer to delay cancer treatment or give it in a different way, to reduce the risk from coronavirus. Any decisions will be based on how urgent it is and the level of risk. Your safety is a priority in making any decisions.

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

- 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.

Some patients may start to see their treatment move to a different hospital as the NHS sets up ‘cancer hubs’ to coordinate treatment and ensure it can continue safely. 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. 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.

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.

Q10 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.

Q11 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

Q12 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.

Q13 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.

Q14 Can you catch this virus more than once?

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

Q15 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.

Q16 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)

Q17 Will my clinical trial continue? / Why has my trial been stopped?

The NIHR has issued guidance on clinical trials, recognising the need to prioritise research on COVID-19 itself, and that many clinical research teams will be asked to redeploy to help with providing patient care.

“Given the scale of the COVID-19 challenge, we are encouraging clinical and academic health and care professionals funded by NIHR who are working on topics other than COVID-19 to prioritise frontline care where requested to do so by their employing organisations. This means that many research studies funded by NIHR or supported by NIHR (via the Clinical Research Network and other NIHR infrastructure) may need to be paused. In addition the NIHR Clinical Research Network is pausing the site set up of any new or ongoing studies at NHS and social care sites that are not nationally prioritised COVID-19 studies”

People already having cancer treatment as part of clinical trials may be able to continue their treatment if it is safe to do so, but hospitals are trying to reduce the number of times patients attend for tests, so the arrangements for people on trials may be changed for safety reasons.

Some trials have stopped recruiting new patients. Where trials can continue they are being done so with reduced patient contact, for example by delivering medication directly to patients and following up by telephone or video rather than face to face appointments.

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

People who have had cancer in the past

Q18 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)

Q19 Should I consider not sending my child with cancer/sibling of a child with cancer to school?

For the time being, the Government has asked parents to keep their children at home, wherever possible, and for schools to remain open only for those children who absolutely need to attend. Please see the Government guidance on school closures: https://www.gov.uk/coronavirus

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.

If your child with cancer is not in one of the clinically extremely vulnerable groups and you feel you need to send them to school (e.g. you are a key worker), please seek advice from the clinical team overseeing your child's care.

The future

Q20 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.

Q21 If the pressure on the NHS grows, will my treatment be delayed?

See Q8.

Q22 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.

Q23 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.