COVID-19 guidance for children and young people with cancer undergoing treatment

Guidance updated 6 April 2020 - the amendments made on 6 April are shown in red so you can find them easily.

This guidance is intended for children and young people on active cancer treatment and up to six months after completion of treatment and those who have received a bone marrow transplant (BMT), also called a stem cell transplant (SCT).

This information is based on the UK Government and Public Health England advice and may differ from guidance issued from other countries. It will be regularly updated as and when new information is available. It has been written by experts in Childhood and Teenage and Young Adult cancer to reflect the particular needs of our patients.

We acknowledge there is a huge amount of information online and this can be overwhelming and sometimes conflicting, causing even more worry and stress. It is important that families make sure that information is filtered and gathered from reliable, easy to understand sources. Our booklet 'Searching for information and support online' has further information.

Update 6 April 2020

Summary of changes:

1. Healthcare professional protective wear while caring for extremely vulnerable group patients and for certain procedures

2. Extension of definition of extremely vulnerable group for transplant patients
New UK Government guidance published on 3 April 2020 reflects the changing level of risk of coronavirus exposure to healthcare professionals. This includes additional respiratory protection to be worn by healthcare teams for certain procedures that release particles into the air.

It has also been updated to reflect the need for enhanced protection of patients in the extremely vulnerable groups to recommend healthcare teams wear disposable aprons, gloves and face masks.

UK Government guidance published on 23 March 2020 urged everyone to stay at home to help stop the spread of coronavirus. This includes people of all ages - even if they have no symptoms or other health conditions. This will initially last for three weeks from 23 March, at which point the Government will look at them again and relax them if the evidence shows this is possible.

The three new measures for everyone to follow are:

- Requiring people to stay at home, except for very limited purposes
- Closing non-essential shops and community spaces
- Stopping all gatherings of more than two people in public

Earlier UK Government guidance published on 21 March 2020 identified a patient group defined on medical grounds as extremely vulnerable from COVID-19. These patients will require shielding where possible. We understand that this guidance may have caused confusion and anxiety as to whether this applies to your child. You may have also received texts or a letter from your GP regarding this.

Reports from Italy and China continue to show that children with cancer are not severely affected by COVID-19. To date in the UK, we have not seen any cases of severe coronavirus disease in children undergoing cancer treatment. The Government guidance on extremely vulnerable people is based on adult data and therefore this is our expert interpretation for children and young people with cancer.
Is my child in the extremely vulnerable group?

New guidance from NICE (National Institute of Clinical Excellence) published on 1 April 2020 has extended the original definition of the extremely vulnerable group for transplant patients. We are seeking to clarify the evidence on which NICE have made their decision with respect to children and young people who have received transplants but have updated our guidance accordingly while this is done.

This group includes all children and young people:

- Undergoing active chemotherapy for any diagnosis
- Receiving treatment for leukaemia or lymphoma
- Who have received a donor stem cell transplant (allogeneic transplant) in the last 24 months (may move into the vulnerable group after this time - see below)
- Who have received their own stem cells back (autograft transplant) in the last 12 months
- Receiving immunotherapy including CAR-T patients
- Receiving other antibody treatments for cancer
- Receiving targeted cancer treatments (these usually end with \(-nib\), for example dasatinib, crizotinib)

What should I do if my child is in the extremely vulnerable group?

The Government guidance recommends shielding for the extremely vulnerable group. Shielding is a practice used to protect extremely vulnerable people from coming into contact with coronavirus. We understand that these measures are very challenging for families with children to follow. We also recognise the difficulties faced by families where children may be cared for in more than one household or where carers may also be key workers. We suggest that families
try their best to follow these measures where possible until we have further evidence that this is no longer required.

**Shielding means:**

- Strictly avoid contact with someone who is displaying symptoms of coronavirus (COVID-19). These symptoms include high temperature and/or new and continuous cough.
- Do not leave your house apart from essential medical visits to the hospital for treatment as advised by your own team.
- Home visits from nurses who provide essential support should continue as advised by your own team.
- Do not attend any gatherings. This includes gatherings of friends and families in private spaces for example family homes, weddings and religious services.
- 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.
- Keep in touch using remote technology such as phone, internet, and social media.

**What protection might the healthcare team be wearing looking after my child?**

For children and young people identified above as the extremely vulnerable group who require shielding, your healthcare team may now be wearing single use disposable plastic aprons, gloves and a surgical mask. This will apply in all settings – in the home for community visits and for inpatients and outpatients within the hospital.

**What protection might the healthcare team be wearing for anaesthetic procedures such as lumbar punctures with intrathecal chemotherapy?**

Certain procedures can result in the release of airborne particles (aerosols) which can increase the risk of transmission of coronavirus. Therefore, if your child requires one of these procedures, the healthcare team may be wearing
extra respiratory protective equipment including a full-length gown, a sealed mask and a face visor.

What about siblings and other members of the household? Do they also need to follow shielding guidance?

Siblings and other members of the household are not required to adopt protective shielding measures for themselves but should follow the strict rules about staying at home as recommended for the whole population.

However, we understand that it will be impossible for families with children to separate themselves at home. We advise that families try their best to follow the guidance and encourage everyone in the household to regularly wash their hands, avoid touching their face and clean frequently touched surfaces.

Is my child in the vulnerable group?

This group includes all children and young people:

- Up to 6 months after completion of standard chemotherapy
- Who have received radiotherapy to the whole abdomen or to the spleen
- Who have received a donor stem cell transplant more than 24 months ago and who received Total Body Irradiation (TBI)
- Who are on long term maintenance steroids
- Who have completed treatment for cancer but have ongoing chronic lung, heart, kidney or neurological conditions

What should I do if my child is in the vulnerable group?

As of 23 March 2020, the Government guidance recommends the whole population should follow strict rules about staying at home and staying away from others. This will include children in the vulnerable group. Everyone in the UK has now been advised to reduce social interaction to reduce the transmission of COVID-19.

New social distancing measures mean:
• Requiring people to stay at home, except for very limited purposes
• Closing non-essential shops and community spaces
• Stopping all gatherings of more than two people in public

**What about siblings and other members of the household? Do they also need to follow the new rules about social distancing guidance?**

Yes. Siblings and other household members should also all stay at home and stay away from others. Current advice recommends we should all be taking steps to stop social interaction between people in order to reduce the transmission of coronavirus (COVID-19). We acknowledge the challenges this will bring but everyone should be trying to follow these measures as much as is pragmatic until we have further evidence that this is no longer required. Although these measures are severe, they are considered necessary to keep everyone as safe as possible and to help the NHS cope with the cases that do happen.

**What if my child does not fall into either extremely vulnerable or vulnerable group?**

Most children who completed standard chemotherapy more than 6 months ago should follow the new rules recommended for everyone in the UK to stay at home and stay away from others. We suggest you check with your treating team if you have specific questions about your child. Children who have received a bone marrow transplant (BMT) should direct questions to their transplant team and refer to COVID-19 guidance produced by the UK Paediatric BMT Group.

**Background information**

**What is COVID-19?**

Coronavirus (COVID-19) is a new strain of coronavirus first identified in Wuhan City, China in December 2019. This is a rapidly evolving situation which is being monitored carefully. The current risk to the UK has been escalated to high. We understand that this is a very challenging time for everyone. We are working
together within CCLG and globally to share our understanding and information through research.

To date in the UK, we have not seen any cases of severe coronavirus disease in children who are undergoing cancer treatment. Furthermore, information from Lombardy which is the most affected area in Italy has reported no positive COVID-19 cases detected in paediatric oncology or transplanted patients so far.

**How is it spread?**

Similar viruses to coronavirus spread by cough droplets or sneeze droplets. These droplets fall on people in the close vicinity and can be directly inhaled or picked up on the hands and transferred when someone touches their face. COVID-19 spreads through close sustained contact with someone who has the virus (for instance being within 2 metres of someone for longer than 15 minutes).

**What are the symptoms?**

The symptoms of this new coronavirus (COVID-19) include cough, fever, shortness of breath, or flu-like symptoms. The current evidence is that most cases in children and young people appear to be mild.

**Is there a treatment available?**

There is currently no vaccine to prevent COVID-19 acute respiratory disease. The best way to prevent infection is to avoid being exposed to the virus. Anti-viral medications have not yet been shown to be effective against coronavirus.

**How might coronavirus affect my child who is undergoing cancer treatment?**

Children and young people undergoing cancer treatment have a weakened immune system which will make it harder for the body to fight off infections such as COVID-19 (in the same way as for seasonal flu). It is important for children with cancer and their families to follow steps to protect themselves where possible.
What precautions should we take?

Children and young people undergoing treatment and their families will already be familiar with the following infection precautions recommended by Public Health England.

- Wash your hands often - with soap and water for at least 20 seconds. Use an alcohol-based hand sanitiser that contains at least 60% alcohol if soap and water are not available. This is particularly important after taking public transport.
- Try to help your child avoid touching their eyes, nose, and mouth with unwashed hands where possible
- Avoid contact with people who are known to be unwell
- Try and cover your child’s cough or sneeze with a tissue, then throw the tissue in a bin and wash hands again after disposal.
- Clean and disinfect frequently touched objects and surfaces in the home and work environment

Should we be wearing face masks to protect ourselves from infection?

Face masks play a very important role in clinical settings, such as hospitals but there is very little evidence of widespread benefit from their use outside of these clinical settings. Face masks must be worn correctly, changed frequently, removed properly and disposed of safely in order to be effective.

What should I do if my child develops a fever or any other symptoms?

You should follow the normal guidance for attending hospital if your child develops a fever. Your child will be assessed and treated as per your local hospital policy. If you are concerned that your child has symptoms of COVID-19 or has a known COVID-19 contact, it is essential that you inform the treating hospital before your arrival so necessary arrangements can be made.
Will my child have a cubicle if they need to stay in hospital?

It is likely that the demand for cubicles will escalate during the current pandemic. Therefore, each hospital team will need to make decisions based on individual patients need for isolation in a cubicle. Please note you might see staff looking after your child wearing additional protection such as surgical masks to help try and stop any respiratory viruses spreading and reduce the risk of transmission to staff.

What if someone in our household develops symptoms?

If other household members develop symptoms (either high temperature or a new continuous cough), the current guidance is to stay at home for 14 days to help protect others in your community (self-isolation). It is likely that people living within a household will infect each other or be infected already. Staying at home for 14 days will greatly reduce the overall amount of infection the household could pass on to others in the community. Self-isolation does not apply to children undergoing treatment for cancer who will need to be assessed in hospital first if they develop symptoms.

What does self-isolation mean?

Self-isolation involves avoiding contact with anyone within 2 metres for 15 minutes or longer. This includes contact with other people in your household and for young children is not always possible.

If any child in your house needs to self-isolate, you might choose to have one parent designated as being in close contact with your child, with both of you isolated from the rest of the household. We understand this might be impossible if there’s only one parent, please see if other family members might be able to help.

Will we still be visited by our outreach/community nurses?

Currently, outreach visits to the home will be going ahead where possible. Please ensure you communicate with staff prior to any planned home visits to let
them know whether any household members are symptomatic and are self-isolating.

**Should my child continue taking oral chemotherapy?**

It is not recommended to stop or change your child’s chemotherapy to reduce the risk of neutropenia or for any other reason during the pandemic. If you have any questions regarding your child’s treatment, please ask your child’s consultant or a member of the team.

**Will the supply of my child’s medications be affected by COVID-19?**

The NHS has been looking at its supply chains to ensure a secure supply of necessary drugs. There is an action plan in place to manage the supply of medicines in the UK. Currently there are no shortages linked to coronavirus and no drug manufacturers have said they expect problems with supply due to coronavirus.

**What about visiting my child in hospital?**

As is usual practice, any visitors who are unwell or who have any symptoms should not visit your child in hospital. All visitors should be reminded to wash their hands frequently with soap and water or use hand sanitiser. Restrictions on the number of visitors (aside from parents) are likely to be imposed by your treating hospital particularly to avoid grandparents and siblings visiting.

**Should we cancel my child’s treatment or follow-up appointments at the hospital?**

If your child has a scheduled appointment for treatment, unless they are unwell, they should attend. In the event of any disruption to the service provided, clinicians will always make decisions to prioritise treatment for those most in need and in consultation with patients. The chief focus will be to provide essential services, helping those most at risk to access the right treatment.
Centres will be encouraged to offer telephone or Skype consultations for those patients who do not necessarily need to travel to the hospital for treatment.

**My child is on a clinical trial. How will this be affected by COVID-19?**

For children and young people already receiving treatment within a clinical trial, the plan will be to continue where possible and to reassess the situation frequently. Some centres have temporarily stopped recruiting to some or all clinical trials until further notice. The main purpose of such difficult decisions is to ensure that all patients get the best possible care available and those already on trials can continue. Decisions will need to be made on case-by-case basis by local teams on basis of patient safety and capacity assessment.

**How might coronavirus affect my child who is due to have a bone marrow transplant?**

Children and young people who are due to receive bone marrow transplant should discuss details with their transplant team. Post-transplant patients should follow standard guidance if they are unwell and any further concerns discuss with transplant team.

**My child has received a bone marrow or donor stem cell transplant. What precautions should they take?**

The British Society for Bone Marrow Transplantation (BSBMT) recommends that children are considered in the extremely vulnerable group and should practice shielding until at least 24 months post transplant and have been off of immunosuppression for at least 6 months. This is longer than the adult recommendation but is based on the expert opinion of the group. Patients who have ongoing chronic graft vs host disease or other health problems must consult their transplant team to check how long they should be considered in the extremely vulnerable group.
Patients who received a donor stem cell transplant more than 2 years ago and received Total Body Irradiation (TBI) as part of their transplant should be considered vulnerable life long (due to effects on the spleen).

If you are unsure then please speak to your transplant team.

Why are children who have received radiotherapy to the whole abdomen included in the vulnerable group?

Whole abdominal radiotherapy, radiotherapy to the left side of the abdomen or total body irradiation might affect the spleen. The spleen is important in preventing some serious bacterial infections. Current Government guidance recommends that those who have problems with their spleen function are in the vulnerable group. Radiotherapy to the lung or the pelvis or other areas of the body will not have affected the spleen and are unlikely to increase the risk of COVID-19.

My child was treated for cancer some time ago. Do they need to take extra precautions?

The Late Effects Group of CCLG has produced their own guidance for the CCLG treatment centres. If your child has ongoing chronic health problems as a result of treatment, then you should contact your Late Effects Service for advice.

What if there are other patients with suspected coronavirus in our hospital? Will they pose a risk to my child?

All testing of suspected coronavirus cases is carried out in line with strict regulations in each hospital. All suspected cases are kept in isolation, away from public areas of the hospital and returned home also in isolation. Any equipment that comes into contact with suspected cases is thoroughly cleaned as appropriate. Patients and their parents can be reassured that their safety is a top priority and are encouraged to attend all essential appointments as usual.

Can my child still go to school?
No. For children and young people undergoing cancer treatment, it is recommended that they do not go to school. Most recent advice (as of 16 March 2020) is that those with a weakened immune system should follow strict social distancing. Teenage and young adult patients should work from home. If your child has a scheduled hospital appointment for treatment, unless they are unwell, they should attend.

How do I keep myself up to date about COVID-19?

Keep checking the Public Health England website for regular updates.

What if I have some more questions?

Please speak to your child’s consultant or any member of the team in your treating centre.

The One Cancer Voice group of charities have developed some further general guidance for cancer patients which you may find useful, although this is primarily aimed at adults with cancer.

Original version written by Dr Jessica Bate, Consultant Paediatric Oncologist, Southampton Children's Hospital and Chair, CCLG Supportive Care Group on behalf of the CCLG Executive.

Updated version 17 March revised by Dr Jessica Bate with Dr Bob Phillips, Honorary Consultant in Paediatric Oncology, Leeds Teaching Hospitals, Prof Richard Grundy, CCLG Chairman and Ashley Gamble, CCLG CEO. This information was discussed and reviewed by a national group comprising medical representatives from all UK paediatric oncology Principal Treatment Centres, with representation from CLIC Sargent and Bloodwise.