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

Guidance updated 22 May 2020

This guidance is intended for children and young people on active cancer treatment up to the age of 18 and for 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 cancer to reflect the particular needs of our patients. This guidance is consistent with the advice from the Royal College of Paediatrics and Child Health and has been developed with them.

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 22 May 2020

Summary of changes:

1. Changes to definition of extremely vulnerable group that require ongoing strict shielding
2. Changes to definition of vulnerable group that no longer require strict shielding
3. Guidance regarding potential return to school for patients and siblings
4. Information about face coverings
5. Information about testing for patients, parents and healthcare professionals
6. Information about black and ethnic minority (BAME) patients
7. Information about the new inflammatory syndrome associated with COVID-19 in children

**How has CCLG decided what the new recommendations should be?**

Previous UK Government guidance published on 21 March 2020 identified a patient group defined on medical grounds as extremely vulnerable from COVID-19. These patients required shielding where possible. You may have also received texts or a letter from your GP or your local cancer centre regarding this. This Government guidance on extremely vulnerable people was based on adult data.

Since our last guidance, we have collected information on children and young people with cancer who have tested positive for COVID-19 from all CCLG centres in the UK. The number of cases is small (46 in total as of 18 May 2020) and importantly, the majority have had a very mild disease course. We have reviewed this UK data along with published data from around the world and this has formed our expert interpretation for children and young people with cancer. As more information has been obtained, there is recognition within paediatric oncology professional groups internationally that the increased risk to children with cancer is not as significant as originally thought to be. We have made the following recommendations for the extremely vulnerable and vulnerable group based on the available information and will continue to review this.

This advice is based on the following facts:

1. Children are far less likely than adults to get COVID-19 infection.
2. The risk of severe COVID-19 disease in children is very low.
3. The risk of severe COVID-19 disease in children with cancer across the world remains low.

4. There is evidence to suggest that children do not spread COVID-19 like adults. Child to child transmission is rare.

Your treating team may choose to follow different advice depending on your child’s individual circumstances. Your treating team may temporarily move your child from the vulnerable group to the extremely group at certain points in treatment.

Is my child in the extremely vulnerable group?

This group includes all children and young people:

- Receiving induction chemotherapy for leukaemia
- Receiving chemotherapy for relapsed and/or refractory disease
- Who have received a donor stem cell transplant (allogeneic transplant) in the last 12 months
- Who have received their own stem cells back (autograft transplant) in the last 6 months
- Receiving immunotherapy including CAR-T patients
- Receiving antibody treatments for cancer (these usually end with -mab, for example dinutiximab, blinatumomab) and up to 6 months following antibody treatment
- Receiving targeted cancer treatments (these usually end with -nib, for example dasatinib, crizotinib) and up to 6 months following targeted cancer treatment
- Receiving replacement immunoglobulin therapy

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:**

- Do not leave your house apart from essential medical visits to the hospital for treatment as advised by your own team
- Avoid going to school when schools are re-opened
- Avoid going to work
- Do not meet up with people outside of your household, including friends and family that don’t normally live with you, even if you are 2 metres apart (3 steps)
- Strictly avoid contact with someone who is displaying symptoms of coronavirus (COVID-19). These symptoms include high temperature and/or new and continuous cough.
- 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.
If my child is in the extremely vulnerable group, do siblings and other members of the household also need to shield?

Siblings and other members of the household are not required to adopt protective shielding measures for themselves but should avoid going to school and work where possible. 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:

- Undergoing active chemotherapy for any cancer diagnosis including Langerhans Cell Histiocytosis (LCH) and up to 6 months after completion of treatment
- Receiving treatment for leukaemia or lymphoma and up to 6 months after completion of treatment
- 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?

Our review of the available data suggests that children and young people in the vulnerable group no longer need to strictly shield. This group should follow the Government guidance for the whole population about staying alert and safe. However, the children and young people in the vulnerable group could attend school when schools are re-opened. They should still follow social distancing measures and good hand hygiene.

Children and young people who have completed treatment for cancer but have other medical conditions should follow guidance from their treating teams.
As of 11 May staying alert and safe (social distancing) measures mean:

- Requiring people to stay at home, except for a limited set of reasons but can take part in more outdoor activities
- **Staying safe outside your home:** washing hands regularly, maintaining social distancing and no gatherings of group of more than two except with members of your household

**What about siblings and other members of the household? Do they need to follow the staying alert and safe guidance?**

Yes. Siblings and other household members should also all stay alert and stay safe. Current advice recommends we should continue to stop social interaction between people outside of the household 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.

**When can my child (and their siblings) go to school?**

Children in the extremely vulnerable group (and their siblings) should not attend school when schools are re-opened in June, even if their year group has. Their siblings should not attend school either. Teenage patients in the extremely vulnerable group should work from home.

Children in the vulnerable group (and their siblings) can attend school when schools are re-opened in June but should continue to follow guidance on social distancing and good hand hygiene. The vast majority of children who no longer require shielding will benefit from returning to school but you may wish to discuss this further with your treating team.

We understand that you may have concerns about your child returning to school. Although not completely free of risk, we believe that it is safe for your child to
return to school based on the information available currently. We suggest that you confirm that your child’s school is able to ensure good hygiene and social distancing measures. Your treating team can help with this. The greatest risk for school outbreaks remains adults. Therefore, it is very important that parents comply with restrictions to minimise the contact that they have with other parents, teachers and students in the school.

We acknowledge that returning to school is a big step. You may, with your treating team, decide that returning to school is not advisable for your child based on individual circumstances.

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

Most children and young people who completed chemotherapy more than 6 months ago and/or received radiotherapy to the whole abdomen or to the spleen are no longer in the vulnerable group. They should follow the rules for the general population. We suggest you check with your treating team if you have specific questions about your child.

**Should we be wearing face coverings?**

Wearing a face covering does not protect you or your child. However, if you or your child is infected but have not yet developed symptoms, it may provide some protection for others you come into close contact with. If you can, wear a face covering in an enclosed space where social distancing isn’t possible and where you will come into contact with people you do not normally meet. This is most relevant for short periods indoors in crowded areas such as on public transport or in some shops.

A face covering is not the same as the surgical masks or respirators used by healthcare and other workers as part of personal protective equipment.
Face coverings should not be used by children under the age of 2 or by children who may find it difficult to manage them correctly. Further information about how to wear and make a cloth face covering can be found here.

For hospital visits, your local hospital will advise on their expectations for face covering or not if you need to attend.

**What about COVID-19 testing for parents, patients and staff?**

On 14 May 2020, NHS England published guidance to minimise the transmission of COVID-19 infection within hospitals through the testing of patients and staff at the right time and frequency. This will be updated as more information is available. Your child’s hospital will have its own policy in place for testing for planned and unplanned admissions. Some hospitals have also started testing staff. Please speak to your treating team if you have further questions about this.

**If my child is from a Black, Asian and Minority Ethnic (BAME) group, should my child be shielding even if they are not in the extremely vulnerable group?**

Black, Asian and Minority Ethnic (BAME) refers to individuals from various ethnic backgrounds other than White. Emerging data has shown that a higher number of BAME adults with COVID-19 become critically ill when compared to White adults with COVID-19. There is not yet enough information to fully understand why this is but research is underway.

As children and young people with cancer have not been shown to be severely affected by COVID-19, it is difficult to draw different conclusions for children from a BAME group. We recommend that all children and young people and their families who are not included in the extremely vulnerable group should continue to follow the Government guidance on staying alert and safe.
What about the new inflammatory syndrome associated with COVID-19 in children? Are children with cancer at higher risk of this?

Most children only develop mild symptoms from COVID-19 infection, including those children receiving treatment for cancer. However, a small number of children have recently been identified who develop a significant whole body inflammatory response. This rare new syndrome has been named Paediatric Inflammatory Multisystem Syndrome Temporally Associated with SARS-CoV-2 infection (PIMS-TS) or you may see it referred to as a Kawasaki-like disease. The current evidence does not suggest that children with cancer are at increased risk of developing this condition. However, we will continue to monitor this as more information becomes available.

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. You may be asked to shield for the 2 weeks prior to any transplant procedure. Post-transplant patients should follow standard guidance if they are unwell and any further concerns discuss with the transplant team.

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

The UK Paediatric BMT Guidelines recommend that children who have received a bone marrow transplant are considered in the extremely vulnerable group and should practice shielding until at least 12 months post transplant. 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.

Why are children who have received radiotherapy to the whole abdomen no longer 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. After review of available data, the guidance has since been changed so that those who have problems with their spleen function are no longer in the vulnerable group.

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

For children and young people identified as being in the extremely vulnerable and vulnerable group, 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.

Potential changes to treatment

You may have heard about 'prioritisation of treatment' for various patient groups during the COVID-19 pandemic. We have been asked to formally plan for what we would do if the Children’s and Young Persons Cancer services came under extreme pressure. We do not want to compromise the quality and effectiveness of current anti-cancer therapy.

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 although human research trials are underway. 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. However, evidence from the UK and around the world appear to show that children and young people undergoing cancer treatment are not severely affected.

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

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?**

The most common symptoms of coronavirus (COVID-19) are recent onset of any of the following:

- a new continuous cough
- a high temperature
- a loss of, or change in, your normal sense of taste or smell (anosmia)

For most people, coronavirus (COVID-19) will be a mild illness. **However, if you have any of the symptoms above you should self-isolate at home.**

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.

**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.

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.

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.

Updated version 23 March and 24 March revised by Dr Jessica Bate with Dr Bob Phillips, Prof Richard Grundy, Ashley Gamble, Dr Geoff Shenton, Consultant Paediatric Haematologist, Newcastle and Dr John Moppett, Consultant Paediatric Oncologist, Bristol.