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


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 30 September 2020

No changes to guidance, but additional information added:

1. Recognition of rising number of cases
2. No changes to description of extremely vulnerable group or vulnerable group
3. School attendance
4. Importance of influenza vaccination
5. Local lockdown guidance
How has CCLG decided what the new recommendations should be?

Since our last guidance (31 July 2020), there has been a rise in the number of cases of coronavirus in the UK. The Government has announced further national measures to address this. During this time, we have continued to collect and analyse 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 remains low (56 in total as of 23 September 2020) and importantly, the majority continue to have a very mild disease course.

There are no current changes to the children and young people in the extremely vulnerable group or in the vulnerable group. Children in the extremely vulnerable group are not recommended to attend school or nursery. These children remain at risk of other infections (apart from coronavirus) and should therefore continue to follow precautions such as regular hand washing, social distancing where possible, avoiding contact with people who have symptoms of infection and avoiding crowded places. These children and their families do not need to strictly shield as a household.

The Bone Marrow Transplant Group have also been collecting data across Europe for how COVID-19 has affected children who have had a donor bone marrow (stem cell) transplant. Specific information about transplant patients can be found here.

We have reviewed 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 vulnerable group at certain points in treatment.

We have written a document to explain the rationale and evidence behind the recommendations we have made:

Is my child in the extremely vulnerable group?

This group includes all children and young people:

- Receiving induction chemotherapy (initial course of chemotherapy with high dose steroids) for acute lymphoblastic leukaemia (ALL) and non-Hodgkin’s lymphoma
- Receiving chemotherapy for acute myeloid leukaemia (AML)
- Receiving chemotherapy for relapsed and/or refractory leukaemia or lymphoma
- Who have received a donor stem cell transplant (allogeneic transplant) until their immune system has recovered
- Who have received their own stem cells back (autograft transplant) until their immune system has recovered
Patients undergoing CAR-T therapy until their immune system has recovered

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

From 1 August 2020, the Government guidance paused shielding. This may change depending on the number of positive cases. Shielding is a practice used to protect extremely vulnerable people from coming into contact with coronavirus.

Children and young people in the extremely vulnerable group remain at higher risk of infections other than COVID-19. Children in the extremely vulnerable group are not recommended to attend school or nursery when schools are re-opened. This is due to the increased risk of infections other than COVID-19 and in keeping with general recommendations prior to the COVID-19 pandemic. Please consult your child’s treating team for further specific advice regarding this.

The extremely vulnerable group should therefore continue to take strict infection precautions such as regular hand washing, social distancing where possible, avoiding contact with people who have symptoms of infection and avoiding crowded places but no longer need to strictly shield as a household.

We understand that you may have concerns about the rise in cases and the need for shielding for your child and that you may choose to continue to shield more strictly. Please speak to your treating team for further advice.

If my child is in the extremely vulnerable group, what should siblings and other members of the household do now that shielding is paused?

Siblings and other members of the household can attend school and work where possible. We advise that families continue to maintain strict infection precautions within the household including 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 acute lymphoblastic leukaemia (ALL) or non-Hodgkin’s lymphoma (NHL) after induction and up to 6 months after completion of treatment
- Up to 6 months after completion of treatment for acute myeloid leukaemia
- Receiving treatment for chronic myeloid leukaemia (CML) with tyrosine kinase inhibitor (for example, imatinib)
- Who are on long term maintenance steroids
- Who have completed treatment for cancer but have ongoing chronic lung, heart, kidney or neurological conditions
- Receiving antibody treatments for cancer (these usually end with -mab, for example dinutuximab – also known as antiGD2) 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 vulnerable group?

Our review of the available data suggests that children and young people in the vulnerable group can follow the Government guidance for the whole population about staying alert and safe. The children and young people in the vulnerable group can attend school when schools are re-opened. They should still follow social distancing measures and good hand hygiene. The Government changes
to restrictions are regularly updated here. Siblings and other members of the household should also follow this guidance.

Children and young people who have completed treatment for cancer but have other medical conditions should follow guidance from their treating teams.

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

Children in the extremely vulnerable group are not recommended to attend school or nursery. This is due to the increased risk of infections other than COVID-19 and in keeping with general recommendations prior to the COVID-19 pandemic. Please consult your child’s treating team for further specific advice regarding this. Teenage patients in the extremely vulnerable group should work from home.

Siblings of children in the extremely vulnerable group can attend school or nursery when schools are re-opened. We understand that this means that they will be in contact with other children, but the risk of child to child transmission appears to be much lower than between adults. We recommend that siblings wash their hands as soon as they come back home.

Children in the vulnerable group (and their siblings) can continue to attend school or nursery and should continue to follow infection precautions including good hand hygiene.

All schools must comply with health and safety law which requires them to assess risks and put control measures in place. If there is a confirmed case within your child’s school, this will be managed within the school community. This should involve engagement with the NHS Test and Trace process to contain any outbreak by following local health protection team advice.

We understand that you may have concerns about your child attending school when the number of cases is rising. Although not completely free of risk, we believe that it is safe for your child to attend school based on the information available currently. 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.

**What about the influenza vaccine? Should my child receive it?**

The influenza (flu) vaccine is recommended for all patients receiving chemotherapy or within 6 months of completing chemotherapy to help protect them against flu and its complications. It will not protect your child from COVID-19. It is recommended that your child receives the flu vaccine now so that they may be protected over the peak season.

Your child should receive the injected (into the muscle) vaccine and not the live nasal spray flu vaccine. Members of the household should also receive the flu vaccine. Other children in the household can receive the nasal spray flu vaccine.

Children who have received a donor bone marrow (stem cell) transplant are recommended to receive the injected flu vaccine from 6 months after transplant.

**What should I do if there is a local lockdown where I live?**

If there is a local outbreak of COVID-19 identified within your area, please follow any guidance set out locally or any specific law which applies to the area you live in to help control the spread of the virus. The guidance on shielding varies in local lockdowns as each has different rules. You can find out the restrictions for your local area [here](#). In some of the local lockdown areas, it is recommended that children and young people in the extremely vulnerable group and their household members should return to strict shielding if there is an outbreak where you live.

**Where can I find more specific guidance regarding my child who has received or is due to receive a donor bone marrow (stem cell) transplant?**
The Bone Marrow Transplant Group have been collecting data across Europe about COVID-19 in children who have had a donor bone marrow (stem cell) transplant. Specific information about transplant patients can be found [here](#).

**What group does my child fall into if they are receiving targeted therapy as part of a clinical trial (usually ending with -nib or -nab)?**

Most of these children will be in the vulnerable group and not require shielding. We suggest you check with your treating team with any specific questions about your child.

I have read about the [RECOVERY trial](#) which has shown dexamethasone should now be used to treat COVID-19. What does this mean for my child receiving dexamethasone as part of treatment?

The RECOVERY trial looked at a range of potential treatments for COVID-19. The preliminary results from the trial have shown that dexamethasone reduces the risk of death among patients with severe respiratory complications from COVID-19. The paediatric part of the study including the dexamethasone arm continues as there isn’t a clear answer in children yet. Dexamethasone is a medication that is used as treatment for many different diseases including certain cancer diagnoses such as leukaemia. It has not been shown to be a preventative medication for COVID-19. Children and young people on dexamethasone should continue to take it as directed by their treating team.

**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. From 24 July 2020, face coverings are now required on public transport, shops and supermarkets and strongly encouraged in other enclosed public spaces. At the time of writing this guidance, the advice on face coverings is being changed again to include more indoor spaces. Please check the lastest government guidance.
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.

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 until their immune system has recovered. 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.

**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.

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 Haematologist, Bristol.

Updated version 6 April revised by Dr Jessica Bate with Dr Bob Phillips, Prof Richard Grundy, Ashley Gamble, Dr Geoff Shenton and Dr John Moppett

Updated version 22 May revised by Dr Jessica Bate with Dr Bob Phillips, Prof Richard Grundy, Ashley Gamble, Dr Geoff Shenton and Dr John Moppett
Other useful information
We've worked with CLIC Sargent to produce some information for schools to help them support a child with cancer during COVID-19. [Read the schools guidance.]

[UK data on childhood cancer patients with COVID-19]

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.

[Download One Cancer Voice advice on coronavirus for people with cancer]

[Additional advice and support from CLIC Sargent and CCLG]

[Information for survivors - produced by our Late Effects Group]