

COVID-19: Updated guidance for people with thalassaemia

This document is a collaboration between the National Haemoglobinopathy Panel and the United Kingdom Thalassaemia Society which aims to offer guidance to people with thalassaemia (transfusion dependent and non-transfusion dependant) and their carers.

In recent weeks, the UK Governments have released updates to shielding guidance and provided dates when shielding will be paused or reviewed.

We know many of you have questions and concerns about what this may mean for you, how and whether to carry on following this guidance, and what happens once shielding ends for you. We hope this information will support you to make the best decision for you and your loved ones.

Shielding in England and Northern Ireland

From Monday 6 July, shielding restrictions in England and Northern Ireland will be partially eased although this may be delayed/suspended in some areas if there are localised increases in COVID patients. Those who are shielding will be able to:

- Spend time outdoors in a **group of up to 6 people** including those outside their household, while **maintaining social distancing** and ensuring strict hand hygiene. This can be in a public outdoor space, or in a private garden.
- No longer observe social distancing with **other members of your household**.
- Those who live alone or are single parents with children will also be able to create a **“support bubble”** with one other household of any size. All those in a support bubble can spend time together inside each other's homes, including overnight stays. Ideally, it is advised they meet with the same household on each occasion.

From **Saturday 1 August**, shielding in England and Northern Ireland will be “paused” but will be under regular review. People will be able to:

- Adopt strict **social distancing practices** rather than full shielding.
- Able to go out more and see more people, visit shops and places of worship.
- You will be able to return to work if you cannot work at home – as long as your workplace is COVID-safe and has measures in place to reduce the risk of coronavirus. However, working from home should be prioritised if at all possible.
- Children will be able to return to school once it is safe to do so.

However, it is advised that all individuals must continue to maintain social distancing, follow strict hand and respiratory hygiene measures and minimise contact with others outside your household or support bubble.

The Government has announced that priority online shopping for the main supermarkets have been guaranteed beyond the end of July for those already signed up. **Those who have not yet registered as vulnerable should register by 17 July.**

The NHS Volunteer Responders scheme will continue to be active and deliver food and medicines where needed. Those who will still need help with shopping, medication or essential supplies are advised to call 0808 196 3646 (8am to 8pm).

However, **the food and medicine boxes** facilitated by the National Shielding Service **will stop** as of **1 August** as individuals will be allowed to visit shops and pharmacies. Those who unable to access medication, are advised to:

- Ask someone to pick up prescriptions from the local pharmacy (if possible, this is the best option).
- Contacting the local pharmacy to ask for assistance in finding a volunteer to deliver medication

The Government has pledged to write to all those on the clinically extremely vulnerable list to formally advise of these changes, and the NHS will retain the shielded list in order to communicate any further changes to **shielding guidance**, which will be reviewed again at the end of July.

Read the **latest shielding guidance from the Northern Ireland Government**.

Shielding in Wales

Shielding is still in place for people with thalassaemia in in Wales until 16 August, and this date is being kept under review. The **Welsh Government's guidance on shielding** was last updated on 12 June.

Shielding in Scotland

Shielding will continue in Scotland until it is next reviewed on 31 July. The **Scottish Government's guidance on shielding** was last updated on 19 June.

What will happen when shielding comes to an end?

Shielding has been tough for many people with thalassaemia and every household has faced their own individual challenges. Some people may feel that they want to go back to work or may have children who want to go back to school, while others may not be ready to do.

We have tried to provide answers to some of the frequently asked questions (FAQs) about coping with the changes to shielding and have also included some other FAQs for the rest of the thalassaemia population. As ever, we encourage you to speak to your haematology team so that you can make the right decision for you and your family.

Is coronavirus over now that restrictions are being lifted?

No, coronavirus is still very much in circulation throughout the UK but at a reduced risk. The Government felt the situation has improved which is why they have decided to reduce restrictions. While this is positive news, it is important to remember that you must stay alert and practice strict hygiene and social distancing measures at all times.

If you have been identified as being “clinically extremely vulnerable”, you may still be at risk of developing severe complications if you contract coronavirus.

Who is defined as the “clinically extremely vulnerable” population in thalassaemia?

Children:

- Children who have had a bone marrow transplant or undergone gene therapy in the last 12 months
- Children who are still on medication which can affect how well their immune system works
- Children with severe iron overload in their heart with another serious illness

Adults:

- Patients who have any of the risk factors highlighted by the government
- Many adults who are 50 years and older
- Adults with severe iron overload in the heart and/ or liver with another serious illness (diabetes, liver disease etc.)
- All adults who have undergone gene therapy in the last 12 months and/or still on medication which may affect how well their immune system works.

If you have any concerns, we recommend you speak to your haematology team and you need to be risk assessed by your workplace according to government guidelines.

Can I keep shielding if I want to?

The guidance for those classed as “clinically extremely vulnerable” continues to be advisory and there are no plans to enforce it, so you can continue shielding if you want to. However, centrally provided food boxes and the Medicines Delivery Service will only be available while the advice is to shield, which is currently until the end of July.

Is there a chance shielding may be back?

The latest scientific evidence shows that the chances of encountering Coronavirus in the community has continued to decline. The Government regularly monitors this position and if the rates of infection in the community rise, then it may be necessary to advise that more restrictive measures will be taken to protect those who are “clinically extremely vulnerable”.

What is the guidance for the clinically vulnerable?

We advise those who are “clinically extremely vulnerable” to follow the [Staying Alert and Safe](#) social distancing guidance available on the gov.uk website. The advice is to stay at home as much as possible and, if you do go out, take particular care to minimise contact with others outside your household or support bubble. By this we mean always staying 2m apart from others outside your household or support bubble, avoiding crowds, and keeping your hands and face as clean as possible.

Should I wear a face covering when I leave the house?

There has been a lot of information in the media about use of face masks/coverings. There is little scientific evidence to support the use of face masks/coverings to limit the spread of COVID-19. However, based on **new government guidelines for everyone**, you should wear a face covering when:

- Attending all hospital appointments
- In shops, supermarkets and other non-open air/ confined spaces
- On public transport (if you have no other alternative method of transport)

Will I have to go return to work?

Consequently, the pausing of shielding will also mean that people who are on the “clinically extremely vulnerable” list will be advised that they can go to work (that is if they are unable to continue working from home), providing their workplace is guaranteed to be ‘COVID secure’. However, working from home should be prioritised if at all possible.

To find out more about what a COVID secure workplace should look like visit the following sites:

<https://www.hse.gov.uk/coronavirus/working-safely/covid-secure.htm>

<https://www.gov.uk/guidance/working-safely-during-coronavirus-covid-19>

What if I don't feel safe to return to work?

- You should contact your haematology team for individualised guidance
- You should aim to come to an agreement with your employer and understand their specific policies around health and safety and workplace attendance, especially in relation to COVID- 19. All employers should provide a COVID-19 safe workplace.
- If you have concerns about your health and safety at work, you can raise them with any union safety representatives, or ultimately with the organisation responsibility for enforcement in your workplace, either the Health and Safety Executive or your local authority.

- You can get advice on your specific situation and your employment rights by visiting the Acas website <https://www.acas.org.uk/contact> or calling the Acas helpline, 0300 123 1100.

What should I do if I think I have been in contact with someone with COVID-19?

If you have been in contact with someone who has a confirmed case of COVID-19, you should self-isolate, and let your clinical team know so that they can monitor you closely.

If you start having symptoms, use NHS 111's **online COVID-19 service** and let your haematology team know as soon as possible.

SELF-ISOLATION – FOR PEOPLE WITH SYMPTOMS (NEW PERSISTENT COUGH AND/OR FEVER).

Self-isolation means staying away from other people because you have symptoms of coronavirus. In order to help stop the spread of the virus, the government has advised the following:

- You should not go to work, use public transport, visit public places, or have visitors to your home (unless they are medical).
- You should not go to the shops or pharmacy – someone else should bring supplies to you. You should follow this advice for 7 days at least, and only when your temperature returns to normal.
- Anyone else you live with should follow this advice for 14 days (from the day you first show symptoms).
- If someone vulnerable lives in the same home, they should stay somewhere else, if possible, for 14 days. If this isn't possible, you should keep your distance, not share a bed, not share towels, and clean surfaces often. The government provides more detailed advice on **self-isolation if someone has coronavirus symptoms**.

For all individuals with **thalassaemia**, please note:

If you are displaying symptoms of the coronavirus or you are unwell at all, please contact your haematology team to let them know as soon as possible.

This is to ensure appropriate guidance and care can be given and other causes of illness or infection during this time are not dismissed.

I am a carer for someone with thalassaemia and I have symptoms of COVID-19 – can I access a test?

The government has advised that all members of the public can access testing if they experience any symptoms of the coronavirus. **Find more information and apply for a test**. You can also find advice and check your symptoms through the **NHS 111 online service**.

I have a holiday booked this summer – is it going to be safe for people with thalassaemia to travel?

We know there has been a lot in the news about holiday destinations planning to open up in the months ahead and it's understandable that people are thinking about whether they will be able to get away for a break this summer. However, we recommend that people should avoid any air-travel at this point. If you are thinking of going on or booking a trip over the summer, please discuss this with your haematology team before you do so.

Practical guidance on some things you can do when you are outdoors or return from being outdoors (and before having any contact with others who are “clinically extremely vulnerable” in your household.

- Keep following the advice to regularly wash your hands thoroughly (for 20 seconds) with soap and water, or use a hand sanitiser, especially when eating, or if you've just coughed or sneezed.
- Continue to avoid touching your face with your hands.
- Remove your shoes and leave them outside or by the door. Leave any bags and coats by the door.
- Avoid touching light switches, door handles etc as you come in if possible.
- Wash your hands and lower arms with soap, for at least 20 seconds.
- Remove your clothes and put them in the wash.
- Wipe your phone, wallet, bags (and any door handles or light switches you had to touch on your way in) with an anti-viral wipe.
- Have a shower with soap and wash your hair.