

Support with shielding and coming out of lockdown for individuals with Mast Cell Activation Disorders (including MCAS and Mastocytosis) and their families.

This document has been created to help share what we currently know about government guidance on shielding vulnerable patients during the Covid-19 pandemic and to share suggestions and experiences to try to help make things easier during this difficult time. However, guidelines are changing daily and although we will continue to try to keep everything as up-to-date as possible, we recommend checking the specific government sites for the regions where you live, as listed below.

There is still much we do not know about Covid-19 and its impact on specific high risk patients, and as new research and information has become available there have been changes made to the medical guidance issued in the UK (and by the devolved administrations in England, Scotland, Wales and N. Ireland). The devolved administrations does mean that guidance can vary slightly between countries and the appropriate guidance should be consulted depending on where you live.

Who is on the shielded patients list?

In March 2020, the government advised all individuals (both young and old) considered at that time to be in a high risk category - "at high risk of severe illness" - to shield in their homes during the height of the pandemic in order to reduce their risk of infection until at least the end of June. These individuals were named as '**vulnerable**' (e.g. >70 or eligible for the Flu vaccine) or '**extremely vulnerable**'. The original shielded patients lists were based on the understanding of the disease at that time. It was intended to be a dynamic list that would be adapted and updated as our knowledge of the disease improved.

Individuals with mast cell activation syndromes (MCAS) and/or Mastocytosis may have been placed in a high risk category (either as vulnerable or extremely vulnerable) and added to the shielding list by their physicians due either to the anticipated impact of their specific symptoms of MCAS/Mastocytosis and/or due to co-existence of specific symptoms (such as cardiovascular or respiratory conditions) and other medical conditions, particularly immunosuppression or the potential for being immunocompromised. You will hopefully have received a letter to confirm your (or your family member's) status, but please speak to your doctor (GP or hospital clinician) if you have not and if you have any questions or concerns.

The government guidance on shielding has continued to change and evolve over time. The latest official guidance for each region can be found here:

Public Health England: <https://www.gov.uk/coronavirus>

Scotland: <https://www.gov.scot/collections/coronavirus-covid-19-guidance/>

Wales: <https://gov.wales/coronavirus>

Northern Ireland: <https://www.nidirect.gov.uk/campaigns/coronavirus-covid-19>

In addition, the RCPCH have provided updated guidance on shielding guidance for children and young people here:

<https://www.rcpch.ac.uk/resources/covid-19-shielding-guidance-children-young-people>

On 1 June 2020 the government relaxed the guidelines on leaving the home earlier than expected, in order to provide some respite from the strict isolation guidance. (The government has provided a list of considerations for how to safely spend more time outside and how to use extended 'support bubbles'.) We know that such changes in the guidance has been confusing at times, and it has not always been clear whether or not specific individuals remain on the shielded list or why specific changes in the shielding policies have been made. As a result there have been calls from numerous charities for greater clarity in the communication of future guidance.

It may not always be clear to you whether you (or your family member) are still considered as vulnerable and/or what shielding you should be undertaking. We would encourage you to have this conversation with your doctor (GP or hospital clinician), so that they are able to consider your own (or your family member's) specific circumstances, to help you decide together on your (or your family member's) unique shielding requirements. Your doctor can ensure that you are placed on the appropriate NHS shielding list where appropriate. You are also able to register yourself (or your family member) for support as a clinically extremely vulnerable person.

The most recent announcement from the government has been to communicate two changes to shielding that will take place on the 6 July and 1 August. And on the 1 August in England shielding will be paused. The latest information on these announcements can be found here:

<https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19#who-is-clinically-extremely-vulnerable>

However, there continue to be differences between England, Scotland, Wales and N. Ireland. Further information on each of these changes can be found on the relevant country websites, as detailed above. In the past week there has also been the first local variation in lockdown policies in Leicester, and there is the possibility that this may happen in other regions. Consequently, we also recommend that you stay informed of your local lockdown policies.

Do we know any more about whether patients with MCAS and/or mastocytosis are more vulnerable to Covid-19?

Anyone who is suffering from immunosuppression continues to be considered clinically extremely vulnerable. In addition, there are several other specific conditions, including cancer, cardiovascular and severe respiratory conditions, that continue place someone on the extremely vulnerable list.

As more information becomes available, we also now know of a number of people with mast cell disorders who have suffered from Covid-19 and have recovered at home without requiring hospitalisation. In many cases it appears that mast cell stabilising medications can be helpful, and indeed some of these medicines are now being tested in clinical trials to find new treatments for Covid-19. This information is reassuring, but we would still continue you encourage you to make your own judgement on your (or your family member's) personal risk of severe illness from Covid-19, and the level of shielding that you would like to use, based on your unique personal circumstance.

A number of doctors have recently published their expert opinion [1] of the risk management of people with MCAS and/or Mastocytosis. They highlight that the key risk factors for severe disease with COVID-19 include advanced age, an impaired immune system, cardiovascular or pulmonary diseases, obesity, diabetes mellitus, and cancer treated with chemotherapy. They recommend that each individual is evaluated on a case by case basis, in order to evaluate the possible effect of mast-cell activation events on the cardiovascular and bronchopulmonary systems (the heart and lungs), whether the patient is being treated with immunosuppressive drugs and/or the presence of other health conditions that would also result in high vulnerability.

They recommend that *“patients with mast cell disorders should follow the general and local guidelines in the COVID-pandemic and advice from their medical provider. And to avoid as much as possible any situation that might be associated with an elevated risk of acquiring and/or distributing the infection”*.

If you have been affected by Covid-19 and would value the support of other individuals who have been similarly affected several websites have now been established. For example:

https://www.longcovid.org/?fbclid=IwAR33aFfsUd5_HScqpjoEfiHcitSX6trG2pi6q0NTwtJiS7oMfXYzdME7Zgc

https://www.post-covid.org.uk/resource-hub/?fbclid=IwAR1YMTv3pet_3hIbvldqsXcyR0kTEGHJo0838N2qXB1h2rMGj-dh_zwVB4

Importantly, many physicians have been highlighting the importance of sunshine and exercise for maintaining good physical and mental health and have been encouraging some of their patients to take some fresh air somewhere quiet, where there is a low risk of contact with others, and whilst adhering to the good practices of social distancing. In addition, it is essential that you and your family do not feel inhibited from seeking medical help, such as urgent healthcare visits or attending A&E, if you need to.

1. Valent P, Akin C, Bonadonna P, et al. Risk and Management of Patients with Mastocytosis and MCAS in the SARS-CoV-2 (COVID-19) Pandemic: Expert Opinions *, Journal of Allergy and Clinical Immunology (2020), doi: <https://doi.org/10.1016/j.jaci.2020.06.009>.

Coming out of lockdown...

As lockdown policies continue to relax, we know that this can be an anxious time for many people as you continue to work out what is best for them and their families. Decisions on when and how to move back into public life, return to work outside of the home or send children to school can each present their own challenges and concerns, and for many it can be a cause of considerable worry and stress.

We would encourage everyone to do what feels right for you, to speak to your medical professional who knows most about your (or your family's) specific medical situation and to not feel under pressure by what others are doing. The government has clearly stated that the guidance provided remains advisory, and ultimately, this is your decision to make based on the specific risk factors, as they apply to you.

The following questions and answers have been created to help you with the process of coming out of lockdown. We have compiled a list of considerations and resources to help support you in making these decisions and how you might best address some of the anticipated challenges, such as the reintroduction of specific triggers, and communicating with your employer or your children's school.

Am I at increased risk of catching Covid-19?

- For mast cell conditions ***without immunosuppression***, we remain unaware of any increased risk for adults or children compared with the general population. Studies are now beginning to show that children appear to get infected with Covid-19 less easily than adults and may be less likely to pass it on to others.
- The important thing is to continue to adhere to the key behaviours that can be used to reduce the risks of transmission and infection. This includes maintaining social distancing and conducting activities in the open air, good hand hygiene using hand sanitisers and regularly washing hands with soap and water, not touching your eyes, nose or mouth if hands are not clean, covering your mouth with a sleeve or a tissue when you cough or sneeze and disposing of the tissues immediately, and wearing a face covering in places where you are unable to maintain social distancing. Face coverings are now required on public transport and in hospitals and other medical facilities. <https://www.nhs.uk/conditions/coronavirus-covid-19/social-distancing/what-you-need-to-do/#prevention> *There are possible face covering exemptions (see below).*
- ***If you are suffering from immunosuppression***, either because of your medical condition or the treatments that you are receiving, you may be at additional risk of contracting the virus and will likely be categorised as 'extremely vulnerable'. Please follow the specific guidance for extremely vulnerable individuals, further information can be found here: <https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19>

If you believe that you may have symptoms of Covid-19 this website provide guidance on what to do: <https://www.nhs.uk/conditions/coronavirus-covid-19/symptoms/>. You should self-isolate immediately and can ask for a test using the following link: <https://www.nhs.uk/conditions/coronavirus-covid-19/testing-and-tracing/ask-for-a-test-to-check-if-you-have-coronavirus/> (NHSE). Please check the appropriate channels for requesting a test in Scotland, Wales and Northern Ireland.

Do I need to make any changes to my medications because of Covid-19?

- We are not aware of anti-mast cell mediator treatments (such as H1 or H2 blockers, montelukast or sodium cromoglycate) increasing a risk of catching or the severity of a viral infection. It is recommended that you take your usual medication and avoid triggers as usual.
- You should take any rescue medication in accordance with the directions from your physician if you do not have signs of Covid-19. We recommend that you seek medical guidance in the specific case of a Covid-19 infection.
- A number of doctors have recently published their expert opinion [1] of the risk management of people with MCAS and/or Mastocytosis. They highlight that the key risk factors for severe disease with COVID-19 include advanced age, an impaired immune system, cardiovascular or pulmonary diseases, obesity, diabetes mellitus, and cancer treated with chemotherapy. They recommend that each individual is evaluated on a case by case basis, in order to evaluate the possible effect of mast-cell activation events on the cardiovascular and bronchopulmonary systems (the heart and lungs), whether the patient is being treated with immunosuppressive drugs and/or the presence of other health conditions that would also result in high vulnerability. They also recommend the delay or avoidance of immunosuppressive agents, heavily cytoreductive treatments, or lymphocyte-depleting drugs (e.g., rituximab, alemtuzumab,

or cladribine) during the pandemic if that is at all possible – but please discuss this with your doctor before you make any changes to your medication.

1. Valent P, Akin C, Bonadonna P, et al. Risk and Management of Patients with Mastocytosis and MCAS in the SARS-CoV-2 (COVID-19) Pandemic: Expert Opinions *, Journal of Allergy and Clinical Immunology (2020), doi: <https://doi.org/10.1016/j.jaci.2020.06.009>.

How can I assess my (my family member's) specific risk of severe illness with Covid-19?

- We recommend that a conversation with your healthcare professional is the first step for assessing your risk status at any time during the pandemic, particularly as more information on the disease becomes available.
- The recent publication by Dr Valent and colleagues specifically highlights that “*patients with mast cell disorders should follow the general and local guidelines in the COVID-pandemic and advice from their medical provider. And to avoid as much as possible any situation that might be associated with an elevated risk of acquiring and/or distributing the infection*”. They highlight the increased risk that may be conferred by mast-cell related effects that impact the cardiovascular system and bronchopulmonary system (heart and lungs) and the impact of immunosuppressive therapies. If you have any concerns please discuss these with your doctor.
- There are also a number of self-assessment tools that have been created to help individuals to assess their vulnerability to Covid-19. One example is the tool created by the British Society of Genetics Medicine (for adults only), which can be found here:
 - <https://redcap.goshdre.com/surveys/index.php?s=TF7YNXMEN7>
- However, we would highlight that we do not know how frequently it will be updated with new information and we would recommend that you still consult with your doctor before making any decisions based on the outputs from this or any other online tool. Indeed Great Ormond Street have explicitly stated that the App is not meant to replace advice from your own physician, but that it hopefully facilitates discussion and could help to clarify any confusion.
- The BSGM have also created a number of additional resources for during the Covid-19 pandemic, which can be found here: <https://www.bsgm.org.uk/coronavirus-covid-19-and-rare-genetic-disorders/>

What if I / my family member is taken off the official governmental shielding list, but I / we do not agree?

- Your GP or hospital clinician can make the decision on whether you are classified as vulnerable or extremely vulnerable and it is important that you discuss this with them if you are concerned that you may have been removed from any shielding lists prematurely (or if you were not included on these when you feel that you should have been).
- Do make sure that your doctor is aware of all of your underlying symptoms and conditions that might be considered to make you particularly vulnerable. Your hospital specialist, for example, may not be as aware of your other conditions as your GP may be. It may be that you will not be officially coded for shielding specifically through a diagnosis of MCAS due to a lack of available codes in the NHS. However, there should be other coding that could capture your symptoms and conditions, so do discuss this with your doctor. Do ensure that you get any decision in writing from your doctor and then if you feel that you have been taken off any lists prematurely, or indeed need to be placed on these lists, you can still currently register directly on the different regional sites provided below. However, the government has now asked that you do so before the 17 July. You can also register for support on 0800 028 8327.

Will I still be eligible for support if I am taken off the 'official' governmental list?

- At the moment you can still receive support, including priority shopping slots, if you register on the appropriate sites. Please find further information from the appropriate government websites below:
 - <https://www.gov.uk/coronavirus-extremely-vulnerable> (England)
 - <https://www.gov.scot/publications/covid-shielding/> (Scotland)
 - <https://gov.wales/get-coronavirus-support-extremely-vulnerable-person> (Wales)
 - <https://www.nidirect.gov.uk/services/register-priority-online-food-delivery> (Northern Ireland)
- In terms of continued access to medicines and foods. We would recommend signing up to a range of different supermarket deliveries or click and collect services to help widen the support available to you. At times you may need to be more flexible than you might ordinarily be – for example looking at places where you do not shop regularly. We appreciate that there are differences around the country in terms of availability of delivery services and the proximity of available supermarkets. We are currently creating a set of communications to supermarkets to make them aware of our specific situation and to ask them to be more prepared to support our needs, should specialised food shortages continue to be a problem or become a problem again in the future. This will also include a template letter that you can personalise and share with your local supermarkets.
- We know that a number of people have received Government food boxes, with mixed success, due to the limitations of the foods provided and inability to tailor these to specific dietary requirements. We have communicated these issues to the government, but this may not be something that they are currently able to address.
- If your food boxes have been deactivated for any reason, it is our current understanding that you can still reactivate these by placing yourself on the (extremely) vulnerable list if you need to.
- As you make your own personal decisions to reduce your level of shielding, you may wish to still maintain your status on these lists for future planning and shielding activities.

Should I go outside if I am still shielding from Covid-19?

- This decision will be very specific to your situation and will depend on whether you are considered 'vulnerable' or 'extremely vulnerable' – every decision will require a level of personal risk assessment and taking appropriate steps to minimise the risk. You may also wish to balance your personal risks from the benefits that you might gain from more fresh air, exercise and social contact with others.
- For those who are extremely vulnerable, the government guidelines continue to recommend avoiding busy places unless for important (urgent) activities. As medical services start to resume following the initial surge of the pandemic, you may be able to return to routine appointments by phone. It may require specific steps to organise taking bloods and you should discuss these with your healthcare providers. If you are in the extremely vulnerable status we would encourage you to ensure that your healthcare provider is making appropriate provisions for your status and that other healthcare services involved in your care are made aware.
- Please do seek medical support if you need it. Our hospitals have put systems in place (such as 'hot zones') to help protect vulnerable patients and those of our members who have needed to spend time in hospital during this time have reported that they have been accommodated for very well.
- You may want to consider getting your own additional protective equipment for hospital visits (e.g. face coverings with filters).
- Further information is available here: <https://www.gov.uk/government/publications/staying-safe-outside-your-home/staying-safe-outside-your-home>

What if I, or my family member, has a medical issue with wearing a face mask?

- Face coverings have been made mandatory in some settings in England, with other guidance applying in Wales, Scotland and N. Ireland. However, there are a number of explicit groups for whom the regulations around face coverings do not apply, alongside 'reasonable excuses'.
- Children under 11 are exempt, and the list of reasonable excuses include:
 - If you have a physical or mental illness or impairment, or a disability that means you cannot put on, wear or remove a face covering
 - If putting on, wearing or removing a face covering would cause you severe distress
 - If you are travelling with, or providing assistance to, someone who relies on lip reading to communicate
 - If you need to eat, drink, or take medication you can remove your face covering
 - This includes autism.
- A number of transport groups have now created exemption cards that can be carried and or displayed. For example:
 - <https://tfl.gov.uk/campaign/face-coverings>
 - <https://disabilitypartnershipcalderdale.org/2020/06/16/mask-exemption-cards-print-wear/>
- Further information can be found here:
 - <https://www.gov.uk/government/news/new-rules-on-face-coverings-coming-in-on-monday-will-help-keep-passengers-safe>
 - <https://www.gov.uk/government/publications/staying-safe-outside-your-home/staying-safe-outside-your-home#face-coverings>

Should I let people into my home if I am still shielding from Covid-19?

- Again we would urge you to consider your own (or your families) circumstances and to follow governmental guidance. Where it is necessary to allow specific individuals into your home - for example for a medical visit, a gas boiler check, a workman, or a cleaner – it is perfectly acceptable to ask if they will be wearing PPE.
- From June 13 the government has also released specific guidance on so-called '**support bubbles**' – allowing adults who live by themselves and single parents with children under 18 living at home in England* can join up with one other household to create a support bubble.
- Forming this support bubble means you effectively become one household - you can act as if you all lived together. This means you can do things such as go round to their house, stay the night and travel together in private vehicles.
- Before you form your support bubble, you may want to think about any potential risks to your health. You might want to avoid forming a bubble with a household that is more exposed to coronavirus, for example if there are people in the home who are healthcare workers.

*Please refer to specific guidance in your region for the creation of support bubbles.

What if I am asked to go back to work outside of the home by my employer? Do I have to go?

- The government has provided specific details for working safely during coronavirus (Covid-19): <https://www.gov.uk/guidance/working-safely-during-coronavirus-covid-19>
- Similar guidance is available in:
 - Wales: <https://gov.wales/workplace-guidance-employers-and-employees-covid19>

- Scotland: <https://www.gov.scot/publications/coronavirus-covid-19-framework-decision-making-scotlands-route-map-through-out-crisis-phase-2-update/>
- Northern Ireland: <https://www.nidirect.gov.uk/articles/coronavirus-covid-19-advice-workers>
- As of 21st June, the guidelines continue to recommend that people who are shielding work from home, and that everyone else continues to work from home wherever possible. You might be eligible for statutory sick pay (SSP) if you are following government advice to self-isolate or you are shielding. However, it is anticipated that there will be some changes as of the 1st August, which should be confirmed by the government in the next few weeks.
- You may also be able to take time off to look after your children if they are shielding or if they are unable to return to school, including parental leave and unpaid leave. Further information can be found here: <https://www.citizensadvice.org.uk/work/coronavirus-if-you-need-to-be-off-work-to-care-for-someone/>
- If you are considering returning to the workplace we recommend that you discuss potential working arrangements, including flexible working, with your employer based on your specific role and work environment, and are entitled to ask that an appropriate risk assessment has been put in place.
- You may wish to check the guidelines on flexible working before discussing this with your employer. Further information is available here: <https://www.citizensadvice.org.uk/work/rights-at-work/flexible-working/flexible-working-what-is-it/>
- A range of resources are available to support you with the process of potentially returning to the work place:
 - [https://www.som.org.uk/Returning to the workplace COVID-19 toolkit FINAL.pdf](https://www.som.org.uk/Returning%20to%20the%20workplace%20COVID-19%20toolkit%20FINAL.pdf)
 - <https://www.hse.gov.uk/coronavirus/working-safely/index.htm>
 - <https://www.acas.org.uk/working-safely-coronavirus/returning-to-the-workplace>
 - <https://iosh.com/media/7811/iosh-risk-assessment-guide.pdf>
 - <https://workingfamilies.org.uk/articles/coronavirus-returntowork/>
- Other resources that may be useful include:
 - <https://www.citizensadvice.org.uk/health/coronavirus-what-it-means-for-you/>
 - <https://www.hse.gov.uk/disability/faqs.htm#separate>
 - <https://www.hse.gov.uk/disability/largeprint.pdf>
- If you do decide not to work, there might be ways to keep getting paid. More support and information is available here: <https://www.citizensadvice.org.uk/work/coronavirus-if-youre-worried-about-working/>
- There are also a number of resources to help with mental wellbeing and working during Covid-19. For example:
 - <https://www.mentalhealthatwork.org.uk/resource/returning-to-the-workplace-after-the-covid-19-lockdown/?read=more>
 - <https://www.mentalhealth.org.uk/coronavirus/looking-after-your-mental-health-during-coronavirus-outbreak-while-working>
- We do not yet know how things will change for those who are shielding, as of the 1 August, however we will continue to monitor the situation and share an update of this document once things become clearer. The government has made it very clear that you have the right to ensure your place of employment can be considered **COVID-safe**, before you return to work.

What if my child's school year is returning to school, do they have to go?

- At the current time, the government have clearly stated that children's attendance at school is not compulsory, that no fines are to be issued for non-attendance and that there needs to be continued provision of remote learning for all year groups. We do not know how that will change over the coming months as more children return to school and we will continue to monitor the situation and share any relevant resources.
- Government guidelines for school closures and reopening in England can be found here: <https://www.gov.uk/coronavirus/education-and-childcare>
- Information for Scotland, Wales and Northern Ireland can be found here:
 - <https://www.gov.scot/news/schools-to-re-open-in-august/> (Scotland)
 - <https://gov.wales/how-schools-will-work-during-coronavirus-pandemic#section-38402> (Wales)
 - <https://www.nidirect.gov.uk/articles/coronavirus-covid-19-advice-schools-colleges-and-universities> (Northern Ireland)
- The RCPCH have created the following guide for talking to children and families about returning to school: <https://www.rcpch.ac.uk/resources/covid-19-talking-children-families-about-returning-school-guiding-principles>. This includes support for children who are considered **clinically extremely vulnerable** who remain advised **not** to go to school. The guidance also considers the balance of the benefits of returning to school versus the risks for children considered **clinically vulnerable**.
- The Mental Health Foundation has also created a number of resource to support school aged children and their families: <https://www.mentalhealth.org.uk/coronavirus/returning-school-after-lockdown>
- A child and adolescent Psychotherapist working within schools has kindly shared this analogy with us, which they have been using to help support parents in their decision to send their children back to school:

"During the pandemic children's homes have become their safe place – we could think of it like a fortress that keeps you and your family safe. But a fortress can also block out lots of good things too – for example, when you are under siege you don't go out to get food, exercise or sunshine and fresh air, and to see other people such as friends and family for emotional support. You can only maintain a siege for so long – but then you need to put on your armour – such as face coverings and hand washing, and make your back way out into the world to get fresh air and exercise and to see your friends and family. Parents can talk with their children to acknowledge that this is scary for everyone – maybe they are scared too and it is ok to be scared. But it is also ok to take steps to minimise the risk and to try going out together as long as you have your armour – social distancing, avoiding crowded places, face coverings and washing your hands can all reduce the risk."

- **Note:** there has recently been media speculation about the potential for fines for children not returning to school in September but, as yet, there is no clear statement from the government on this, and no explicit information for children not returning to school due to increased health risks to either them or their families.
- It may well be that when schools reopen your child is still considered unable to attend through health reasons. If this is the case, there is clear governmental guidance that exists to ensure that your child continues to receive a good education, and support should be available to you from your local authority:
- https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/269469/health_needs_guidance_-_revised_may_2013_final.pdf

What is the relevance of the 'kawasaki' type syndrome in some children, is this something I should be worried about?

- In April, researchers in the UK and Europe with recognised a new inflammatory syndrome in children that was similar to Kawasaki disease, a rare syndrome known to affect young children.
- Several research studies have now been published on this condition and it has been named Paediatric Inflammatory Multisystem Syndrome Temporally associated with SARS-CoV-2 (PIMS-TS) by researchers.
- Doctors have said that *“with early identification and treatment the outcome is excellent”*. The RCPCH have created a guide for clinicians and released the following guidelines for families:
<https://www.rcpch.ac.uk/resources/pims-covid-19-linked-syndrome-affecting-children-information-families>
- This syndrome is very rare, and most children will not be seriously affected. However, we are aware of one episode of PIMS-TS in a child in our MCAS community. Importantly, the parents were not aware that their child had been infected with Covid as they had been asymptomatic. If you are at all worried, we would advise you to consult the RCPCH guidelines and seek medical help .
- More research is ongoing to better understand this condition and its link to Covid-19. At this time we are not aware of any direct link that has been reported to MCAS or Mastocytosis, but we continue to speak with specialists to understand this better and will share any further information as soon as it becomes available.

I am concerned that there may be new triggers in the environment due to the increased use of cleaning products, for example, or a lack of exposure to triggers where I (my family member /child) had previously built up a tolerance. What should I do?

- We know that coming out of lockdown can be a challenging time when it comes to the potential exposure to new triggers or re-exposure to triggers where you (or your family member) may have previously built up a tolerance. Particularly with the increased use of cleaning products and the expectations for using hand sanitisation products in public spaces for those with chemical or fragrance allergies and sensitivities. We would highly recommend finding a sanitiser that works for you and carrying this with you to use as an alternative to those provided in shops and other public places. We have heard of shops trying to insist that their sanitising products be used, but there is no legal requirement for you to do so.
- When returning to work or to school it should be perfectly acceptable to ask what cleaning products are being used, and whether they have been changed since the emergence of Covid-19. Some people have had success with taking small samples of cleaning products home to help to gradually increase their (or their families) exposure to certain chemicals and fragrances and to help build up a tolerance.
- Increasing your exposure to pollens by going outside again could also be another problem, and we have seen that this has been a particularly strong pollen season this year. The recent high temperatures may also be a problem.
- Anxiety is another factor that many people have mentioned. On listening to the experiences of many of our members, we would encourage baby steps before making any big strides. This could mean just sitting outside for a small amount of time at first or taking a walk nearby when there aren't many people about. It might take a little while to get used to mingling with people again, and to finding ways that you feel comfortable with maintain social distancing. Not everyone is as strict with adhering to these distances and that can be unsettling and upsetting. It might help to remember that it is your overall exposure that has been shown to be important – both distance, time and context (e.g. inside or outside, with or without good ventilation with open windows and doors). A short, close encounter is not as likely to result in infection as a long time spent in close proximity (such as travelling on public transport).

- Some people have mentioned that thinking through the possible scenarios in advance, and anticipating how you might manage them has helped them. You might also want to ask for help from friends or family so that you don't have to take the first steps on your own, and as a good way to get used to being around others in a socially distanced way.
- For many stress and anxiety can be their own triggers and so it is really important that you do things in a way that feels right to you and will not increase your anxiety levels too much. Our Mast Cell Action and UK Masto online communities are here to help you to share your experiences and concerns with other people who understand what you are experiencing, and can support you as you take each baby step forward.

This document has been created to help share information and resources that may be helpful to you whilst dealing with the various challenges of the Covid-19 pandemic. We will seek to update this on a regular basis and continue to share as many resources as we can. If you are aware of any information or resources that you think would be useful to share in future updates please do share this either via our Facebook moderators or by email us at: info@mastcellaction.org. We look forward to hearing from you.