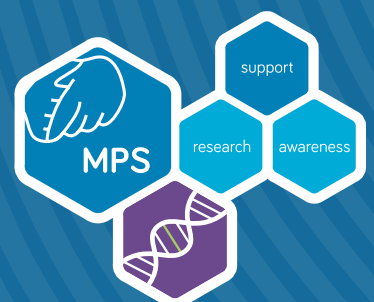


Expert guidance on COVID-19

for patients

A general guide for patients with lysosomal storage diseases (LSDs) and their families and carers



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Disclaimer

The information contained in this booklet is intended as a guide to finding relevant information on shielding and vaccination during the Coronavirus pandemic. This guide does not provide medical advice, always seek the advice of your specialist doctor with any questions you may have regarding your medical condition.

Introduction

This is a general guide for patients with lysosomal storage diseases (LSDs) and their families and carers.

The MPS Society hosted a meeting for representatives from the LSD Collaborative, the patient community, the inherited metabolic disorder specialist centres and the British Inherited Metabolic Diseases Group (BIMDG) to address the conflicting advice that many patients are receiving about COVID-19.

This guide explains why you may receive conflicting advice and provides summaries of important information in relation to your condition and COVID-19. Sources of reliable and up to date information are given so that you can access these as government advice changes and lockdown measures are lifted or re-introduced.

Why might I get conflicting advice?

You may have received a letter from Mr Matt Hancock, the Secretary of State for Health and Social Care, issuing personal advice on shielding according to your condition which might conflict with the information and guidance given to you by your specialist doctors.

This may occur because your specialist treating centre has more information on your personal condition(s) and has tailored the advice given to you specifically for your disease profile.

As specialist treating centres will receive the updates on guidance at the same time as the public, they will need time to review it and ensure they can send appropriate advice out to patients by taking their specific disorder and circumstances into account. This can cause a delay in getting the relevant information out to you.

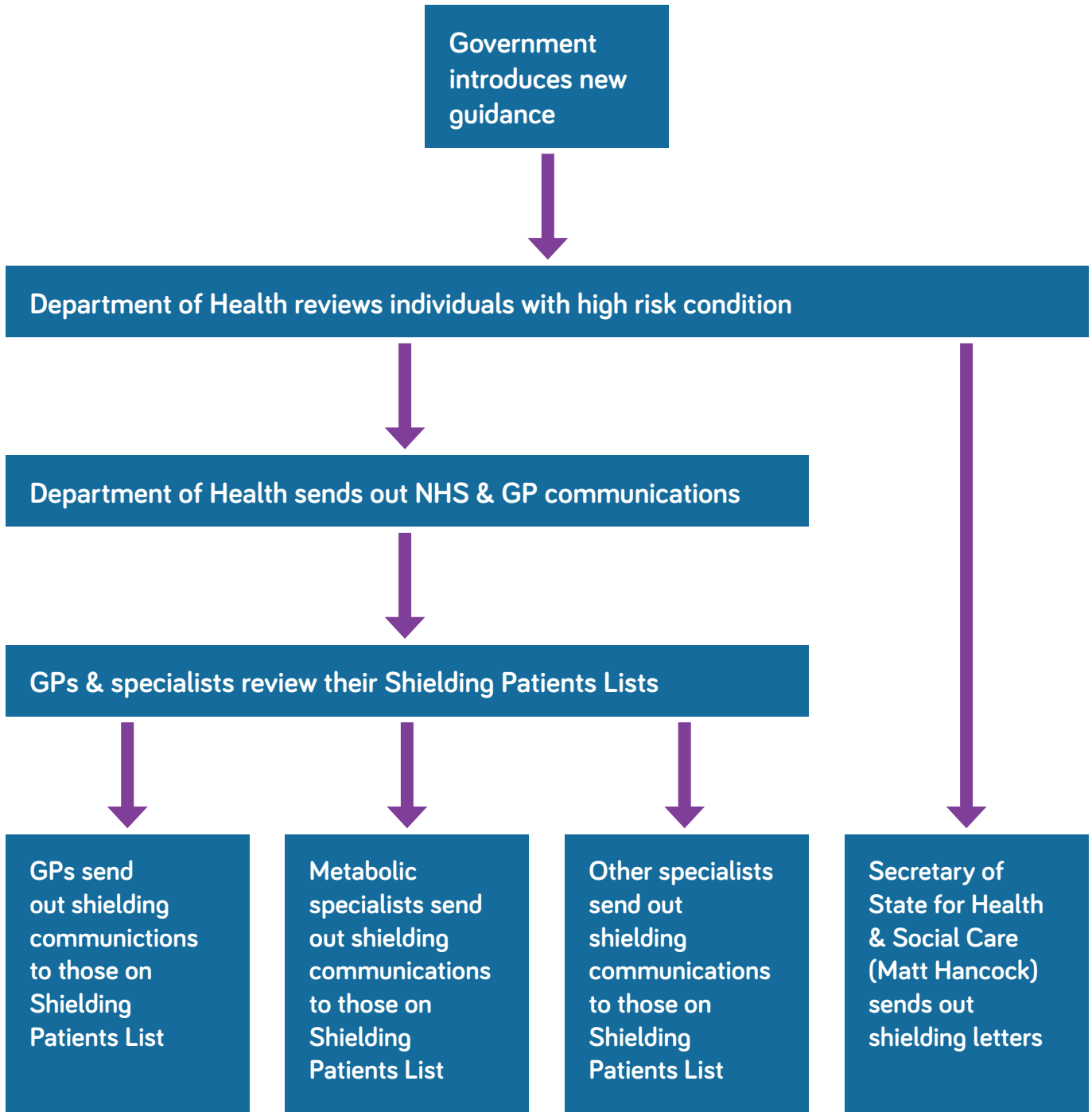
Your specialist treating centre has more information on your personal condition(s) and has tailored the advice given to you.



The British Inherited Metabolic Diseases Group (BIMDG)

The **BIMDG** is a professional society for doctors, nurses, dietitians, scientists and psychologists involved in the diagnosis and management of individuals with inherited metabolic diseases, that aspires to relieve individuals suffering from inherited metabolic diseases by advancing the education of the above professionals involved in their diagnosis, care and treatment as well as to promote research into treatment of inherited metabolic disorders (1).

Sources of shielding advice (2)



Specialist centres will communicate advice based on your condition and common guidelines agreed on by the British Inherited Metabolic Diseases Group or the Royal College of Paediatric and Child Health. However, if you have other conditions e.g. asthma, the relevant specialist might contact you separately regarding shielding requirements in light of these.

As government guidance and restrictions change, the British Inherited Metabolic Diseases Group works with the specialist treating centres to decide a common

framework of specialised guidelines on shielding for patients with rare metabolic disorders.

All treating specialist centres have agreed to work to these same guidelines to care for patients with inherited metabolic disorders. If you feel you are not being taken care of using this framework, please flag this up to your specialist doctor or centre.

BIMDG specific advice for patients with Inherited Metabolic Disorders

You will have heard the terms 'Clinically Extremely Vulnerable' and 'Clinically Vulnerable.' People have been grouped into categories based on their risk of developing severe life-threatening disease from an infection of COVID-19. Although everyone is at some risk of becoming seriously ill with Coronavirus, the risk is higher for some people. Identifying risk groups can help those at higher risk to protect themselves better and prevent high infection and death rates. The group at highest risk is termed Clinically Extremely Vulnerable, followed by Clinically Vulnerable.

The BIMDG have developed guidance to explain which groups those with inherited metabolic diseases may be put into. Advice for adults is published on the [BIMDG website](#) (3). For children,

advice developed by [The Royal College of Paediatric and Child Health](#) should be referred to (4).

The majority of individuals with an inherited disorder of metabolism are not considered to be 'Clinically Extremely Vulnerable' (3).

Any individual patient who feels they have been put on the Clinically Extremely Vulnerable list in error, or who feels they may have been omitted from this list in error should contact their treating specialist centre directly for advice.

Summary of the main categories of people considered to be Clinically Extremely Vulnerable

ADULTS

Those with an inherited metabolic disorder whose condition is also associated with one or more of the following issues:

- Treatment with immunosuppression therapies sufficient to significantly increase the risk of infection
- Significant neurological impairment which includes difficulty swallowing, impaired ability to cough or clear the airway
- Decompensated liver disease
- A previous solid organ transplant (e.g. heart, liver, or kidney)
- Significant renal failure – on dialysis or chronic kidney disease (stage 5, eGFR < 15 ml/min)
- Long-term life dependency on ventilation – either via tracheostomy or CPAP/ BiPAP
- Severe lung disease (e.g. requiring supplemental home oxygen)
- People who have, or are undergoing treatment for, some specific cancers

Further information can be found on the [BIMDG website](#) (3).

CHILDREN

Children with an inherited metabolic disease who are also:

- At risk of severe infection due to immunodeficiency caused by disease or immunosuppressive therapy

Children with an inherited metabolic disease and certain other conditions or specific symptoms may be Clinically Extremely Vulnerable. This will be determined on an individual basis, in discussions between the doctor, the child and their family.

These conditions/symptoms include heart abnormalities or disease, difficulty swallowing, impairment in the ability to cough and to clear airway secretions, life-dependency on long term ventilation, both invasive (via tracheostomy) and non-invasive (CPAP and BiPAP).

The full list of conditions that may make a child Clinically Extremely Vulnerable can be found on the [Royal College of Paediatric and Child Health website](#) (4).



What should I do when I receive new information from my specialist centre?

If you receive advice from your specialist treating centre, you should follow this as this information has been tailored to your disease stage and other conditions that you might have. If you receive conflicting advice from different specialists, this is because you have other conditions that have different shielding requirements. In this instance, you are advised to follow the strictest advice and contact your patient organisation for further assistance (please see page 14 for contact details).

National restrictions

The UK Government regularly updates their guidance to reflect constant changes to the national lockdown restrictions placed across the UK.

You can find the most up to date information regarding restrictions in your area as soon as they are announced and put into place on the [Government's website](#) (5).

Restrictions relating to school and further education

The government website will also include restrictions involving school, colleges and universities. If current restrictions mean that children who are Clinically Extremely Vulnerable should shield you will receive a letter notifying you of this from the government. This may include advice not to attend school. Parents should contact their child's specialist or GP if their child receives a letter telling them they are Clinically Extremely Vulnerable and should shield, that they did not expect (4).

Support available to people who are shielding



Essential supplies

Make use of the supermarket priority delivery slots that are available for this group. When a Clinically Extremely Vulnerable person registers online as needing support with food, their data is shared with supermarkets. This means if they make an online order with a supermarket (as both a new or existing customer), they will be eligible for a priority slot. You can register for this [here](#) (6).

If you need urgent help and have no other means of support, contact your local council to find out what support services are available in your area (7).



NHS volunteer responders

NHS Volunteer Responders can support you with:

- Collecting shopping, medication (if your friends and family cannot collect them for you) or other essential supplies
- A regular, friendly phone call which can be provided by volunteers or by someone who is also shielding and will stay in contact for several weeks
- Transport to medical appointments

Please call 0808 196 3646 between 8am and 8pm to arrange support or speak to your health care professional for transport support. A carer or family member can also do this on your behalf. More information is available [here](#) (8).



Income and employment support during shielding

Those shielding due to being Clinically Extremely Vulnerable will be eligible for Statutory Sick Pay on the basis of their shielding status until the 31 July 2021 (eligibility criteria apply).

The Government is asking employers to work with them to ease the transition back to a more normal way of life for their shielding employees. It is important that this group takes careful precautions, and employers should do all they can to enable them to work from home where this is possible, including moving them to another role if required.

Where this is not possible, those who have been shielding should be provided with the safest onsite roles that enable them to maintain social distancing.

If employers cannot provide a safe working environment, they can continue to use the Job Retention Scheme for shielded employees who have already been furloughed. The latest guidance on financial support during Coronavirus can be found [here](#) (9).

Access to Critical Care

We are aware that some families have been concerned about access to critical care during the COVID-19 outbreak. NICE have amended their guidelines, which now state that access to critical care for those people aged less than 65 years with learning disabilities and/or stable long term disabilities should be assessed on an individual level and that the Frailty Scale should not be part of that assessment (10).

People in the Clinically Extremely Vulnerable group should continue to access the NHS services they need during this time. This may be delivered in a different way or in a different place than they are used to, for example via an online consultation, but if they do need to go to hospital or attend another health facility for planned care, extra planning and protection will be put in place (7).

Access to Support Services

Physiotherapy

- Many patients will not have had access to their usual physiotherapy program since the start of the pandemic due to social contact restrictions. If you normally undergo physiotherapy sessions as part of a tailored care program and have not had access to this in recent months, you are advised to contact your specialist centre to find out whether or not they are able to offer a virtual physiotherapy session to you
- Shielding patients who cannot go outside for exercise may be able to get exercise advice to keep active from their specialist centre's physiotherapy service

Psychological support


- Maintaining your mental health is just as crucial as looking after your physical health over the periods of lockdown. With most patients shielding long term, staying indoors with little contact with others outside their family or support bubble can have detrimental effects on mental health
- If you feel you would benefit from more mental health support over periods of shielding at home, the **Mind** mental health charity offers a range of support services from counselling, housing and finance related mental health support to bereavement and crisis services (11)
- Your specialist centre may be able to offer virtual psychological support clinics. Contact your specialist centre to find out more

Vaccination guidance

While behavioural measures such as isolating while symptomatic, mask-wearing and physical distancing have slowed the spread of the virus, vaccines provide a better path out of the COVID-19 pandemic, and scientists have now developed several highly effective vaccines against COVID-19 (12).

Specialist advice on vaccinations for people with inherited metabolic disorders is published on the BIMDG website as it becomes available (13).

The Pfizer vaccination is available for those over 16 years. GPs will contact 16 to 18 year olds if Clinically Extremely Vulnerable. The Astra Zeneca vaccination is currently not approved for use in those under 18 years but a paediatric study is due to soon.



Who will be offered vaccination first?

The **Joint Committee on Vaccination and Immunisation (JCVI)** determine in which order people will be offered vaccination (13).

The current guidance as of 6th January 2021 on priority groups scheduled to be vaccinated is below:

1. residents in a care home for older adults and their carers
2. all those 80 years of age and over and frontline health and social care workers
3. all those 75 years of age and over
4. all those 70 years of age and over and **Clinically Extremely Vulnerable individuals**
5. all those 65 years of age and over
6. all individuals aged 16 years to 64 years with underlying health conditions which put them at higher risk of serious disease and mortality
7. all those 60 years of age and over
8. all those 55 years of age and over
9. all those 50 years of age and over

Frequently asked questions on vaccination

The following frequently asked questions and answers have been adapted from the British Inherited Metabolic Diseases Group, published on the 4th January 2021 (14). As this information is likely to update constantly, you are advised to check the [BIMDG website](#) for the most recent advice (14, 15).

The BIMDG is strongly supportive of the vaccination programme for COVID-19 and hopes that any patient who is offered vaccination will take up the offer.

1. Is there any particular inherited metabolic or lysosomal storage disorder where patients would be advised not to have a COVID-19 vaccination?

NO. Vaccination is considered safe for all inherited metabolic disorders.

2. Can I have the vaccine if I need to follow a prescribed low protein diet?

YES. The amount of protein in the vaccines is negligible and having the vaccine will neither affect how well your condition is controlled, nor will you need to reduce your protein intake.

3. If I am offered vaccination would I need to have it done locally or with my specialist centre?

The NHS will aim to give you the vaccination within your local area. If they are not able to do so then you will be invited to a designated hospital which has been identified as a vaccination centre. You do not have to go to your specialist centre to be vaccinated.

4. Which vaccine should I have? Do I get to choose?

At this moment, the NHS is not able to give you a choice as to which vaccine you will be offered. Patients will be given the vaccine that is available in their local area.

5. Do the vaccines contain any live COVID virus?

NO. The current vaccines do not contain any live COVID virus. The current vaccines also do not contain any animal products or egg.

6. What side effects might vaccination have?

Most side effects are mild and should not last longer than a few days to a week such as;

- A sore arm where the needle went in
- Feeling tired
- Headache
- Feeling achy

7. Why are some patients with the same inherited metabolic disease being offered vaccination before (or after) me?

Even if patients have the same named condition, it does not mean that they are affected in the same way. Some patients may be very mildly affected with their inherited metabolic disease; others may be much more seriously affected with many complications of their condition. It is these complications that may put them more at risk of complications of COVID-19. Older patients and those who are deemed 'Clinically Extremely Vulnerable' will be offered vaccination earlier on in the programme.

Other patients may have a second, more common condition, such as diabetes or severe asthma, that makes them more vulnerable – and so it will be this, rather than their inherited disorder of metabolism, that puts them more at risk of complications of COVID-19.

8. Do you have to follow restrictions once you have been vaccinated?

YES. After vaccination, most people will be protected against COVID-19 symptoms. However, there is a small chance you might still get COVID-19 even after vaccination. We also do not know for certain yet whether people who have had the vaccination might be able to pass on COVID-19, even if they have no symptoms. For these reasons it is important that EVERYONE continues to follow social distancing guidance, wear a face covering in public and adhere to local lockdown measures.

9. I am pregnant - can I be vaccinated?

The available data do not indicate any safety concern or harm to pregnancy, but there is insufficient evidence to recommend routine use of COVID-19 vaccines during pregnancy. If you are currently pregnant therefore – you should wait until after your baby is born to be vaccinated.

However, if a pregnant woman meets the definition of being Clinically Extremely Vulnerable, then she should now discuss the options of COVID-19 vaccination with her obstetrician and/or doctor. This is because her underlying condition may put her at very high risk of experiencing serious complications of COVID-19. The benefits and risks of COVID-19 vaccination in pregnancy should be discussed on an individualised basis and for some Clinically Extremely Vulnerable pregnant women vaccination may be offered.

10. I am breastfeeding - can I be vaccinated?

There is no known risk in giving these vaccines to breastfeeding women. Breastfeeding women will therefore be offered vaccination if they are otherwise eligible.

11. Will the vaccines affect any of my medication?

The current vaccines are not known to interact with any medications. If you are worried about this please contact your specialist centre or speak with your pharmacist.

12. Will I be able to go abroad following vaccination?

It is recommended to follow government guidance on travel abroad - this is regularly updated.

13. Can I eat and drink as normal, do my normal activities on the day I have my vaccination?

YES. You should be able to continue activities that are normal for you, as long as you feel well.

14. I have severe allergies – can I be vaccinated?

It is advised that any person with a significant allergic reaction to a vaccine -- such as previous history of anaphylactoid reaction, or those who have been advised to carry an adrenaline autoinjector -- should not be vaccinated at present.

You will be asked about allergic reactions when you attend for vaccination and the nurse / doctor / pharmacist will determine if it is safe for you to go ahead with vaccination.

15. Can my child be vaccinated against COVID-19?

NO. Not just yet. COVID-19 vaccine trials have only just begun in children and there are, therefore, very limited data on safety and effectiveness in this group.

Children and young people have a very low risk of COVID-19, severe disease or death due to COVID-19 compared to adults and so the vaccines are not routinely recommended for children and young people under 16 years of age.

Recommendations on vaccinating children with other underlying conditions will be reviewed after the initial roll-out phase by which time additional data on use of the vaccines in adults should allow a better assessment of risks and benefits.

17. I am receiving regular intravenous enzyme replacement therapy (ERT) - do I need to consider the timing of this in relation to COVID vaccination?

If you are offered COVID vaccination over the next few months, then we suggest you prioritise this. If you turn down the initial time-slot(s) offered to you then you may have to wait a bit before you are offered another slot.

Some basic principles to consider:

1. You should feel well, without a temperature on the day you have your COVID vaccination, and on the day you have your ERT infusion.
2. Avoid having your COVID vaccination and your ERT infusion on the same day.
3. If time-slots for COVID vaccination are very limited then please take up the offer of vaccination and arrange to delay or miss your ERT infusion that week if needed.
4. Because some people have reactions to vaccines (slight temperature, muscle aches, sore arm, flu-like feeling), then you should wait 3 days (until these symptoms settle) after your COVID vaccination before having your next ERT infusion.
5. It is however fine to have your COVID vaccination the day after your ERT infusion as long as you feel well.

18. Will the current vaccines impact on my ability to have potential gene therapy for my inherited metabolic disease in the future?

NO. Some confusion has arisen on social media because of the similarity in the names of adeno-associated viruses (AAVs) – which are used in gene therapy, and adenovirus-based vaccines.

However, the two types of virus are completely different from each other and do not share any genes or proteins. Having an adenovirus-based vaccine will not produce any antibodies which could react with AAV and will therefore have no effect on whether or not a person can take part in a gene therapy trial using an AAV vector.

When will carers get vaccinated?

The government's vaccine committee has revised its recommendations to include unpaid carers in the vaccine priority list.

It now recommends unpaid carers who get Carer's Allowance or who are the main carer of an elderly or disabled person (child or adult) whose welfare may be at risk if the carer falls ill should be prioritised alongside people with underlying health conditions.

This means unpaid carers are now in priority group 6 (please see page 8 for the list the priority groups). It is not yet clear when unpaid carers will be offered the vaccine (16).

COVID-19 myth busters

A large amount of information is circulating the internet regarding COVID-19 and shielding, but not all the information sources are trustworthy, which can impact on your safety. The sources below will help to clarify some myths you may have come across around Coronavirus (17).

[World Health Organisation](#) (18)

[BBC News](#) (19)

Frequently asked questions on shielding

The following frequently asked questions and answers have been adapted from those received in patient webinars that were hosted by the MPS Society. This information updates regularly so it is best to check the [MPS Society website](#), your patient organisation website or call your patient organisation for the latest information on shielding (please see page 13 for contact details) (20).

1. What should I do if I have a medical emergency (especially as clinics are cancelled)?

Please call an ambulance or visit your local Accident & Emergency department. It is a good idea to have your specialist doctor's contact details and your care plan at hand.

2. Should I be getting in extra supplies of certain medicines?

Your prescribing specialist doctor will be able to advise you on how to manage adequate supplies of your required medication according to your treatment plan.

3. I can't get through to my specialist centre, who should I contact?

Get in contact with your patient organisation and an advocacy specialist will be able to help you.

4. How will my treatment be affected by the pandemic?

Individuals are being contacted by their GPs and specialist centres regarding both shielding and access to treatment. No specialist centres are currently advising treatment holidays unless this is specifically requested.

5. Should we be withdrawing children with inherited metabolic disorders from school and isolating them? What about siblings and parents?

Please see the latest guidance on schools and education settings by visiting the [Government's website](#) on national restrictions (5).

6. When one self isolates are they able to go out for short walks for some fresh air?

Please see current guidance on the [Government's website](#) (5).

7. How safe is it to have carers coming into the house?

Home care companies have provided assurance that adequate Personal Protective Equipment is available for carers with protocols in place and necessary checks having been carried out to ensure it is safe for both carers and patients.

Transition from Paediatric to Adult healthcare during COVID-19

Each hospital trust will have different policies and processes in how transition will be managed during COVID-19. Some may proceed with the transition virtually where as some may be able to invite you into hospital if routine appointments are allowed and it is safe. Many factors will be taken into consideration including: whether you are currently shielding, how safe is it for you to travel, whether the transition process is just starting or nearing the end, whether you have had the opportunity to meet the adult team and whether there is any ongoing or

outstanding clinical care that has been delayed due to COVID-19. It is important to note that in most cases if the patient's transition clinic was held virtually they would remain under the care of the paediatricians until they have a face to face visit in the adult hospital. The paediatric centre will also continue to prescribe ERT until then.

Your paediatric team will support you through this process and inform you of what the next steps are for you or for your child/young person.

Attending school

The government have stated that it is mandatory for all children/young people (if they can) to attend school. Any concerns regarding a child/young person's attendance should be discussed with their school.

All schools have been provided with [guidance](#) (21) and a [checklist](#) (22) to support pupils back to school.

It is recognised and understood that a small number of pupils may not be able to return or attend school. For example:

- COVID-19 symptoms or a positive test
- living with someone who has symptoms or a positive test
- close contact of someone who has tested positive (i.e. a carer)
- shielding (to be reviewed, currently in place until at least 31 March 2021)

In these circumstances schools should provide remote learning.

Find out more about [safe working in school](#) (23).

Read more about [SEND guidance](#) (24).

Access to community and specialist therapies should continue to be prioritised.

Testing in school

It is expected all children and young people in secondary school to be regularly tested with these tests being carried out at home in the long term. However, minimal testing should be maintained at school to allow onsite testing for those who are not able to do it at home.

Specialist settings have the flexibility to make reasonable adjustments to testing to support their pupils.

Informed consent is essential to allow tests to be carried out. Pupils must not be excluded from attending school if they refuse or are not able to participate in testing.

Department of Health and Social Care have a series of videos showing a [step-by-step guide to COVID-19 self testing](#) (25).

Family members can voluntarily test twice weekly. Tests can be picked up at your local home test collection point.

Face coverings

It is a requirement for secondary school pupils to wear face coverings. Exemptions to this rule includes: those that cannot put on, wear or remove their mask due to physical limitations, disability, illness or mental health.

The government has published the [COVID-19 Response - Spring 2021](#), setting out the roadmap of the current lockdown for England (26).

Useful links

[Association for Glycogen Storage Disease \(AGSD\)](#) (27)

[Batten Disease Family Association \(BDFA\)](#) (28)

[Cure and Action for Tay-Sachs \(CATS\)](#) (29)

[Gauchers Association](#) (30)

[Krabbe UK](#) (31)

[LSD Collaborative](#) (32)

[Mind](#) (33)

[MPS Society](#) (34)

[Niemann-Pick UK](#) (35)

[Pompe Support Network](#) (36)

[The British Inherited Metabolic Diseases Group \(BIMDIG\)](#) (37)

[The Joint Community of Vaccination and Immunisation \(JCVI\)](#) (38)

[The Royal College of Paediatric and Child Health \(RCPCH\)](#) (39)

Patient organisation contacts

Association for Glycogen Storage Disease (AGSD): info@agsd.org.uk

Batten Disease Family Association (BDFA): support@bdfa-uk.org.uk

Cure and Action for Tay-Sachs (CATS): info@cats-foundation.org

Gauchers Association: ga@gaucher.org.uk

Krabbe UK: info@krabbeuk.org

MPS Society: mps@mpssociety.org.uk

MPS Society Advocacy: advocacy@mpssociety.org.uk

MLD Support Association: admin@mldsupportuk.org.uk

Niemann-Pick UK: info@npuk.org

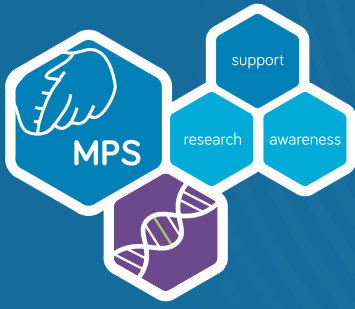
Pompe Support Network: hello@pompe.uk



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