

Advice created by all the NHS LSD Specialist Centres in the UK

ADULT ADVICE

The clinical centres are working tirelessly to manage the huge volumes of calls and enquiries from our patient communities. For many they have had to either cancel all clinics and non-emergency appointments or move them to telephone appointments. These are unprecedented times and many of our doctors and nurses have already been, or are on standby, to be called to the front line.

Each centre has an answerphone to ensure that they do not miss any calls. Please bear with them as they filter through the many calls that are coming through on a daily basis.

The current advice is that critically ill LSD patients should not be transferred to the specialist centres and should continue to receive treatment at their local hospital as appropriate. Advice and support should be sought by your specialist centre as required. Keep to hand your specialist centre telephone numbers, any medical alert cards, care plans or leaflets for medical staff that explain your condition. Speak with your closest family members and advocates to ensure they know where information is kept.

Please be aware that advice is changing daily and it is important that you keep yourselves up to date with the news and any Government / NHSE guidance.

High-risk patients

Clinical centres are already reviewing all their patients and will be in contact with those patients deemed to be high risk. Please find below the link to the government advice on shielding.

<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>

Self-isolation / Social distancing

Social distancing - vulnerable groups and families

Social distancing measures are steps you can take to reduce the social interaction between people. This will help reduce the transmission of coronavirus (COVID-19). Please use the government website link below for up to date information.

<https://www.gov.uk/government/publications/covid-19-guidance-on-social-distancing-and-for-vulnerable-people/guidance-on-social-distancing-for-everyone-in-the-uk-and-protecting-older-people-and-vulnerable-adults>

Self-isolation - symptomatic and unwell or someone you live with is symptomatic

In this instance you should self-isolate at home. Please see the link to the NHS self-isolation advice below for up to date information on what this means.

<https://www.gov.uk/government/publications/covid-19-stay-at-home-guidance/stay-at-home-guidance-for-households-with-possible-coronavirus-covid-19-infection>

<https://www.nhs.uk/conditions/coronavirus-covid-19/self-isolation-advice/>

The clinical centres are following the current government advice on this but expect it to change imminently to include all high-risk patients or those with specified medical conditions.

The clinical centres will however support any patients who choose to social distance themselves in advance of this advice.

Homecare / ERT infusions

Patients who are not isolating but may be social distancing themselves

Patients who are not self-isolating and do not have a person in their household who is required to, may be able to receive their infusions as normal. You will be contacted by your clinical centre or homecare provider, to discuss this. Nurses will be following the current guidance in respect of good hygiene but will unlikely be wearing protective clothing (PPE). Nurses will unlikely have provisions such as facemasks as these are in short supply. If you are concerned about the risks to you or other family members, please discuss this with the homecare company or your clinical centre before the nurse is due to visits. Please be advised that they are also receiving a high volume of calls and may not be able to answer you straight away.

Patients who are self-isolating due to illness thought to be coronavirus related

If a patient is self-isolating, (this includes isolating due to another member of the household presenting with symptoms) nurse visits for ERT infusions are paused for the duration of self-isolation. You should inform your treatment centre if you are self-isolating and let them know also when you resume infusions.

Orally administered therapeutic options (such as pain relief for example or fabry specific oral treatments for gaucher and fabry, if applicable) should be considered and discussed with your clinician.

The clinical centres will keep in contact with self-isolated patients by regular telephone calls, the frequency to be determined by need and staff availability.

Independent ERT users

For patients / parent / carers who independently give infusions your treatment can continue. Please see the attached information sheet, which details measures you will need to take in respect of deliveries. <https://www.clinicalhomecare.org/covid-19-update-17th-march-2020/> (this is currently being updated)

Becoming semi independent /fully independent in giving ERT infusions

There may be options for some patients /carers, to have training to become semi-independent / fully independent in giving ERT. This is however wholly dependent on homecare resources and the level of demand from patients.

Full independence would mean that you would be able to do all aspect of your ERT

Semi independence means that a nurse can assist with cannulation / port access or make up the drug meaning that the nurse attendance is shorter.

Please discuss this with your clinician or nurse specialist.

Patients who have to undergo a drug holiday

Decisions regarding drug holidays (which is highly likely for many patients) will be made, in the, patient's best interest, based on the greater risk to them of being infected with COVID-19, than any effect of missing treatment for a period.

Patients with indwelling venous access devices who are on a treatment holiday (for example port-a-caths)

Patients will need to have these flushed but this should be done at the longest interval possible in line with the specific guidance for your device. This may appear to contradict the statement in relation to infusions but it is a balance of risk and meeting patients critical health needs. This would be done by a homecare nurse. However, training for carers / patients to flush potentially unused ports would be offered as a priority.

Patients enrolled on an MAA

We expect guidance and further information to be available from NICE and NHSE within the next few days.

Patients waiting to start ERT

Patients will be reviewed by their treating clinician. There may be delay in establishing patients on ERT due to overstretched resources and the risk of bringing patients into the hospital.

Patient / carer wellbeing

We acknowledge that this is a very anxious time for many of our patients, carers and their families and the wellbeing of you all is important to us. Please find attached a resource called first aid to worry which gives some helpful advice to help with those feelings on anxiety. In addition to this there is a link to mind who also have resources to support you.

<https://www.mind.org.uk/information-support/coronavirus-and-your-wellbeing/>

Please do not forget your patient support group is there to support, advise and to be a listening ear. We are all here for you.

To be reviewed on 27.03.2020

Attachment

First Aid for Worry

It is normal to feel anxious right now because worrying things are happening. This anxiety is a normal, human response that people across the country and the world are sharing right now.

You can try these things to help you to manage your worries.

- Only check the news once or twice a day. Although it can feel like you are doing something useful when you check the news, this may actually maintain your anxiety.
- Interrupt worrying thoughts by noticing: 5 things you can see, 4 things you can hear, 3 things you can feel, 2 things you can smell, 1 thing you can taste.
- Stay active. Plan small, useful tasks to do each day.
- Look out of the window. How many different shades of green can you see? Or blue? Or another colour?
- Listen to all the noises you can hear outside the room. Now listen to all the noises you can hear inside the room. Listen to the noises your body is making – can you hear your own breathing? Listen to that for a minute or two.
- When you wash your hands, do it mindfully. Notice the feeling of the warm water, the slipperiness of the soap, the sensation of one hand moving on the other and the water running over your hands. Dry them gently and notice this sensation. You can do this for other activities, such as showering or washing up.
- Talk to a friend or family member about something you both enjoy. Start off by asking to have a conversation about this, and asking not to mention the coronavirus.
- Try a breathing exercise: Breathe in for the count of four, and then out for the count of four. Do this gently for a few minutes. Notice the feeling of the air moving in and out of your nose and your chest rising and falling.
- Offer encouragement and support to someone else.
- At the end of each day, write down three things you are grateful for today.

<https://www.mind.org.uk/information-support/coronavirus-and-your-wellbeing/>