

Update from the [adult LSD clinical centres](#) on clinical support and homecare (17 April 2020)

Please find below some updated information from our **adult clinical centres**.

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 regularly and it is important that you keep yourselves up to date with the latest government advice:

<https://www.gov.uk/coronavirus>

Extremely vulnerable patients

Clinical centres have now reviewed all their patients and will have contacted those patients deemed to be 'extremely vulnerable' and discussed shielding if appropriate.

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>

We are aware that many patients may have received a letter or text to suggest that they were extremely vulnerable – as various NHS lists were used centrally to generate these lists. If you have received a letter that you do not feel is appropriate for you, or has not come directly from your LSD team, then please don't hesitate to contact your LSD team to discuss this further.

Social distancing

Social distancing measures are steps we should all be taking 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/coronavirus>

Self-isolation – if you are symptomatic or unwell or someone you live with is symptomatic (with COVID-19)

In this instance you should self-isolate at home. Please see this link to the NHS self-isolation advice:

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

Homecare / ERT infusions

Patients who are not shielding

Patients who are not shielding should be able to receive their infusions as normal. You will be contacted by your clinical centre or homecare provider, to discuss this. 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 visit. 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 COVID-19 related

If a patient is self-isolating (this includes isolating due to another member of the household presenting with COVID-19 symptoms), then 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.

Independent ERT users

For patients / parent / carers who independently give infusions your treatment can continue. Please see the attached website link, 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 just assist with cannulation / port access or making up the drug - meaning that the nurse attendance is shorter.

Please discuss this with your clinician or nurse specialist.

Patients who are shielding at home

Patients who have been advised to shield due to being classed as extremely vulnerable to complications of COVID-19

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

Patients who are advised to undergo a drug holiday

Decisions regarding drug holidays (which may be highly likely for many patients) will be made, in discussions with patients looking at their best interests, based on the greater risk to them of being infected with COVID-19, balanced against the effect of them missing intravenous ERT treatment for a period of time.

Fully dependent on homecare

In most cases, if an adult patient has been advised to shield then a treatment holiday is suggested.

Orally administered therapeutic options (such as pain relief or options to switch to specific oral treatments for Gaucher and Fabry disease, if applicable) can be considered and discussed with your clinician.

Fully independent patients

If safe, can continue with their treatment. Circumstances where further discussions may be needed is around those patients who although they are not having homecare nurses come in to the home, are reliant on others outside of their household (eg. could be a friend or another family member who lives in a different household) coming in to do the infusion. This would effectively 'break' shielding and so for some patients a treatment holiday might also be advised.

Semi-independent patients

Individual decisions will be made based on the risk / benefit of continuing treatment. For some patients a treatment holiday may be suggested.

It is important for patients to discuss their individual circumstances with their clinical centres around the risk / benefits of treatment.

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.

So in summary – patients should be reassured that the general messages are similar across centres – with some individual decisions needing to be made. Any patient who feels uncomfortable with the decision for them should get back in touch with their own team to discuss further. If patients feel that their condition is deteriorating when intravenous ERT is discontinued – then they should let their clinical team know – so that decisions can be reviewed.

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.

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.