

# Update from the Adult LSD clinical centres

## Clinical support and homecare

Updated 26 March 2020

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 Government and NHS guidance:

[www.gov.uk/coronavirus](https://www.gov.uk/coronavirus)

## Shielding high-risk patients

Clinical centres are already reviewing all their patients and will be in contact with those patients deemed to be high risk.

This link gives government advice on shielding:

[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](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)

## Social distancing and Self-isolation

### Social distancing for 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).

The government website provides up to date information:

[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](http://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 for symptomatic and unwell patients, or if someone you live with is symptomatic

In this instance you should self-isolate at home.

These links provide government and NHS self-isolation advice below for up to date information on what this means.

[www.gov.uk/government/publications/covid-19-stay-at-home-guidance/stay-at-home-guidance-for-households-with-possible-coronavirus-covid-19-infection](http://www.gov.uk/government/publications/covid-19-stay-at-home-guidance/stay-at-home-guidance-for-households-with-possible-coronavirus-covid-19-infection)

[www.nhs.uk/conditions/coronavirus-covid-19/self-isolation-advice/](http://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 and ERT infusions

Patients who are not self-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. 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 self-isolating due to illness thought to be COVID-19

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, parents and 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.

[www.clinicalhomecare.org/covid-19-update-17th-march-2020/](http://www.clinicalhomecare.org/covid-19-update-17th-march-2020/) (currently being updated)

## Becoming semi-independent or fully independent with ERT infusions

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

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

**Full independence** would mean that you or a family member would be able to do all aspect of your ERT, including drug reconstitution and cannulation (inserting the needle)

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-cath)

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 and patients to flush potentially unused ports would be offered as a priority.

## Patients enrolled on a Managed Access Agreement (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 and 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 the accompanying resource called "First aid to worry" which gives some helpful advice to help with those feelings on anxiety. In addition, there is a link to mind who also have resources to support you.

[www.mind.org.uk/information-support/coronavirus-and-your-wellbeing/](http://www.mind.org.uk/information-support/coronavirus-and-your-wellbeing/)

## Patient Support Group

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.

Pompe Support Network

[www.pompe.uk](http://www.pompe.uk)

01730 231554

**POMPE**  
**SUPPORT NETWORK**