

INFORMATION SHEET

Going into hospital with COVID-19

Introduction



Many families are understandably worried about their family member with a learning disability being admitted into hospital with COVID-19.

All our information sheets are available to download free of charge.

To enable us to continue our work [please support us](#) or donate £3 by texting CBF to 70450.

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Here are some steps that you can take to prepare in case your family member is admitted to hospital with COVID-19.

Preparations should your family member be diagnosed with COVID-19

- 1) **Be clear about the risk status of your family member**- whether they are considered in an 'at risk' group, or extremely clinically vulnerable. You should know if they are in the latter group, as they will have been shielding from the virus. You may want to contact the Community Learning Disability Team (CLDT) and / or GP practice to discuss the risks your family member may face and what steps can be taken to reduce them.

Find information about visiting your relative in our [Covid-19 FAQs from legal panel which can be accessed here](#). If your family member lives at home, or is staying with you now, help them to self-isolate by reducing the number of people they need to come in to contact with as much as possible. You should also ensure that those people they need to have contact with are following government hygiene and distancing advice at all times. *You can read government guidance on social distancing [here](#) and self-isolation [here](#).*



- 2) **Update/create a hospital passport**- (Example hospital passport templates are available to download from [MyCompass](#), [Mencap](#), [Include Me Too](#) and the [CBF Covid-19 Information and resources page here](#)). The passport should easily display the most critical things that a nurse or doctor should know- such as any

medication the person is taking and if they are sensitive to medication – often people with Learning Disabilities have a heightened sensitivity to the medications used in Intensive Care Units (ICU) and advice is needed. You may not be with your family member in the hospital, so it is important that you enable medical staff to quickly understand essential information. Provide a telephone number for you, or a key support who can talk the hospital through any issues. A laminated ‘grab sheet’ that quickly informs medical staff of the most important things can help.

A hospital passport should also include any advance decisions or discussions that may have been held, such as about the circumstances in which a Do Not Attempt Resuscitation (DNAR) may be applied. Remember that a DNAR should never be applied without the consent of the individual or without consulting family members – see letter issued by NHSE [here](#). Please also find information around DNAR notices in our *Covid 19 FAQs from Legal Panel* resource that can be accessed [here](#). Add next of kin names and contact details to this section of the passport. All treatment decisions must be made in the person’s ‘best interests’ and involve family members.



- 3) **Have a bag ready packed** with everything your family member may need, including their Hospital Passport and any medication they are taking, ensuring that the dosage is clearly marked. If pads are used, ensure they know the size and type, to avoid bed sores/discomfort or include them in the bag.



Add some comforting things to the bag- bearing in mind the need to keep any items very hygienic. The bag could include laminated photos of family or an activity they like doing, a special object/toy/mascot or a small bag of sensory objects. Try adding a message for the nurses to read with names and a few hints of what to say to the person to engage them.

- 4) **If your family member has a communication passport do include this to assist the medical team in communicating with them** [plus some resources such as easy read information that will help them explain about the treatment they may be receiving](#). Ask that the nursing staff always explain what they are about to do, prior to doing things – this reduces stress and fear for anyone in hospital.
- 5) **Find out the contact details of the Acute Hospital Learning Disability Liaison Nurse** who can help to make sure that the information about how to care for a patient with a learning disability reaches the front line team and can help the medical team adjust care and treatment to meet their needs. Check with each hospital in your catchment area if they have one of these teams as your family member may not be admitted to your nearest hospital. Contact details are

usually published on the hospital website. Add this information to your packed bag.

- 6) **Write/review your emergency plan**- remember that you or another family member may become unwell with COVID-19 too. Think about the scenarios that could happen in your situation and work out who can help and who needs to be informed if that happens. (*Find an example emergency plan [here](#)*). Think about who can help from your circle of support/family/friends.

Being admitted to hospital

- 1) If the 111 service advises that your family member should be admitted to hospital, they will also arrange for an ambulance to take the person to the hospital. 
- 2) Be prepared for the fact that if the person is an adult you may not be allowed to accompany them. CBF are waiting for clarification on whether family members of people with a learning disability may accompany them. The latest NHS Visitor Guidance is [here](#).
- 3) Contact the Learning Disability Liaison nurse in the hospital (see point 8 on page 2) to tell them your relative is being admitted so they can make sure they provide support. Please also see information around DNAR notices in our *Covid 19 FAQs from Legal Panel* resource which can be accessed [here](#).
- 4) Try and prepare your family member for how things will be in hospital- you can use resources such as the [Books Beyond Words](#) series that include illustrations of hospital staff wearing protective clothing (PPE) such as face masks and the equipment they may use such as oxygen masks and ventilators. 
- 5) If a member of the family is allowed to accompany the person to hospital think about who is best placed to do this- think about the risks they will be exposed to themselves and underlying health conditions they may have before deciding who should go.
- 6) Remember to take the bag you have prepared with everything your family member may need whilst in hospital (see above).

Being treated for COVID-19 in hospital

- 1) Remember that most people recover from COVID-19 and that there is every chance that your relative will be discharged from hospital safe and well.



- 2) Be vigilant for worsening symptoms. You know the person better than anyone else so make sure you are communicating any concerns/signs you have noticed to the medical team.
- 3) Try to reduce the risk of 'diagnostic overshadowing' (where medical staff miss signs of deterioration because of the way the person looks or behaves as they think this is something to do with their disability). Show staff the section on the Hospital Passport about how they are when well and how you know when they are unwell/their condition is worsening. Highlight the sensitivity to medication or any allergies the person may have as in very busy hospital wards things can be missed.
- 4) Be alert to the application 'Do Not Attempt Resuscitation (DNAR)' notices and any discussion about treatment decisions, such as a decision 'not to escalate' - meaning not to place in a critical care bed or admit to intensive care. Ask for a second opinion if you do not agree with the treatment plan. NICE has published [NICE Critical Care guidance](#). This is a tool to help medical teams decide who would most benefit from critical/intensive care. The guidance was challenged and revised to say that it should not be applied to people with a learning disability. However, doctors will consider the impact of any underlying health conditions and whether these will reduce the chances of that person benefiting from treatment, especially if they are linked to the respiratory system. However, they must make best interest decisions on the same basis as they would for any other patient regardless of their disability and in line with the Mental Capacity Act and the Equality Act. Please also find information around DNAR notices in our *Covid 19 FAQs from Legal Panel* resource that can be accessed [here](#).


Going home from hospital

- 1) Most people will recover from COVID-19 and return home to continue to recover from the illness. The hospital should give you a discharge letter to give to your GP practice and arrange for any further treatment or monitoring the person may need.
- 2) If you think that you will need extra support to care for your family member at home you should contact your Care Manager and ask for this.
- 3) You can also look on the council website for any additional support. Most councils have a COVID-19 Helpline and can arrange for groceries and prescriptions to be dropped off at your home.



Supporting the end of life

If your family member is critically ill and it is thought they may not survive, consider the following end of life planning:

- 1) Try to think about the end of life care you would wish for your family member, whether you are able to be with them or how they can be supported by nurses. Write down your thoughts and wishes on this so that the medical team are able to stay as close to these as they are able to. A guide to end-of-life care planning for people with learning disabilities is available [here](#). (*Palliative Care for People with Learning Disabilities have collated resources which might be useful [here](#)*) 
- 2) Find out if you are able to visit your family member in hospital. See this [information sheet](#) and the further reading below.
- 3) Consider how you would like them to be in contact with you at this time if it has not been possible for you to be present. Some families of people dying of COVID-19 have been able to share the last minutes with their loved one by video calls and have been able to say goodbye in this way. (*The National Bereavement Alliance have a helpful guide for keeping in touch with your loved one [here](#).*)
- 4) Use easy read information about dying to help your family member to understand what is happening, available from Easy Health here: www.easyhealth.org.uk/index.php/health-leaflets-and-videos/dying/

Summary

Finding that your family member needs to be admitted to hospital with COVID-19 is understandably very worrying. However, you can do much to reduce the risks and enable medical staff to understand their needs and ensure that they get the best possible treatment. The better prepared you are, the more easily you will be able to support your loved one whilst they are in the care of the NHS.

If you are concerned about the care and treatment your family member is getting in hospital please call our Family Support Service on 0300 666 0126.

You can also call:

Mencap COVID-19 Helpline on: 0808 808 1111

National Autistic Society Helpline on: 0808 800 4104

Links to useful resources and guidance

Clinical guide for front line staff to support the management of patients with a learning disability, autism or both during the coronavirus pandemic (NHS Speciality Guide): <https://www.nice.org.uk/Media/Default/About/COVID-19/Specialty-guides/learning-disability-autism-during-pandemic.pdf>



Alexander, R.T. (2020). *People with Intellectual Disability and Mental Health/Behavioural Problems: Guidance on COVID-19 for Community Settings*. Norwich: RADiANT.

http://radiant.nhs.uk/uploads/2/7/2/5/27254761/alexander_2020_guidance_on_covid-19_for_community_id_settings.pdf

Include Me Too Hospital Communication Passport and Supporting Resources:
<https://includemetoo.org.uk/covid19/>

NHS Grab and Go form for people with learning disabilities and autistic people going into hospital during Covid 19. (To be used in addition to hospital communication passport) <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0381-nhs-covid-19-grab-and-go-lda-form.pdf>

[Guidance notes to help you complete the Grab and Go form for your relative can be found here.](#)

Palliative Care for People with Learning Disabilities – Coronavirus Resources
<https://www.pcpld.org/links-and-resources/>

Clinical guide for supporting compassionate visiting arrangements for those receiving care at the end of life.

<https://www.nice.org.uk/Media/Default/About/COVID-19/Specialty-guides/supporting-compassionate-visiting-arrangements-for-those-receiving-care-at-the-end-of-life.pdf>

National Bereavement Alliance – guide to keeping in touch when you can't be with someone who is so ill that they might die
<https://nationalbereavementalliance.org.uk/keeping-in-touch-when-someone-is-seriously-ill/>

Information and support from Dying Matters -
<https://www.dyingmatters.org/overview/need-support>

If you are worried our family support line remains open and can be reached at 0300 666 0126. You can also always email us directly, support@theCBF.org.uk

A range of free resources are available on our website. We have a new page called *Covid-19 Information and Resources* which can be accessed [here](#). This page is being regularly updated so please keep checking back.

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**The Challenging
Behaviour Foundation**

making a difference to the lives of people with severe learning disabilities

The Challenging Behaviour Foundation

We are a registered UK charity specifically focussed on the needs of children, young people and adults with severe learning disabilities whose behaviour challenges, and their families.

We will make a difference to the lives of people with severe learning disabilities, whose behaviour challenges, and their families by:

- Championing their rights
- Ensuring timely information and support
- Raising awareness and understanding
- Promoting and sharing best practice

To access our information and support, call 01634 838739, email

info@thecbf.org.uk or visit our website: <https://www.challengingbehaviour.org.uk>