

INFORMATION SHEET



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

Going into hospital with COVID-19

Many families are understandably worried about their family member with a learning disability being admitted into hospital with COVID-19. There has been a lot of discussion and information in the media and on social networks about how disabled and elderly patients will fare as NHS beds fill up and doctors and nurses are faced with difficult decisions about who will have access to critical care beds and intensive care.

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

Prepare

- 1) **Be clear about the risk status of your family member-** Community Learning Disability Teams (CLDTs) have been asked to RAG rate this- Red/Amber/Green. Most people with a learning disability will be rated RED and some people will be designated as having risks that place them in the category of needing them to have 'the most stringent social distancing measures' to shield them from the virus. *Read the guidance for Community Learning Disability Teams [here](#).*
- 2) **Contact the Community Learning Disability Team (CLDT) and / or your GP practice to discuss the risks your family member may face and what steps can be taken to reduce them-** this may mean not visiting them where they live. 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 advice at all times. *You can read government guidance on social distancing [here](#) and self-isolation [here](#).*
- 3) **Ask for any practical help you may need to shield your family member from the virus.** Register with the government vulnerable person service so that you can receive support for food etc. at home here <https://www.gov.uk/coronavirus-extremely-vulnerable>. Most councils have a COVID-19 Helpline and can arrange for groceries and prescriptions to be dropped off at your home.
- 4) **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*

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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.

- 5) **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.
- 6) **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.
- 7) **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.
- 8) **Find out the contact details of the Acute Hospital Learning Disability Liaison team-** these nurses 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 (see 5 above)
- 9) **Help your family member understand as much as they can about keeping safe during the COVID-19 crisis-** there is now lots of good easy read material and resources to help you do this. Have a look under ‘Info sheets’ and ‘Resources, examples and templates’ on our [Covid 19 information and resources page](#)

Particular resources that might be useful include:

- [Books Beyond Words 'Beating The Virus'](#)
- [CBF Handwashing Information Sheet](#)
- [Mencap's 'Helpful advice and information on coronavirus' website page](#)

10) **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.

What to do if you think your family member has symptoms of COVID-19

- 1) **Follow Government advice if you think your family member has developed symptoms of COVID-19.** Call the 111 service and they will talk to you about what you should do. Make sure that you explain that your family member has a disability and what you have been told about their risk status (see above).
- 2) If the 111 service says that it is okay for the person to remain at home in your care, help them to self-isolate and only allow essential care to be provided by as few people as possible. Government guidance on self-isolation is [here](#).
- 3) Inform any support services/community health service that you may be receiving about the advice given so that they can plan how to support the person as safely as possible at home.

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

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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 (points 4&5 on pages 1 & 2)

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

- 1) Sadly, not all people who contract COVID-19 will survive. Recent reports say that only half of people admitted to Intensive Care Units will survive because by this stage people have become very critically ill.
- 2) 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.
- 3) 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](#)*)
- 4) Include 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](#).*)

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 – relevant to all clinical specialities (NHS England and Improvement):

https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0031_Specialty-guide_LD-and-coronavirus-v1_-24-March.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/>

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/>

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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