



## Going to Hospital

### This information sheet may be useful for families who are:

- Looking for information when their family member is going into hospital
- Looking for information to help prepare their family member for hospital admission



All our information sheets are available to download free of charge because we believe that money should not be a barrier to getting the information you need when you need it.

Please see the end of this information sheet for details of how to support us.

We want to make sure our resources are helpful. Please spend a few minutes giving us some feedback: [Feedback form](#)

### Introduction

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

Here are some steps that you can take to prepare your family member for a hospital admission.

1. **Update/create a hospital passport-** 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 medications 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](#). 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' in line with the [Mental Capacity Act 2005](#) involve family members.



Example hospital passport templates are available to download from [MyCompass](#), [Mencap](#), [Include Me Too](#).

2. [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.

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.

3. [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.
4. [Write/review your emergency plan](#) 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. Think about who can help from your circle of support/family/friends.

Find an example emergency plan [here](#).

## Being admitted to hospital



If the 111 service advises that your family member should be admitted to hospital, they may also arrange for an ambulance to take the person to the hospital.

Contact the Learning Disability Liaison nurse in the hospital (see point 4) to tell them your relative is being admitted so they can make sure they provide support. Please also see information around DNAR notices.

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'



If a member of the family or carer/ carers are able to accompany the person to hospital think about who is best placed to do this

Remember to take the bag you have prepared with everything your family member may need whilst in hospital (see above).

## Being treated in hospital

You know the person better than anyone else so make sure you are communicating any concerns/signs of pain or discomfort you have noticed to the medical team.

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.



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. 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.

## Going home from hospital



Most people will return home to continue their recovery. 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.

If you think that you will need extra support to care for your family member at home you should contact your Social Worker or Care Manager and ask for this.

More information can be found on the CBF website [here](#).

## 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:

- 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](#).

- 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 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.
- Use easy read information about dying to help your family member to understand what is happening, available from Easy Health [here](#).

## Summary

Finding that your family member needs to be admitted to hospital is understandably very worrying. However, you can do much to 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.

## Links to useful resources and guidance

Some of the following information was produced during the Coronavirus pandemic. However, the information and suggestions may still be helpful when a family member with a learning disability is admitted to hospital. [Clinical guide for front line staff](#) to support the management of patients with a learning disability and autistic people – relevant to all clinical specialities. (NHS Guidance).

[Include Me Too](#) Hospital Communication Passport and Supporting Resources.

[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)

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 - <https://www.pcpld.org/>

[National Bereavement Alliance](#) guide to keeping in touch when you can't be with someone who is so ill that they might die.

Information and support from [Dying Matters](#).

If you are worried about your family member going into hospital or are concerned about the treatment they are receiving our family support line can be reached at 0300 666 0126. You can also always email us directly, [support@theCBF.org.uk](mailto:support@theCBF.org.uk)

A range of free resources are available on our [website](#).

**Last reviewed : July 2024**

#### **The Challenging Behaviour Foundation**

We are the charity for people with severe learning disabilities who display challenging behaviour. We make a difference to the lives of children and adults across the UK by:

- Providing information about challenging behaviour
- Organising peer support for family carers and professionals
- Giving information and support by phone or email
- Running workshops which reduce challenging behaviour

To access our information and support, call 01634 838739, email [info@theCBF.org.uk](mailto:info@theCBF.org.uk), or visit our website: [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)

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