

# I have a learning disability or I am autistic



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- **This guide is really important during the COVID-19 pandemic**
  - The Human Rights Act means that staff in the NHS must respect and protect my human rights when making decisions about my care even in the time of the COVID-19 pandemic.
  - Decisions about treatment should be made on an individual basis and in consultation with families, taking into account my usual health. Decisions about my treatment and resuscitation should not be made based on my learning disability or autism or the Clinical Frailty Scale.
  - All decisions must be made in accordance with the principles of the Mental Capacity Act.
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**My name is:**

**I like to be called:**

**Date of birth:**

**My NHS Number is:**

**My next of kin/  
representative:**

**Their phone number:**

**I am able to indicate  
YES and NO to  
your questions by:**

**I have previously had the following  
breathing problems (asthma/  
history of infections, etc):**

**Any other things that may  
comprise my airway, e.g. past  
surgery:**

**What you need to know about my other past and current health (e.g. diabetes / epilepsy):**

**I usually take the following medication (include dose of tablets or liquid or any other way I take medicine):**

**This is the help I need to understand what is happening and the support I may need with any treatment:**

**Swallowing and oral care, including how I drink (e.g. small amounts or thickened or cooled, or any other way I need to take it):**

☐ **No issues**      ☐ **Detail below**

**This is how people usually know if I am in pain:**

**If I'm worried or upset I may:**

**I communicate by:**

**My hearing and my eyesight (e.g. hearing aids, glasses or anything else I need to help me hear or see):**

**This should be read in conjunction with my hospital passport**

# Use these guidance notes to help you complete the Grab and Go guide form

The Grab and Go guide has been designed in partnership with people with learning disabilities, families and nurses.

It gives the information that doctors and nurses will need if you go to hospital because of COVID-19 and, for example, are struggling to breathe.

**It is not a replacement for the everyday, detailed hospital passport.** You should update your hospital passport and take that to hospital along with the Grab and Go guide if you need to be admitted.

If you haven't got a hospital passport you can download your local passport by searching on the internet for (hospital name) hospital passport or choose one you like from here:

<https://www.autism.org.uk/about/health/hospital-passport.aspx>

<https://www.mencap.org.uk/advice-and-support/health/health-guides>

### If you need help completing the form please ask:

- someone who knows you well like a family member or support worker
- a social worker
- a support group you are in touch with
- sign up for a webinar with Learning Disability England. You can sign up at <https://www.learningdisabilityengland.org.uk/what-we-do/events/ld-e-webinars> or email [info@LDEngland.org.uk](mailto:info@LDEngland.org.uk) to suggest a webinar topic or get a recording of any previous ones.

## How to complete the Grab and Go guide form

The information in the form must be short and clear. Everyone is different but we have given some examples to show what kind of information is useful in answer to each question in the form.

You must fill in the form to show the best way you can be supported (or the person you are supporting).

### **I am able to indicate YES and NO to your questions by:**

The doctors need to know if you can indicate yes and no without speaking. Nobody with serious breathing difficulties can speak easily.

If you have a unique way of doing this you must write it clearly, for example:

- *I sign yes by clenching my right hand.*
- *I indicate no by sticking my tongue out.*

### **I have previously had the following breathing problems (asthma / history of infections etc):**

The doctors need to know your history so they can give you the right treatment.

If you have had breathing problems in the past, list the issues you have had. For example:

*asthma, lots of chest infections, pneumonia, etc.*

### **Any other things that may compromise my airway, for example past surgery:**

The doctor needs to know about any conditions or past surgery that might affect your airways to treat you safely. For example:

*smaller airways because of a genetic condition like Down's syndrome, past surgery, tracheotomy, a stomach procedure like fundoplasty (you or the people who support you will know if you have any problems with your airways).*

### **What you need to know about my other past and current health, for example diabetes, epilepsy, etc:**

Your medical history is important. List any health conditions you have now or have had in the past. Include surgery you have had.

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**I usually take the following medication (include dose of tablets or liquid, or any other way I take medicine):**

The doctors need to know this to make sure the medicine they give you works with the medicine you are already taking. Use the name and dose details that are on the packaging. If you can, take all your medication with you in a clear plastic bag.

If you need any support to take medication, describe that support clearly. For example:

- *I need my tablet to be crushed in a spoonful of jam.*
- *Tip my tablets into my mouth one at a time, hand me a glass of juice and stay with me until I have swallowed them. I might need a whole glass of juice.*

**Swallowing and oral care, including how I drink (for example, small amounts or thickened or cooled or any other way I need to take it):**

If you have difficulties drinking and swallowing, give clear support instructions to avoid choking and becoming dehydrated. For example:

- *I need 4 teaspoons of thickener in a cup and to be fed this one teaspoon at a time. It will take me 15 minutes to drink a cup of tea.*
- *I need my drink in a sippy cup. Please remind me to drink every five minutes to keep me hydrated.*

**This is how people usually know I'm in pain:**

If you are not able to say when you are in pain and where it hurts, it is important to be specific so that doctors and nurses know when something is wrong. For example:

- *If I say I've got a headache, ask me to point to where it is.*
- *I'm usually in pain when I fidget a lot.*
- *I might be in pain if I go quiet and avoid eye contact.*

**If I'm worried or upset I may:**

If you can't say what's wrong, how might you show you are worried or upset? How can someone help or reassure you?

Give clear descriptions of what might happen and what to do about it. For example:

- *If my eyes are darting around and teary, sit with me and let me know what is going on. Ask if I would like to listen to my playlist. Help me to phone or Facetime my mum.*
- *If I try to leave, I might be feeling overwhelmed. Stay with me and offer quiet reassurance. If possible, lower the lights and reduce distractions.*

**I communicate by:**

Good communication is very important. What do people need to know? For example:

- *It takes me a while to understand information and respond. Give me 30 seconds to reply (that feels like ages).*
- *Use easy words and short sentences. Give me information in small chunks.*
- *It's complicated – check my detailed hospital/communication passport.*

**My hearing and my eyesight (for example, hearing aids, glasses or anything else you need to help you hear or see):**

Is there anything people need to know that will help you understand each other? For example:

- *My hearing isn't brilliant especially when there is background noise. So get my attention before you start speaking to me.*
- *I need information in large font (say what size if you know).*
- *Please clean my glasses every morning and evening.*

**Top tips for family and paid carers**

- Laminate, double laminate or put the Grab and Go guide in a sealed plastic bag.
- Find out the name and contact details of the Learning Disability Liaison Nurse at your hospital, write it down somewhere safe in case you need it.
- Check your local hospital trust's policy about allowing carers to be present if a person with a learning disability or autism is admitted to hospital with coronavirus.
- Family carers – make plans for if you get unwell yourself. Make sure:
  - You have a list of phone numbers of people who can help out in an emergency.
  - You have enough supplies for two weeks.
- Put a hospital bag together now for the person with a learning disability or autism, you won't have time in an emergency. Include:
  - Laminated COVID-19 Grab and Go guide.
  - Ordinary hospital passport.

- Phone and charger, headphones and a playlist of favourite music.
  - Toothbrush, soap and towel and change of clothes/pyjamas.
  - Prepare a similar bag for yourself, include money to buy food and drink for yourself (carers aren't fed).
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- Look after your own health, do something, however little, for yourself every day.
  - Stay in touch with friends and family by phone.
  - Check <https://www.learningdisabilityengland.org.uk/> for updates and easy information.

## Additional note from Mencap for carers and supporters (not endorsed by NHS England)

Remember to keep the information in the Grab and Go form as short and clear as you can. It is important that the form is completed as if the person is well, and tells healthcare professionals what they are like normally. This not only gives them information about how to get to know the person and meet their needs, but will also help them to monitor how unwell a person is.

Mencap would like to give you **one extra note of guidance** for completing the form.

One of the boxes on the form reads as follows: 'I am able to indicate YES and NO to your questions by...'

- If you support someone who is not usually able to indicate yes and no clearly, it is important to also say this here.
- You could also give information here about how the person uses yes and no, for example, is it usually a reliable way for the person to give information or answer a question? For example, does the way someone says yes, or no, usually tend to match up with what they really seem to want, or what they have understood?
- You may also wish to signpost the reader to additional information in the questions on the back of the form regarding understanding information and communication.