

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.

The Grab and Go Guide form gives the information that doctors will need if you are admitted to hospital and 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 as with the Grab and Go Guide form if you need to be admitted.

If you haven't got a hospital passport you may 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 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 for each question in the form. You must fill in the form showing the best way to support yourself (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.

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 e.g. past surgery:

The doctor needs to know about any conditions or past surgery that might compromise your airways to treat you safely.

For example, *smaller airways because of a genetic condition like downs syndrome, past surgery, tracheotomy, a stomach procedure like Fundoplasty (you or the people who support you will know if you have this.)*

What you need to know about my other past and current health e.g. 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, tablets/liquid etc.):

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 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. this might need a whole glass of juice.*

Swallowing and oral care/ how I drink (e.g. small amounts, thickened, cooled etc.):

If you have difficulties drinking and swallowing give clear support instructions to avoid choking and stay hydrated. 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.*

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I communicate by:

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

- *It takes me a while to process 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 (e.g. hearing aide, glasses etc.):

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 it 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 hospital trust policy about allowing carers to be present if a person with learning disability is admitted to hospital with Corona virus.
- 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 COVID19 Grab and Go guide
 - Ordinary hospital passport
 - Phone and charger, headphones and a play-list 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)
- 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