



Health

Hospital admissions: being prepared

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It's good to be prepared in case of unexpected hospital admissions.

Healthcare/hospital passports

At this time it is really important to make sure the person you care for has a healthcare/hospital passport that can accompany them if they are admitted to hospital.

These typically contain contact/personal details and:

- information about health issues
- support needs
- medication
- allergies
- likes and dislikes
- fears and phobias
- sensory needs
- communication styles/needs
- how the person prefers to receive information
- behaviours and their possible meaning.

This will be vital information for healthcare professionals looking after a person who has Down's syndrome.

A number of passports are based on the 'traffic light system':

- **Red** - things you must know about me
- **Amber** - things that are important to me
- **Green** - my likes and dislikes

Your Community Learning Disability Team, Hospital and/or NHS Trust may produce their own local versions of healthcare/hospital passports. If available, these can usually be found on your local NHS Trust website.

You could make your own or use one of the examples below.

If you are making your own version, a single page profile/passport might be a useful model to follow in that it will help you to focus on the most important information you would like healthcare professionals to know.

There are some examples of single page profiles at the Helen Sanderson website here:

<http://helensandersonassociates.co.uk/person-centred-practice/one-page-profiles/>

Health and hospital passports – some examples:

<https://www.royalfree.nhs.uk/patients-visitors/disabled-facilities/patients-with-a-learning-disability/hospital-passport/>

<https://www.downs-syndrome.org.uk/download-package/health-book/>

<https://www.publichealth.hscni.net/publications/hsc-hospital-passport-and-guidance-notes>

<https://www.ouh.nhs.uk/patient-guide/leaflets/easyread/documents/hospital-passport.pdf>

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

<https://www.rdehospital.nhs.uk/documents/patients/learning-disability/hospital-passport.pdf>

<https://aldhc.keele.ac.uk/repos/AccessToHealthcare/Hospital%20Communication%20Passport%20for%20web.pdf>

<https://curve.coventry.ac.uk/open/file/3f493cbd-2ddd-7aeb-0d89-0fa671dcda10/1/Toolkit.zip/leaflets/traffic%20light%20assessment.pdf>

https://councilfordisabledchildren.org.uk/sites/default/files/field/attachemnt/myhospitalpassport-1_1_.pdf

Other useful resources:

Hospital Communication Book

A resource for healthcare professionals to help make sure people who have difficulties understanding and /or communicating get an equal service in hospital

<https://www.mencap.org.uk/sites/default/files/2016-06/hospitalcommunicationbook.pdf>

Covid-19 Grab and Go guide

The NHS have published a two-page Grab and Go guide form (with accompanying guidance) to be used during the current crisis **alongside an existing hospital passport**.

The Grab and Go guide was 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.

You can download the form to complete here:

<https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0381-nhs-covid-19-grab-and-go-lda-form.pdf>

The guidance on using the form is downloadable here:

<https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0381-nhs-covid-19-grab-and-go-lda-guidance-notes.pdf>

Going into hospital – Learning disabilities

The NHS have published (8 April 2020) the following guidance on visiting hospital:

https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0030_Visitor-Guidance_8-April-2020.pdf

It makes clear that while visiting is suspended until further notice, exceptions include when you *'...are supporting someone with a mental health issue such as dementia, a learning disability or autism, where not being present would cause the patient to be distressed'*.

General information from the NHS

<https://www.nhs.uk/conditions/learning-disabilities/going-into-hospital/>

Book about me – learning disability

Booklet for others to find out crucial information about a child or young person with high support needs

<https://www.mefirst.org.uk/resource/book-about-me-learning-disability/>

Top tips for triaging and treating children with Down's syndrome

This infographic was created Elizabeth Herrieven (EM Consultant and Mum of Amy) & Linda Dykes (EM Consultant and GP).

<https://www.downs-syndrome.org.uk/download-package/top-tips-for-triaging-treating-children-with-downs-syndrome/>

Learning disability liaison nurses

Find out if your local hospital has a learning disability liaison nurse.

They are nurse specialists who provide support for people who have a learning disability whilst they are in hospital. Not every hospital will have this service.

If available, details are usually to be found on your local NHS Trust website (see here for an example <https://bwc.nhs.uk/learning-disabilities/>) and/or your local Community Learning Disability Team may be able to help.

If your hospital has a learning disability nurse, make a note of their contact details in case your relative is admitted to hospital.

Making emergency plans

If you care for a person who has Down's syndrome, now is a good time to put together a plan about what will happen if you are taken ill and have to be admitted to hospital. You will need to think about whom you will share the plan with.

The Foundation for People with Learning Disabilities has a resource about making a plan for emergencies – you can download the plan here:

<https://www.mentalhealth.org.uk/sites/default/files/thinking-ahead-guide-section-7.pdf>

You may like to think about talking to the person who has Down's syndrome about what they must do in an emergency situation and what will happen if you are suddenly admitted to hospital. This is particularly relevant if you are the sole carer and there is nobody else living with you and your relative who has Down's syndrome.

As a parent/relative you are best placed to know what level of information to tell your loved one. We realise it is a difficult balance as you don't want to overwhelm or upset the person with too much information.

You could make a visual resource/social story as a useful prompt/reminder for the person with Down's syndrome as to what they need to do.

There is information about visual resources and social stories in our new resource about supporting adults and young people through times of change. See here: <https://www.downs-syndrome.org.uk/download-package/supporting-young-people-and-adults-through-times-of-change/>

