

Guidance notes for My Health Passport

For autistic people

Guidance notes for completion

This passport is intended to help healthcare staff provide you with care, both as an outpatient and as an inpatient.

Use these guidance notes to help you, or your carer, to complete the passport with the most useful information for healthcare professionals when they are assessing and treating you.

The questions listed are designed to prompt you to think about what might be important for you. Don't just answer yes or no, but go into detail about your needs and how these can be met.

When you have completed your passport, take it with you as a printout when you're in hospital. Show it to doctors, nurses and any other healthcare professionals you come into contact with. If you're admitted to hospital, ask a nurse to keep your passport with your notes at the end of your bed.

If you have any feedback, suggestions or improvements for the passport, please email us at policy@nas.org.uk.

Remember: You might be in hospital as an emergency, when the doctors and nurses need to treat you as quickly as possible.

Only write down the most important information to allow doctors and nurses to help you.

Personal information and contacts

On the first page, fill in details about yourself.

Find your NHS number on any correspondence with your GP or hospital. If not, ask a healthcare professional to complete this when you're in hospital.

If there's someone who it's really important for hospital staff to speak with about your care, fill in their name and contact details here. This could be your partner, parents, carer, GP or community nurse.

You can also include the names and contact details of other people that you would like the hospital staff to contact when you're in hospital.

If you have an Advance Directive (a statement about how you'd like to be treated in certain situations), tick the relevant box.

In the 'really important information to know about me is' box write one or two things that you want a doctor or nurse to know about you if you are in hospital or feeling very unwell. For example, you might want to include things like 'when I'm in pain, I can't communicate verbally' or 'I can be very distressed if I don't have my blue blanket with me'. When deciding what to put in this box, it might help if you fill out the rest of the passport first to help you think about what sorts of things are really important for a doctor or nurse to know.



Medication and medical history

List all the medication you take including the dose and times.

Sometimes it can be unhelpful or even dangerous to make changes to or stop someone's medication without knowing all the right information.

If there is someone that hospital staff should speak with before making any changes to your medication, eg your GP or psychiatrist, put their name, role and phone number in your passport.

List any medical problems you have now or have experienced in the past, for example:

- epilepsy
- diabetes
- asthma

Also list any allergies you have, for example:

- certain medications, such as antibiotics
- adhesive plasters
- latex
- iodine

Communication and pain

In order to help you, the healthcare staff will need to gather lots of information.

How can staff communicate with you?



For example:

- Can they ask you questions?
- Do the questions need to be short and very specific?
- Do they need to write things down for you?
- Would you prefer pictures or symbols?
- Will it help if they point at things or demonstrate things?
- Whichever way they communicate with you, will you need a lot of time to think about the question before you can answer it?
- Do you need extra time when asked questions?
- Should they ask your carer to help explain things to you?

How I communicate



For example:

- Will you talk back to them?
- Will you need to write the answers down?
- Would you prefer to use pictures or symbols?
- Will you be able to point at things or demonstrate them?
- Would you prefer that your carer answers the questions?

One of the ways that healthcare staff know what is wrong with you and how to treat you is by your experience and description of pain. They will, therefore, ask you lots of questions about pain and also ask you if you feel any pain when they examine you.

How I experience pain



For example:

- Do you experience pain?
- What do you do when you experience pain?
- If you don't experience pain, how do you know when you are unwell or ill?

How I communicate pain



For example:

- Will you be able to tell the healthcare staff that you have pain?
- How will you tell them? What words will you use?
- Will you be able to describe the pain?
- Will you be able to point to where the pain is?
- Do you become very quiet and withdrawn when you are in pain?
- Or do you become very upset and maybe even angry or appear aggressive?

Causes and avoidance of distress

Healthcare staff will need to examine you and carry out tests. This will involve touching you with their hands and using various equipment.

If you have any sensory or other issues that will need to be taken into consideration, describe them here.

Things I struggle with and cause me distress



For example:

- Do you dislike people getting too close to you?
- Do you find physical touch unpleasant or distressing?
- Do you find the smell or feel of rubber gloves unpleasant or distressing?
- Some of the equipment will be hard and cold – will this be a problem for you?
- Do you dislike bright lights, especially if they are shining in your eyes?
- Do you dislike tight things such as blood pressure cuffs?
- Do you dislike having your blood taken?
- Will you find it difficult being in an enclosed space, such as a scanner?
- Do you have difficulty swallowing tablets?

Ways to help me avoid distress



For example:

- Can you cope with bright lights if you are given warning and support – what sort of support?
- Can you cope with the unpleasant noise(s) if you are given warning and support – what sort of support?
- Can you cope with tight things if you are given warning and support – what sort of support?
- Can you cope with having your blood taken if you are given warning and support – what sort of support? Does anaesthetic cream help?
- Can you cope with enclosed spaces if you are given warning and support – what sort of support? Would 'calming' medication help?

Other things

Other things you should know about me

Use this section to list other things that it will be helpful for healthcare staff to know about you.

For example:

- Any routines or rituals you need to follow, such as meal times
- Any special interests you need to follow, such as TV programmes
- Any sensory needs that you haven't mentioned already
- Anything else that might cause you distress or anxiety
- Do you need help washing or dressing?
- Any spiritual or cultural needs

Updating passport

You will need to keep your Health Passport updated, especially if you have a change in medication or your medical condition.

Don't forget to update your passport!

If you have any comments, questions or concerns about this guide, please email policy@nas.org.uk. Your feedback will help us improve future editions of this guide.

About the National Autistic Society

The National Autistic Society is the UK's leading charity for autistic people. Since 1962, we have been campaigning for autistic people's rights and providing support and advice to autistic people and their families. We want to create a society that works for autistic adults and children.



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