

Healthcare Resources for Autistic Patients and their Supporters

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(NB Information offered in this file is by kind courtesy of the organizations or individuals named).

To autistic readers and their supporters: This document is the first part of ASK Trust's compilation of resources to help improve the healthcare experience of autistic patients. Our broader goal is for all healthcare providers to become more aware of the barriers to good healthcare for autistic patients and to adapt their practices accordingly. However until that becomes a common reality, we suggest you access some of the resources listed here, to use when preparing for a healthcare visit, and / or to take with you (printed, or downloaded onto your electronic device). Many of these were devised by, or in collaboration with, autistic adults:

AASPIRE Healthcare Toolkit www.autismandhealth.org

A set of resources to facilitate better healthcare for autistic adults, including:

Autism Healthcare Accommodations Tool: An interactive computerised survey that generates your own customised accommodations report to give your healthcare provider.

Checklists and worksheets to download or print:

Symptoms worksheet: Outlines the types of questions healthcare providers are likely to ask you about your symptoms, to help you prepare for your visit

Making an appointment worksheet

What to bring to a healthcare visit checklist

After the visit worksheet: with a page for each of the main things your provider may ask you to do:

- Make a follow-up appointment with your healthcare provider.
- See a specialist or make an appointment with a different healthcare provider.
- Get a lab, x-ray, or other test.
- Take a medication.
- Do something to manage your health condition at home.

Information for autistic adults on:

- healthcare
- staying healthy
- your rights in healthcare
- autism information
- medical information.

Communication tips for your practitioner – by autistic adults

- *What I Wish my Doctor Knew About Me as a Person on the Autism Spectrum (Aspie)* www.DevelopmentalMedicine.ucsf.edu (author anonymous)
- *Communicating Better with People on the Autism Spectrum* by Paddy-Joe Moran (2015) – available as paperback or kindle book

Royal College of GPs ASD Toolkit

<http://www.rcgp.org.uk/clinical-and-research/toolkits/asd-toolkit.aspx>

See “resources and guidance for patients and carers” to download or print the following resources for healthcare visits:

- **Making the most of your visit to the GP: a guide for those on the autistic spectrum**
- **Going to your doctor** - An easy-read version of the above, with pictures.
- **My hospital passport** - Developed by the National Autistic Society (NAS) to help people with autism to communicate their needs to doctors, nurses and other healthcare professionals. Can be used in all health settings.
- **Guidance notes for ‘My hospital passport’**.
- **A guide for women with autism when engaging with health professionals** - Produced by Scottish Women’s Autism Network.
- **Getting older** - About the challenges people with autism face in older age.
- **Diverse perspectives** - The challenges for families affected by autism from black, Asian and minority ethnic communities

Autism CRC Health Hub Resources

<http://autismcrc.com.au/health-hub>

Links and resources to download or print include

Emergency communication board - A Queensland Government initiative - provides visual support for people to express their needs in a medical situation.

For autistic patients and supporters:

Health, human rights and you - to help you to better understand health, human rights, and the right to health and wellbeing.

Quality and safe healthcare - Available in three formats

Understanding autism - What do health professionals need to better understand autism? A snapshot for autistic adults. See section "What issues are important to tell health professionals about?" under header "What health professionals told us."

For Health Providers: Autism-friendly Resources

Besides the above, comprehensive lists of links to autism information and training opportunities for health providers (some general, others oriented to specialist services such as eye, dental and mental health practitioners) can be found at

-Autism CRC - see <http://www.autismcrc.com.au/online-tools-health-professionals>

- UK Department of Health on-line resources "to enable frontline staff to better recognise and respond more effectively to the needs of adults with autism" - see

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215651/dh_128203.pdf

For autistic children & dependent adults

Prescription for success: Supporting children with autism spectrum disorders in the medical environment by Jill Hudson (2006) available as kindle or physical book with a CD of resources. A detailed guide on adapting effective autism strategies to medical encounters in general, and when preparing to undergo specific procedures, using a range of visual, hands-on, sensorimotor, games and role-play approaches.

Other Visual / Systematic Communication Supports for healthcare encounters

- **Visual supports** - For a summary of possible formats and uses, including applications for healthcare encounters, see <http://www.autism.org.uk/about/strategies/visual-supports.aspx>
- **‘Show Me Where?’ and related resources:** visual tools for those with communication difficulties to convey symptoms, sites and needs. Available as *Plastic Fan* with handy belt loop; *Magnetic Wall Chart* or *App* for iPad and Android. See <http://www.cardiffandvaleuhb.wales.nhs.uk/products-available>
- **Systematic ‘communication forms’ and info on healthcare issues** - see *Understanding Death and Illness and What They Teach About Life: An Interactive Guide for Individuals With Autism and Asperger's Syndrome and Their Loved Ones* by Catherine Faherty (2008). Covers a range of topics related to health, illness, death and grief, with examples, templates, and advice on adapting them to the topic and person. From ‘check-in forms’ to help an autistic convey their current state and concerns to a practitioner, through to specific topics such as ‘*What is an emergency?*’; ‘*What should I do when I’m sick or injured?*’; or *What may happen during a visit to a person who is dying?* Each topic includes basic information for the autistic individual, followed by a systematic format for them to convey their experience, needs, questions etc. without speaking.

Visual resources to help prevent / manage Meltdowns

‘Five-scale approach’ –See the series of diagrammatic books and sets of resources by Kari Dunn Buron; also downloadable formats from

http://www.autismwestmidlands.org.uk/upload/pdf_files/1403678560_6VisualResources-FivePointScale.pdf

Visual ‘intervention plan’ for meltdowns: guideline for documenting individual needs in the event of a meltdown can be found in the book by Deborah Lipsky and Will Richards *Managing Meltdowns Using the S.C.A.R.E.D Calming Technique with children and adults with autism* (2009)

‘Autism Alert’ Cards

Usually the size of a credit card, these cards alert emergency services and members of the public about your autism diagnosis if you are in an accident or other situation where you may not be able to communicate by yourself. Designs vary. Sources include:

NZ **ASK Trust** www.asknz.net

USA **Asperger’s Association of New England** www.aane.org

UK www.arghighland.co.uk

www.rcgp.org.uk/clinical-and-research/toolkits/asd-toolkit.aspx - See
“resources and guidance for patients and carers”

www.autismwestmidlands.org.uk/attention

Examples of how to tailor alert cards to individual needs can be found in the following books:

- *Ask and Tell: Self-advocacy and Disclosure for People on the Autism Spectrum*. Ed. Stephen Shore (2004)
- *Friendships: The Aspie Way* by Wendy Lawson (2006)

Other Communication Supports

Alternative & augmentative communication (AAC) assistive technology: A wide range of such devices are available for non-speaking autists, and those who on occasions, such as stressful situations, may lose their ability to speak. See for example

- the website <http://www.asha.org/public/speech/disorders/AAC/>
- or options outlined in the article

http://www.aaspire.org/inc/publications/AASPIRE_PC_ASD_Med_Clinics_Accepted.pdf

‘Autism-friendly healthcare’ posters

Ask your healthcare provider to display one of the following freely downloadable posters to remind all staff of accommodations commonly needed by their autistic patients:

- <http://journals.rcni.com/page/ns/resources/posters/autism-poster>
- Or ‘How autism-friendly is your practice?’ poster from <http://www.autism.org.uk/professionals/health-workers/gp-info.aspx>