

Useful contacts

A guide for health professionals

We hope you find this brief guide useful in updating and developing your professional practice with

- women with an autism diagnosis
- women undergoing autism diagnosis
- women who present with issues associated with autism

We hope you find our suggestions helpful and thought-provoking.

We welcome your comments and feedback.



Produced by SWAN, the Scottish Women with Autism Network, under the wing of the Autism Scotland Network © SWAN, 2013



A guide for health professionals working with women with autism

**Listen to your patient.
Make sure she can listen to you!**

Who we are

You may already be treating some of us. You may not be aware of this. Women with autism are an under-diagnosed, under-acknowledged group.

We cover the full range of intelligence, ability, education, interests and experiences.

We are daughters, mothers, carers, partners and singletons. We are straight, gay and transgender. We are of all races, ethnicities and nationalities.

Certain conditions are co-morbid with autism – most commonly Epilepsy, Neurofibromatosis, and the Dyspraxia family.

We often experience poor mental health because of the challenges we face, and our experiences of life.

We won't just see you about our autism diagnosis. We have all the same health worries and issues as typically-developing women.

In common with other women we often look after other people's health as well as our own.

Our autism is a filter for our experiences: it doesn't go away just because we have a broken leg, attend ante-natal classes, or bring a child for vaccination.

How autism affects us as patients

Common features of autism, and what they mean for our medical professionals:

We need structure and reassurance that we are in the right place with the right person

▶ Drop-in clinics and casual arrangements are often inappropriate for us.

We find communicating difficult and may struggle to speak with people, especially if we don't know them

▶ extra time may be needed for consultations and we may bring notes or documents – or even a friend to sit in

We find it hard to understand things quickly

▶ more time may be useful in a consultation. A second visit may be needed, or a quick check that all is clear before we leave. Written instructions can be very helpful.

We may need help to understand a situation, people or advice which can make it hard for us to give informed consent, or to follow treatment regimes

▶ An introductory visit to discuss communication and other difficulties can be useful for both parties. A second visit to deal with the medical issue can then take place. Offering written instructions and guidance can be very useful.

We may need support from a third-party

▶ Sometimes it will be appropriate for us to bring another person as an advocate. They can also help us to understand your guidance, and to ask questions.

We may have unusual reactions to pain and have neuropathy to a greater or lesser degree

▶ We may not be able to answer meaningfully when you ask "Does it hurt?" Pain or sensation can be referred to other body parts or be experienced as, for example, heat.

We often have difficulty with right and left

▶ We may struggle to define where something hurts, or to follow instructions.

We can be very literal and find vagueness confusing

▶ Try to ask precise questions, or use several questions to make communication clear.

We often have low self-esteem and lack self-confidence

▶ it can take a long time for us to come to see you. We need reassurance that we are in the correct place and that you do not think we are wasting your time.

And finally...

▶ Please do not use the time to question or cast doubt on the autism diagnosis. Health professionals still don't always understand that females have autism for example. We will find this very confusing and frightening – and your expertise in helping us will be lost!

www.autismnetworkscotland.org.uk/swan