

CFE November 2023: Accessing Healthcare Services

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A READING FROM ECCLESIASTICUS (APOCRYPHA) *Honour physicians for their services, for the Lord created them; for their gift of healing comes from the Most High. The Lord created medicines out of the earth and the sensible will not despise them. And he gave skill to human beings that he might be glorified in his marvellous works. By them the physician heals and takes away pain; the pharmacist makes a mixture from them. My child, when you are ill, do not delay, but pray to the Lord, and he will heal you. Cleanse your heart from all sin. Then give the physician his place, for the Lord created him; you need him. There may come a time when recovery lies in the hands of physicians, for they too pray to the Lord that he will grant them success in diagnosis and in healing, for the sake of preserving life.*

God saves us **IN** our bodies, not **FROM** our bodies. Jesus places high value on our bodies by becoming incarnate himself. Our bodies are temples of the Holy Spirit. But we are called to honour God with our bodies and offer them to him as living sacrifices. Do we honour the gift of our bodies by the way we care for them? We will need healthcare services from time to time to support us. And that can be challenging for autistic people so let's look at what can help us engage with services.

Healthcare services are not designed with autistic people in mind. Autism is often overlooked by healthcare professionals, and this creates barriers to accessing support and services. Some professionals still hold stereotypes about autism. Barriers to accessing healthcare can be associated with adverse health outcomes. Many autistic people have coexisting mental and physical disorders, and other neurodivergent conditions.

We feel vulnerable and anxious when we're ill. We may worry about whether our symptoms warrant a GP visit and so may delay getting in touch, or may not go at all due to past negative experiences that have put us off. We might feel we are a burden to hard-pressed GPs. We may struggle with new ways of accessing medical care post Covid. Medical conditions may present differently in autism and we may respond differently to medications (e.g. may need a higher or lower dose). I think that GPs probably read about autism but often fail to apply that knowledge to the individual patient with his/her unique issues and needs.

The 2019 NHS Long Term Plan included a new "digital flag" in patient records by 2023/24, to ensure staff know a patient is autistic (we can ask for this to be checked); and the provision of information and training to NHS staff to support autistic people. This should ensure reasonable adjustments are made so that wider NHS services can support autistic people.

It's important that we recognise **our specific** challenges, so we can advocate for ourselves when needing to access difficult healthcare environments. A team of academically minded autistic doctors have developed a simple framework which may promote accessibility without adding to current clinical burdens (see below for link). Although primarily designed for use by doctors, I think that we, as service users, can use this to help us identify what accommodations might help us. They use the acronym 'SPACE'. These letters stand for the following needs: Sensory, Predictability, Acceptance, Communication and Empathy. Three additional domains are represented by Physical space, Processing space and Emotional space "PPE".

Sensory needs –Sensory sensitivities can make healthcare environments inaccessible. We might benefit from an appointment time or arrangement that will make it more likely for us to attend. Think about your sensory needs in a healthcare setting. Examples:

SIGHT - lighting, crowds, flashing indicator boards

SOUND - We may not filter out environmental sounds and therefore may struggle to hear a conversation

TOUCH - Difficulties commonly arise with light touch, whereas a strong deep touch may be more acceptable.

INTEROCEPTION AND PAIN – difficulty in accurately interpreting internal bodily sensations. Difficulties with pain perception can lead to unrecognised injuries. While reduced pain sensitivity occurs for some, others experience increased pain sensitivity. It can be difficult using pain scales: 1 - 10

Predictability - We need predictability and may experience extreme anxiety with unexpected change. Healthcare is an unpredictable environment with unpredictable outcomes. E.g. not knowing when to expect a phone call. Having a narrower time slot (e.g. between 3 and 4 as opposed to “any time between 2 and 6 allows us to prepare for the appointment and ensure we are in an environment which facilitates our engagement).

Access is facilitated when predictability is maximised. Waiting is difficult for us, especially for an unknown duration in the sensory stress of a typical healthcare waiting-room. Interacting with unknown people is also challenging so it can help to ask for the same doctor. Providing the maximum possible information in advance is likely to reduce anxiety e.g. what to expect at appointments. Any unavoidable or unexpected changes will be more easily accepted if explained clearly and openly. It helps to know what will happen at appointments and how long procedures will take.

Acceptance - Many feel that being autistic makes it more likely that professionals won't believe them, minimise their concerns and treat them poorly. Let's encourage a neurodiversity-affirmative approach that recognises that neurodevelopmental differences are part of the natural range of human development and acknowledges that attempts to make autistic people appear non-autistic can be harmful.

Acceptance leads to appropriate accommodations, including understanding that so called 'challenging behaviour' is usually a response to autistic needs not being adequately met. GPs etc. need to understand and accept stimming behaviours, and monotropic thinking patterns. We need to be listened to and believed. We are experts as we've lived with autism all our lives.

Communication – often impaired by sensory or anxiety issues. Many have difficulty using phones, so a flexible approach to appointment booking (e.g. online) is desirable. People tend to share less on the phone than face to face. And we may be missing out on vital care if we avoid making a phone appt due to stress. It might help ask for 1st or last appt (the 1st is preferable if the clinic is likely to run late). Or to be offered an e-consultation. Clear, unambiguous language is desirable – avoiding hints, or vague information. The traditional signs of distress or pain, for example, may not be evident. An autistic person might tolerate a painful examination silently without even wincing, leading a healthcare provider to misinterpret findings. So let's share our eye contact and communication needs. And how we prefer to receive info and advice – verbal or written. And in as much detail as we need.

Empathy - The bi-directional, mutual misunderstanding that often occurs between autistic and non-autistic people, is termed 'the double empathy problem'. As such, non-autistic staff may struggle to empathise with us. Recognising this challenge and making a particular effort to consider our perspective is the first step towards bridging this gap. Advise medic what we need if distressed. It helps if they ask us directly for our interpretation of events rather than making assumptions based on non-verbal communication. Checking comprehension verbally and ensuring both parties have a shared understanding of treatments plans or goals will facilitate successful engagement. Increasingly skilful communication with autistic patients will develop, as practitioners 'improve their expertise in autism through training and experience, and by familiarity with the autistic world'.

The concept of space is also useful in three other domains of autistic experience.

Physical space - We may need more physical space, we don't like being crowded or touched. So attention to physical space can facilitate a successful consultation. May need a quiet waiting area.

Processing space - This is the additional time required to process new information or unexpected changes. Allow increased time for decision making. A longer appointment might help us not feel rushed.

Emotional space - Identifying, processing and managing our emotions can be challenging, particularly when our autistic ways of expressing emotions are not understood or accepted. Sensory overload or overwhelming emotions may lead to meltdown or shutdown. If it occurs, the best approach is for the professional to allow space to recover.

WHAT PEOPLE SAY: *It would help so much if healthcare professionals just ask us, how does your autism affect you? Or, what's the best way for us to communicate? Or what does being autistic mean for you? At beginning of consultation, ask us if we have any communication preferences or sensory needs. It can be hard to trust when we fear that we won't be taken seriously and believed. I practise in my own mind what I'm going to say in advance. The onus is on us to adapt rather than the doctor to adjust to our needs.*

Reasonable accommodations for autism-specific needs are as necessary as ramps for wheelchair users. Access to effective healthcare and feeling heard and validated by healthcare professionals is of paramount importance for us.

TIPS FOR EMPOWERMENT

1. Get an advocate from a local charity or organisation who can advocate for you when you can't do this for yourself. Or have a friend who can help.
2. Find a Hospital Passport to print NAS
3. Make a 1-Page Profile which has your adjustments on, and the things professionals need to know about you. Include any communication needs. Take this to appointments
4. Some people find it helpful to practice in their heads in advance what they want to say.
5. Contact PALS if you're unhappy about something. Find template letters online e.g. if you wish to complain about your care there are examples online you can just fill in.
6. Have some advocacy phrases prepared you can say or type in a letter/email e.g. "As someone with autism, I am protected by the Equality Act and am entitled to reasonable adjustments to remove / reduce barriers".

If you want to read the article that explains the SPACE framework, here is the link:

<https://www.magonlinelibrary.com/doi/full/10.12968/hmed.2023.0006>

And here is a link to the latest version of the hospital passport template:

https://dy55nndrxke1w.cloudfront.net/file/24/.ZuLn47.Z3Oq7eJ.ZkJP.0QsoHD/Health_Passport_A4_Editable_2022.pdf