

Preparing for Appointments with Medical and Clinical Professionals

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Introduction

Working with professionals can be a daunting experience for people with Autistic Spectrum Conditions (ASC). Throughout their lifetime the people that we support will come into contact with a range of professionals including Doctors, Dentists, Opticians, Psychologists, Speech and Language Therapists, Occupational Therapists and Social Workers.

What will they do?

Structure and routine is required to support individuals with autism to make sense of the world around them. Appointments with professionals can raise a number of questions. Often there is an uncertainty about what a professional is going to do and so the experience can feel very unpredictable. It is common for people with autism to draw on their past experience meeting with professionals and if these have not been positive experiences, it can impact upon how they may feel about future appointments.

Environments

The way we think, feel and act is based on the way we perceive the world through our senses. Many people on

the autism spectrum have difficulty in processing sensory information, however there are strategies we can put in place to help.

Appointments with professionals tend to take place in unpredictable environments and patients with sensory processing differences may be highly sensitive to light, sound and odour (Gurney, McPheeters and Davis, 2006).

For people with autism, many of the senses may be over or under sensitive or both. This may result in an individual becoming stressed or anxious. Examples of common sensory problems include:

Smell

Due to the cleaning and medical products used in hospitals and dental surgeries, they often have strong and at times overpowering smells. For people with autism who are hyposensitive to smells this can be overwhelming.

Lighting

Some people with autism are oversensitive to lights. Flashing fluorescent and overhead lighting can be particularly difficult to tolerate. These are often present in hospitals and clinic rooms.

Touch

People with autism may be over or under sensitive to different forms of touch. Those that are oversensitive may not like being examined and any form of touch may be intolerable (e.g. dental and optical examinations).

Some people can be under sensitive to pain, this means that they may be unable to express physical trauma/ ill health.

Staying still to be examined may also be problematic.

Sounds

The sounds experienced whilst meeting in medical environments with professionals can often be scary and unpredictable.

Waiting rooms are often busy and very loud (e.g. babies crying, doors banging, people being called in for appointments). Giarelli et al (2014) found that the waiting room in a large emergency department had very high and fluctuating noise levels.

Equipment used by health professionals may also be loud and unfamiliar (e.g. dental drills).

Communication

Mind (2015) reported that some adults with autism had difficulties interpreting written information.

If professionals are not used to working with people with autism the level of language they use to communicate with the patient may not be appropriate.

Strategies to support medical appointments

During monthly multidisciplinary team meetings upcoming medical appointments are discussed. This enables members of the clinical team to provide the appropriate support to parents, carers and professionals prior to the appointment taking place. The following strategies may be recommended:

Preparation

It is often beneficial to book the first appointment of the day to prevent waiting in busy, noisy waiting rooms.

Double appointments also work well so that more time can be taken to implement strategies to ensure that the consultation runs smoothly.

It is beneficial to find out if there is a space that can be used as a 'retreat area' if it becomes overwhelming for the individual and it is often worth requesting a consultation with a professional that has experience in working with people with autism.

If possible, visit the place of the appointment to enable the person to become more familiar with where it is

taking place.

Photographs of the environment could also be taken and used to familiarise the individual with the new setting. These photographs could also be used in storyboards.

- **Smell**

For people that are oversensitive to smells within environments, objects with comforting/ relaxing smells are often helpful. It is worth carrying a rescue handkerchief with a preferred smell.

- **Lighting**

Florescent and overhead lighting should be turned off or dimmed and where possible natural lighting is preferable. Sunglasses, visors or blinds could also be trialled.

- **Ear defenders**

These are often recommended for people with autism or sensory processing issues who are sensitive to noise and certain sounds. They work by reducing/ blocking out certain frequencies (e.g. waiting room noise, medical equipment).

- **Music**

Listening to calm and relaxing music via headphones prior to or during appointments may support the individual to feel relaxed and calm during medical appointments and minimise the effects of unexpected sounds in the environment.

- **Weighted jackets/ lap pads**

An Occupational Therapist may recommend sensory tools that offer weight or deep pressure. Weighted lap pads are particularly helpful for people with autism because deep pressure input has a calming, grounding effect. It provides deep touch pressure to a person's legs as it rests on their lap when in a seated position.

- **Move 'n' sit cushion**

Some medical appointments require a person to sit for longer periods of time. In this situation a move 'n' sit cushion may be beneficial. These tactile wedge cushions help improve posture, provide sensory feedback and calm people that need to move a lot, therefore helping an individual to remain focused for longer periods of time.

Communication

Social Stories/ Storyboards

Social stories and storyboards can be used to assist the people that we support in understanding the purpose of the appointment. Social stories were created by Carol Gray in 1991 and are short descriptions of situations, events or activities, they often include information on what to expect in a situation (e.g. where the appointment is and

who they are seeing) and why (e.g. the person needs to see the Doctor due to stomach pains). Storyboards are simplified versions of social stories and are created to support the people that we support with what to expect in particular situations, events or activities. They are created in the form of photographs/ symbols and simple written cues. They include less written information and often fewer steps than social stories.

The resources created should appeal to the interests of the person it is written for and words that cause the person anxiety or distress should be avoided.

It is important that the content and presentation of the social story/ storyboard is appropriate to the age and level of understanding and age appropriate photographs and symbols are used. The resource should be presented when the person is feeling calm and relaxed.

Schedule

To support individuals in understanding what to expect during the consultation, a visual schedule could be put into place. This may include the stages of a procedure (e.g. a smear test, operation) or photographs of the order that tests are being carried out (e.g. blood test, blood pressure and temperature).

Body chart

A body chart works well to support individuals in communicating where they are experiencing pain (e.g. by pointing to the foot on the chart). If the person finds it difficult to express where the pain is, it may be worth going through each of the body parts using symbols (for example show them the hand, foot and leg and encourage them to express if this area is painful).

It is also beneficial for them to have access to a 'stop' card to enable them to communicate if they want the professional appointment to stop.

Timers - These are useful to ensure that it is clear how long the appointment is going to last without needing to know how to tell the time. A range of timers are available including digital and sand timers.

Rewards - It is often worth following an appointment with a professional with a motivating reward (e.g. a special trip out somewhere). Positive praise should also be given throughout the appointment.

Health passport - The strategies above can all be documented in an individualised communication passport. This can then be taken to all professional appointments.

Conclusion

At Options Autism we use the strategies outlined above to ensure that the people that we support have successful appointments and interactions with professionals. If attending an appointment in a clinic would cause anxiety, staff at Options endeavour to arrange appointments on site. When this is the case visual support tools are provided and a low arousal, private setting is used for these appointments to take place in.

References

- Mind (2015). Supporting people living with autism spectrum disorder and mental health problems- A guide for practitioners and providers.
- Giarelli, E Fisher, A, (2016). Integrated Healthcare for people with Autism Spectrum Disorder. United States of America. Charles Thomas Publisher LTD.
- www.autism.org.uk
- www.autismspeaks.org/ways-give
- www.sensorydirect.com/sense
- www.carolgraysocialstories.com

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