



## Carers' Hints and Tips For Supporting Autistic Adults

A handy booklet of approaches our carers have found useful when supporting their family member. These suggestions may not work for everyone, but we hope you will find some of the following ideas useful in supporting your own family member.

# Emotional Communication

- Emails, notes and text messages can help as they can reduce the emotional content of the message, allow time for consideration and remove the need to understand nonverbal communication.
- Keeping your own voice calm and level can help to ensure that you do not overload your family member with so much emotional information that they can't understand the intended meaning.
- It might help to explain yourself literally – people on the spectrum can struggle with figures of speech (e.g. it's raining cats and dogs; like a fish needs a bicycle).
- It could help to explain clearly how you feel as your family member may find it hard to tell the difference between different emotions

# Making Spoken Communication Easier

- Agreeing a time and place to sit down and talk each week can help create a good space for communicating, and can allow both parties to prepare properly. Things that need a little more time to address such as plans for the week or finances could be discussed at this time.
- When there is complicated information to communicate, using visuals such as a PowerPoint slideshow or flashcards may help your family member to process the information at their own pace, and might help you to organise your thoughts.
- It may help if you speak slower to help your family member process what you are saying - even if they speak fluently they may not understand you if you speak at your normal rate.
- If your family member struggles to make decisions, it may help to reduce the number of available options - this can make it easier for them to process decisions.
- If your family member has difficulty making telephone calls, it may help to plan and write down what is likely to be said, in advance, especially if they will have to leave a message.

## Expression and Self-Awareness

If your family member has difficulty expressing or evaluating their experiences, encouraging them to score their experiences out of ten can be useful.

E.g. You: “How would you rate your day out of ten?”

Family member: “Seven.”

This could lead onto a discussion about why it was a seven and not an 8 or a 6. Rating could also be done visually on a scale.

## Reminders and Instructions

- Sometimes being extra specific (e.g. Please put the washing machine on at 10.30; please make sure you have washed your dishes before your support worker gets here at 12.30) can help to make sure that they remember to do things during the day.
- Some people find that using alarms on a mobile phone can help to remind people about specific tasks that need done, and can help people keep track of their own daily routine. Post-it notes in strategic places (on the juice carton in the morning; on trainers for before going out) can also be helpful reminders.

- If you want your family member to do tasks around the house, it may help to give them detailed instructions, perhaps in step-by-step form, so that they are able to check that they are doing everything correctly.
- Doing tasks like laundry on the same day every week, at the same time may help to ensure that they are always done as they become part of the routine.
- It may help to talk over instructions once you have given them to ensure that your family member fully understands.
- It may help to calendar, diary or notebook to write down anything to be done on a particular day, including times and places, and any other helpful details.
- Email communication can be a good way of communicating instructions, especially if your family member lives independently from you, as they will be able to refer back to them when necessary, and can print them off and keep them somewhere handy if they wish.
- If your family member has difficulty navigating when out and about, mobile phones may be helpful as a means of navigating, such as by using Google maps, or for them to call someone to seek assistance.

## Difficult Behaviour

- Most undesirable or aggressive behaviours probably have underlying causes such as frustration or anxiety.
- Keeping your own behaviour calm and controlled may make it easier for your family member to remain calm. If you are struggling to remain calm, try leaving the room for a while until you feel ready to return.
- Where possible, try not to put too much pressure on your family member to do things or go places that they do not want to go. If something is unavoidable, it might be helpful to prepare them for it by explaining clearly why it is necessary and preparing them for what to expect. Pictures of the place/task or written information may help.
- If your family member talks out loud to themselves, it may seem strange to you, but it may help them to organise and understand their own thoughts and opinions.

# Social Interaction

- Many people with autism want to be sociable even though they may find social interaction difficult. Your family member may avoid social interaction because they find it difficult, not because they don't want to be sociable.
- Some people on the spectrum may find it easier to interact with people outside their own peer group or culture. For example they may find more to talk about with their grandparents, or they may get on well with children. This may be because people from a different demographic may have more flexible social expectations.
- In some cases eye contact can make people with autism feel uncomfortable. Your family member may prefer not to look you in the eye but this may not be a sign of disinterest.
- If your family member has difficulty reading body language, it may help to raise their awareness of body language by teaching them what different signals mean, perhaps through role play or use of images or TV.

- Facebook and other social media can help your family member to have more social interaction and form a kind of support network. Online interaction can be easier because the need to understand non-verbal interaction is removed. There may also be less pressure to ‘socialise’ when you don’t feel up to it. However, it is worth being aware that there is a risk that negative interactions and misunderstandings can occur.
- Supportive peers or other family members may be able to support your family member to use social media safely if you are unsure.

## Going to Appointments and on Other Trips

- For some people, planning in advance can make trips less stressful. Even for simple things like visiting the supermarket, advance warning may make a difference. It may also be helpful to stick to a plan if one has been made, as this may reduce stress.

- If you and your family member worry about them getting into difficulty when going out on their own then it may help for them to carry an autism alert card. An autism alert card is designed to tell members of the public about autism and asks them to show respect and tolerance. It can be particularly useful if a person who has autism comes into contact with criminal justice professionals, such as police officers, magistrates and solicitors. Autism alert cards are available through organisations such as the National Autistic Society and Autism Initiatives. If you feel that the “official” version does not meet your family member’s needs then it may be helpful to create a personalised autism alert card. You may wish to include information that could help other people to understand your family member on one side, and on the other side, include information that will help reassure your family member.

## Relationships with others in the Family

- Your family member may feel more able to offload their anxieties and/or frustrations at home, so if it seems that they are often angry with you about things which are not your fault, it may not be personally aimed at you.

## Romantic Relationships

- It may help to prepare your family member in advance with clear advice regarding what they might expect when they begin to have close friendships and/or romantic relationships.
- Whilst your family member's relationship with their significant other may seem unconventional in your eyes, especially if both parties are on the spectrum, this is not necessarily a cause for concern.

## Visiting Medical Professionals

- Be aware that not all healthcare professionals are knowledgeable about autism spectrum conditions.
- Your family member may be accompanied at medical appointments if they wish – a support worker, or someone they do not know closely, may sometimes feel preferable to a parent.
- Encourage the professional to address questions to your family member, not yourself – it is their appointment after all.
- Before you go to the meeting, agree who will do most of the talking, and what they are going to say. Writing things down, especially things which are difficult or emotionally charged, can make it easier in the actual appointment.

# Diet

- If your family member has difficulty knowing when they are hungry or full it may help to support them to have an understanding of regular eating patterns and portion sizes.
- If your family member has quite a rigid diet and finds dietary changes distressing then it may be helpful to reassure them that they can try new foods a very small bit at a time. This may allow them to gain confidence and familiarity with new food over time.

# Common Acronyms

**3Di** - Developmental, Dimensional and Diagnostic Interview

**AAC** - Augmentative and Alternative Communication

**ABA** - Applied Behaviour Analysis

**ADD** - Attention Deficit Disorder

**ADHD** - Attention Deficit Hyperactivity Disorder

**ADI** - Autism Diagnostic Interview

**ADOS** - Autism Diagnostic Observation Schedule

**AGRE** - Autism Genetic Resource Exchange

**AI** - Autism Initiatives

**AQ** - Autism-Spectrum Quotient

**AS** - Asperger's Syndrome

**ASA** - Autism Society of America

**ASC** - Autism Spectrum Condition

**ASD** - Autism Spectrum Disorder

**BAP** - Broader Autism Phenotype

**CA** - Chronological Age

**CAMHS** - Child and Adolescent Mental Health Service

**CBT** - Cognitive Behavioural Therapy

**CDC** - Child Development Centre

**CEC** - City of Edinburgh Council

**CFCS** - Child and Family Consultation Service

**CHAT** - Checklist for Autism in Toddlers

**CPN** - Community Psychiatric Nurse

**CSPs** - Collaborative/Coordinated Support Plans

**CT** - Complimentary Therapy/Therapist

**DEA** - Disability Employment Advisor

**DfES** - Department for Education and Skills

**DIR** - Developmental, Individual-difference, Relationship-based

**DISCO** - Diagnostic Interview for Social and Communication Disorders

**DLA** - Disability Living Allowance

**DSM** - Diagnostic and Statistical Manual of Mental Disorders

**DTT** - Discrete Trial Training

**DZ** - Dizygotic

**EEG** - Electroencephalography

**EF** - Executive Function

**EIBI** - Early Intensive Behavioural Intervention

**EMT** - Enhanced Milieu Teaching

**EQ** - Empathising Quotient

**E-S** - Empathising-Systemising

**ESA** - Employment and Support Allowance

**FMRI** - Functional Magnetic Resonance Imaging

**GABA** - Gamma-aminobutyric acid

**GP** - General Practitioner

**HFA** – High Functioning Autism

**ICD** - International Classification of Diseases

**IEP** - Individual Education Plan

**IMGSAC** - International Molecular Genetic Study of Autism Consortium

**IQ** – Intelligence Quotient

**JSA** – Job Seekers Allowance

**LAC** – Local Area Coordinator

**LAC Team** – Local Area Coordination Team

**LEA** - Local Education Authority (*some organisations use just LA*)

**LFA** - Low Functioning Autism

**MA** - mental age

**MAA** - Multi Agency Assessment

**MEG** - Magnetoencephalography

**MMR** - Measles, Mumps and Rubella

**MRI** - Magnetic Resonance Imaging

**MZ** - Monozygotic

**NAP-C** - National Autism Plan for Children

**NAS** - National Autistic Society

**NIASA** - UK National Initiative for Autism: Screening and Assessment

**NLP** - Natural Language Paradigm

**NT** - Neurotypical

**PDD** - Pervasive Developmental Disorder

**PDD NOS** - Pervasive Developmental Disorder Not Otherwise Specified

**PDD-unspecified** - Pervasive Developmental Disorder, Unspecified

**PECS** - Picture Exchange Communication System

**PIP** - Personal Independence Payment

**PMT** - Prelinguistic Milieu Teaching

**PRN** - Pro Re Nata, which is Latin for 'as the circumstance arises' and is used to refer to medication that is administered 'when necessary'.

**PRT** - Pivotal Response Training

**RAD** - Reactive Attachment Disorder

**RCT** - Randomised Control Trials

**RDI** - Relationship Development Intervention

**RMI** - Rapid Motor Imitation

**SCERTS** - Social Communication Emotional Regulation  
Transactional Support

**SDS** - Self Directed Support

**SEN** - Special Educational Needs

**SENCo** - Special Educational Needs Coordinator

**SLT**- Speech and Language Therapist (*some organisations use SALT*)

**SPELL** - Structure, Positive, Empathy, Low arousal, Links

**SQ** - Sytemising Quotient

**SA** - Scottish Autism

**SSRIs** - Selective Serotonin Re-uptake Inhibitors

**TEACCH** - Treatment and Education of Autistic and related  
Communication handicapped

**ToM** - Theory of Mind

**VB** - Verbal behaviour

**WCC** - Weak Central Coherence

**WCST** - Wisconsin Card Sorting Task



Supporting families of adults with autism