



“Supporting Me”

A guide for Personal Assistants employed by or for someone with Autistic Spectrum Condition





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1. Introduction

You have been employed to support me to live my life as I choose. I may employ you through my Direct Payment that I manage myself, or people close to me may employ you on my behalf through my individual/ personal budget.

This guide contains information about what it means to have Autistic Spectrum Condition and how to provide good support. Not all of this information may apply to me. Please take time to find out what does.



Using “I” and “me” in this guide

People with Autistic Spectrum Condition can find the 1st person (‘I’ and ‘me’) difficult. I may talk about myself using my name or ‘him’, ‘her’, ‘you’ etc where other people use ‘I’ or ‘me’. I may also find it difficult when something written in the 1st person does not apply to me. There is a copy of this guide that can be tailored to suit me. My photos can be added and it can use the form of speech I prefer.

The guides in this series on learning disabilities and challenging behaviour may also be useful to you. The local Independent Living Advice Service has copies. (See back page.)



Respect

It's important that you understand me and the support I need. This is more likely if you treat me, my family and friends with respect. Please respect the choices I make, my culture and the lifestyle I have chosen for myself.

Treat my home and possessions with consideration. Don't assume that you can do things in my home without checking.



Whilst you may encourage, support, advise and guide me, please don't be 'bossy'. I am an adult and you cannot (and should not try to) **make** me do things.

I need to feel in control of what's happening to me.



You need to accept me with my autism.
Don't try to change behaviours that you may find odd or quirky but which I may use to help me cope with the world around me, or find comforting.

Remember it's my life not just your job.



Don't 'gossip' about me to your friends and please get my permission (or the permission of those close to me) before you give other people personal information about me.



Getting to know me

Everyone with ASC is an individual with their own strengths, abilities, personalities, needs and aspirations. Each person is affected differently by their ASC.

Understanding how I experience things and joining me in my world will help you get to know me.

Take time to find out what I like, need and want. Don't assume. If I can't tell you myself, ask the people close to me. I may have a person-centred plan or guidelines that will give you some useful information about my preferences, what I want to achieve in my life and how you should support me. If this is available to you, please make sure you read and follow it.



2. What is Autistic Spectrum Condition?

I have an Autistic Spectrum Condition (ASC), formally known as Autistic Spectrum Disorder. ASC probably affects about 1 in 100 people.

It is a lifelong, developmental disability that can affect how the brain processes information.

Some people with ASC also have a learning disability. Those without a significant learning disability may be described as having Asperger Syndrome or Higher Functioning Autism. ASC is not a mental illness but some people with it may also have mental health issues.



How ASC can affect people

People with ASC are affected, to different degrees, in four broad areas:

- ***Communication:*** having problems with understanding and using speech and body language
- ***Relationships:*** having difficulties in social relationships and interacting with other people
- ***Social Understanding:*** having trouble with understanding, or being able to imagine why other people do things and in being flexible
- ***The Senses:*** experiencing sound, smell, taste, touch, sight, balance and how the body feels in space in very different ways to other people

3. Communication

Having ASC means I may experience problems in using and understanding communication – both verbal (speech) and non-verbal (body language, facial expression, tone of voice etc.).

This can make it hard for me to communicate my feelings and needs or to ‘read’ other people (know what they are feeling, what they really mean and what their reaction to me means).



Understanding communication

I may have a very literal or pedantic understanding of what someone says, and believe words mean exactly what they say.

I may find it difficult to understand:

- the meaning of some words/phrases
- what someone's tone of voice means
- jokes and sarcasm or language exaggerated for effect
- everyday expressions (e.g. "I could eat a horse" - I may think you are going to eat a horse)
- other people's gestures, body language or facial expressions.



Using communication

I may use communication differently from most people. For example, I may:

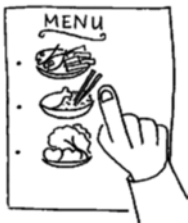
- only use speech to ask for things I want
- not appreciate the social role of communication (e.g. value of chatting)
- speak very formally, or in repetitive/inflexible ways
- repeat back (echo) what others say or have said
- talk incessantly regardless of other people's responses
- show little desire to communicate.



To help me with communication

You need to understand my communication and may need to change the way you communicate so that I can understand you. Use pictures, photos and other visual aids if this helps.

Give me time to understand what's been said (often a long time) and tell me when I manage conversations well.



Keep your communication clear

I am less likely to understand non-verbal communication so your speech must be very clear.

A lot of talking is likely to be stressful for me, so use minimal, simple, clear language that is specific to the situation. Avoid metaphors, abstract language and every day expressions that I may find confusing (e.g. 'raining cats and dogs').

Act as my 'interpreter' – translate situations, events and concepts into language I can understand.



4. Relationships

The range of different relationships

Different people with ASC may want, or be able to manage, very different levels of contact with other people.

I might:

- give little or no attention to the responses or reactions of other people
- only be interested in the task/role someone performs, not the person
- be aloof, over-formal or stilted in social contact
- try to be sociable, but do it in “odd”, unusual, eccentric ways or want friendships but be unsure how to go about getting and keeping them
- find it difficult to be tactful – tell the literal truth all the time, which might make me unpopular.



To help me with relationships

- Find out what level of contact I want with other people.
- Explain other people's behaviour to me (simply). I may find social situations difficult and need more support from you (even with things I usually do for myself). I may need you to explain social rules and how to behave.
- If I am managing, let me know all the things I am doing well.
- Provide me with 'silent companionship'. This means actively being with me without talking or feeling the need to fill silences with chat.



5. Social understanding

My ASC may make it difficult for me to understand other people or social rules or to think in a flexible way.

Understanding other people

I may find it very difficult to understand how it might be for someone else (to 'put myself in someone else's shoes' or empathise).

I may not be able to guess/work out what other people are thinking or understand that other people may have a different point of view.

I may expect other people to have experienced what I have (e.g. expecting someone else to know what has happened to me without being told).



Understanding social rules and behaviour

Because I have difficulty understanding social rules and behaviour, I may have difficulty with things like waiting, co-operating, queuing, sharing and taking turns.

You should:

- help me to understand what to do in any given situation
- provide well-planned and structured activities, so I know exactly what is happening and what will be next
- role-play or practice with me to prepare me for new events. Do “dry runs”.



Needing “sameness”

My ASC affects my ability to imagine or to think flexibly or in abstract ways. This means that I may:

- have difficulty being flexible or changing routines and plans, especially at short notice
- have inflexible routines, which other people want to change
- learn in a rigid, inflexible way (doing things by rote) but not understand why or grasp the bigger picture
- not be able to take my previous learning or experience and apply it to new or slightly different situations
- become anxious, agitated, distressed and/or angry if things are not as I expect.



To help me with social understanding

- support me closely each time there is a change in a known routine and involve me in any changes (inform me at the very least)
- use visual aids rather than talking to help me understand (things like visual schedules, sequences, rotas, diaries, charts and photos)
- help me to increase the number of life experiences I have so I have more specific memories to refer to
- review how things have gone with me afterwards.



6. The senses

My ASC means that I may respond to noises, smells, tastes, touch or sight in a different way from other people.

I may be more sensitive or less sensitive than most people.

Something that has no effect on you may be a very unpleasant or very satisfying sensory experience for me.

I may have difficulty with bright or fluorescent lighting, high-pitched beeps/sounds (e.g. mobile phone text alerts), food mixers, lawn mowers, Hoovers, or 'scratchy' clothing like wool or denim.

I may avoid or have extreme reactions to things I am oversensitive to, and/or seek stimulation from things I am less sensitive to (to get a reaction).



I may:

- feel tired and stressed because I am over-stimulated
- need 'recovery' or rest times, or to follow a routine or ritual regularly in order to cope
- be unable to filter out background noise
- need to do things that provide me with firm physical pressure or touch that I am in control of (e.g. wearing tight or heavy clothing or jewellery, having bedclothes tucked in tightly, being in water etc.)
- find it difficult to have eye contact
- jump, rock or flap my hands and arms
- have an unusual way of walking or odd posture; be "clumsy"
- be able to spin around without getting dizzy
- have erratic eating, drinking and sleeping patterns and/or need to drink a lot.



To help me with the senses

You should:

- help keep physical environments consistent, predictable and with a lack of sensory distractions
- try not to move my furniture or belongings
- avoid sudden, unexpected noises and the smells or lighting that I find difficult
- help me avoid things I am over sensitive to and/or have access to things I need stimulation from
- be aware that I may find touch very difficult. Find out what touch, if any, I like. If in doubt, don't use touch.



7. Some common problems faced by people with ASC

People with ASC are living in a world that isn't ASC friendly. Getting help and support from people who understand the condition can be difficult.

Mental health and anxiety:

Having ASC makes me more vulnerable to mental health issues - especially depression, obsessive-compulsive disorder and anxiety.

I may experience high levels of anxiety, fear, confusion, frustration or phobias. You need to be able to recognise when I am becoming anxious and do all you can to help reduce my anxiety.



People with ASC also often behave in ways that other people find odd or challenging. I may have unusual mannerisms and behaviours. These behaviours may be:

- a reaction to my sensory experiences or
- my way of dealing with a difficult situation or anxiety (a coping strategy).

If you don't understand this you may try to stop the behaviour or mannerism, which means you will be stopping a coping strategy. This usually makes things worse.

Finally, some people with ASC don't understand the condition itself but do have a sense that they are 'different'. I may want to change but find it very difficult to do so.



8. The support that will help me

Try to understand the challenges I face and the stress these may cause me. Do not rush me or put me under added pressure.

Your support needs to be honest, creative and sensitive. You need to accept my differences and eccentricities. I may seem abrupt and unsociable at times, but I am not being deliberately rude. This is part of my condition. Don't expect me to behave in ways that are alien to me. Adapt your support to meet my needs.

Anxiety may make me angry at times – please don't take this personally.



I need:

- structure, planning and a routine
- consistency, predictability and stability
- choices I understand
- an appropriate physical environment
- support with sensory issues
- help to learn new skills
- explanations and demonstrations
- effective communication
- time to think about and do things.





9. Helping me to develop my skills

People with ASC can have a wide range of skills.

To help me develop my skills, focus on the things that I am good at, my special interests and strengths. This will help me to develop expertise and will improve my self-confidence. I may be able to learn other skills as I focus on my special interests.



10. Keeping safe



I have the right to live my life free from abuse (this includes bullying).

There are some things that can place me at particular risk of abuse. These may include finding it difficult to communicate what is happening, not understanding that it is not ok or can be stopped, and being more dependent on others for help.

I may find it difficult to tell anyone that I am being abused. Changes in my behaviour, my mental and physical state or the amount of money/possessions I have are potential signs that I am being abused or neglecting myself in some way.



If I tell you something or you see something that you think may mean I am being harmed, seriously neglecting myself or I am at risk of this, you have a responsibility to report your concerns.

Do not:



- press me for details
- assume someone else will report it
- contact the alleged abuser
- promise to keep what I have told you a secret.

Do:



- make a note of what you have seen or I have told you
- help me to preserve any physical evidence – or do so yourself
- report it – and tell me you have done so.

TO REPORT SUSPECTED ABUSE

If you witness abuse, or think someone may be abusing me, you need to alert Social Services and report your concerns. Do this by calling:

East Sussex: 0845 60 80 191

(Out of hours: after 5pm, at weekends, on bank holidays, call: 07699 391462)

West Sussex: 01243 777100

(Out of hours: after 5pm, at weekends, on bank holidays, call: 01903 694422)

Brighton and Hove: 01273 295555

(295550 if I have a learning disability)

(Out of hours: after 5pm, at weekends, on bank holidays, call: 07699 391462)

If I, or someone else, is in danger, you suspect a serious crime may have been committed, or I require medical attention, phone 999.

11. Further information

Developing your skills

I am (or those close to me are) responsible for making sure that you can develop the skills and knowledge you need to support me. Much of this will come from me – as I (or those close to me) explain how I want things done. If you think it would be useful to learn more skills to support me better, talk to me (or those close to me). I can contact the following people for advice about training that may be available to you:

East Sussex: Brian Andrews tel: 01323 463114
email: Brian.Andrews@eastsussex.gov.uk

Brighton and Hove: Kevin Murphy tel: 01273 295279
email: Kevin.Murphy@brighton-hove.gov.uk

West Sussex: Gill Brady tel: 01903 839453
email: Gill.Brady@westsussex.gov.uk

It may be helpful for you to gain knowledge/skills in the following areas. Which areas are useful will depend on my needs, the hours you work and the tasks/activities you support me with:

- Person-centred approaches
- Communication
- Active support and skills teaching
- Social stories (a way of helping someone with ASC understand what is expected of them in different social situations)
- Sensory issues for people with ASC
- Supporting people who can behave in ways that are challenging
- Working with the senses – for people who are more severely disabled or have sensory impairments
- Safeguarding vulnerable adults from abuse
- Choice and capacity



Some training providers run courses on these subjects. The council may run some free courses, other training providers charge and we would need to work out if and how we can pay for this. You can also find out more by reading – e.g. looking at websites.

Useful websites:

- National Autistic Society (see also their ‘think differently’ website)
www.nas.org.uk
- British Institute of Learning Disabilities (BILD)
www.bild.org.uk
- Mencap
www.mencap.org.uk
- Foundation for People With Learning Disabilities
www.learningdisability.org.uk

- Mental Health Foundation
www.mentalhealth.org.uk
- Valuing People 2001 and Valuing People Now 2009
(The government's plan for making the lives of people with learning disabilities better)
www.valuingpeople.gov.uk
- 'Better services for people with an autistic spectrum disorder: A note clarifying Government policy and describing good practice' Dept of Health Nov 2006
[http://www.dh.gov.uk/en/Publicationsandstatistics
Publications/PublicationsPolicyAndGuidance
DH_065242](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_065242)
- In Control (a website promoting self-directed support)
www.in-control.org.uk



Autistic Spectrum Condition

This Personal Assistant guide has been developed in 2009 by Southdown Housing Association on behalf of Sussex Skills for Care, with funding from Skills for Care.

Other guides/leaflets in the “Supporting Me” range and copies that can be tailored to me are available from the local Independent Living Advice Service:

Brighton & Hove: Federation of Disabled People
Tel 01273 229264 Email: bhfederation@bhfederation.org.uk
Website: www.bhfederation.org.uk

East Sussex: A4e
Tel: 01323 414674 Email: ilss@a4e.co.uk
Website: www.a4e.co.uk/ils

West Sussex: Independent Living Association
Tel: 01903 219482 Email: info@ilawestsussex.org
Website: www.ilawestsussex.org

Southdown

**Southdown Housing Association
2 Bell Lane, Lewes, East Sussex,
BN7 1JU 01273 405800**

www.southdownhousing.org

Southdown Housing Association is an exempt charity, Registered with the Tenant Services Authority/TSA, the Regulator of Social Housing (L1829) and The Industrial and Provident Society (20755R)



www.skillsforcare.org.uk

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