



How to be a great

personal assistant for someone with autism

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Are you are a personal assistant already or perhaps are thinking of becoming a personal assistant (PA) for someone who has autism?

Have you ever considered what makes a really great personal assistant for someone with autism? What attitudes and knowledge are needed? And how much your actions can actually make a difference?

The content of this guide has been written by people with autism, their carers, families and professionals because they want to help you understand how to be the best PA you can be.

To accompany this guide we have produced resources two additional guides called 'how to be a great autistic individual employer' and 'how to do a great assessment for someone who has autism', as well as two videos called 'important things to remember as a personal assistant for someone with autism' and 'important things to remember when doing any type of assessment with someone with autism'. These resources can be found online at

www.skillsforcare.org.uk/autism.



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Do you know what autism is?

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them and often autistic people will have sensory differences. Some people with autism will not have any social care or special health care needs – others might need a little or a lot.

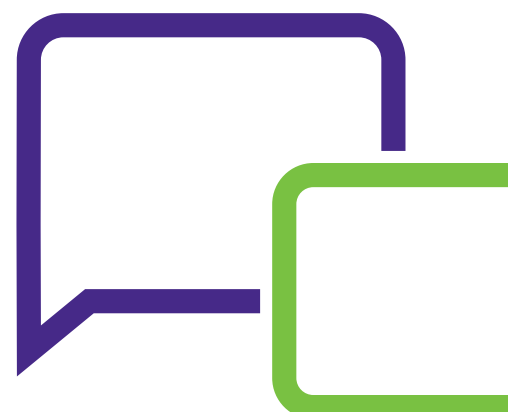
It is a condition that covers a wide spectrum of differences, sometimes including a learning disability, which means that while many people with autism share certain difficulties, autism will affect them in very different ways.



If you know ONE person with autism, you only know one person with autism. We are all different. Autism affects us and how we behave in very different ways.



The next two pages give examples of some common differences that autism might make to the usual working relationship between personal assistants (PA) and individual employers.



Difficulty with social communication

What this might mean for the employer	What this might mean for the PA
<p>Taking spoken or written language very literally.</p> <p>Misinterpreting or being oblivious to body language, facial expressions or tone of voice.</p>	<p>Discussions about your role and your skills or written information like care plans, notes or diary entries need to be as factual as possible. Sarcasm, irony or 'matey' jokes are unlikely to be good ways of communicating, especially if they rely on tone of voice or facial expression to be understood.</p> <p>It might not be obvious to you when your employer is happy or unhappy with something you have done. It is part of your job to learn how he/she communicates and to agree ways of knowing that they are happy with your support.</p>

Difficulty with social interaction

What this might mean for the employer	What this might mean for the PA
<p>Not understanding unwritten social rules.</p> <p>Avoiding interaction – especially when stressed or anxious.</p>	<p>Your employer could appear insensitive to you. They may try to act like 'an employer' or like 'a friend' based on role models available to them that are not suitable for this situation. A person with autism might behave strangely or inappropriately in public and your role might include helping them explain this to other people or helping the person develop other skills.</p>

Difficulty with social imagination

What this might mean for the employer	What this might mean for the PA
<p>It is harder for people with autism to know or guess what another person knows or is thinking or feeling.</p> <p>It is harder to anticipate situations or predict what might happen.</p>	<p>An autistic individual employer might think that you know what they need you to do without actually telling you.</p> <p>Your employer may need sensitive help to prepare for change, to plan for the future or to cope in new or unfamiliar situations.</p>



Difference between verbal and actual abilities

What this might mean for the employer	What this might mean for the PA
Some people with autism might appear to have a learning disability but not in fact have one. Other autistic people can describe in detail how to do an activity but can't put this into practice without help.	You might assume that someone who is really good at one (possibly 'difficult') thing can do another 'easier' thing without help and this might not be the case. Your employer might be much better or more knowledgeable than you at some aspects of life. People with autism might be embarrassed about the things they really need help with and struggle to ask for that help.

Sensory differences

What this might mean for the employer	What this might mean for the PA
People with autism can have very different reactions to various sensory stimulation, for example strong smells may make people feel sick, loud noises or bright lights might be painful or very strong flavours be delicious.	<p>As a PA for someone with autism you might be asked to refrain from wearing perfume or to deal with a noisy situation when the employer is feeling overwhelmed.</p> <p>When the employer is stressed or anxious their ability to communicate is likely to be less and they might need you to be more pro-active in knowing what they need.</p>

Many people with autism also have routines that are very important, or 'self-stimulating' habits which help them cope but which they might not wish to explain. Some people have special interests which really matter to them. Some people also get very anxious or have had bad experiences in the past that they fear will reoccur. Any of these differences may need a sensitive and flexible approach from a personal assistant.

The best and worst workers

Most people who work with people want to do a good job and that's no different for personal assistants with employers who are autistic. The majority of personal assistants want to know how they can best assist and support their employer. Sometimes people don't realise that the things they say and do are actually causing more harm than good. Working together to find ways of communicating is essential and for people with autism 'sitting down and talking about it' is often not the best way. Your role means being open to all forms of communication including written, behavioural, verbal, technological and non-verbal and being sensitive and willing to explore new ways of finding out what your employer wants.

To try and help personal assistants who work, or want to work, with autistic people, the next three pages identify some examples of the best and worst attitudes, knowledge and actions workers might have or do.

The best workers are always...



**100% devoted to their work
during the time they are with me.**



We have also developed an accompanying video which contains real life examples of the points made throughout the guide by the people who participated in its development. You can find this online at www.skillsforcare.org.uk/autism.



Attitudes

Have you ever thought about how your attitudes affect the way you work and how they affect the person you are working for?

The best workers...

Think about how I might feel and react to something that they say, even if it isn't meant to sound bad.

The best workers...	The worst workers...
<ul style="list-style-type: none">■ communicate with me clearly■ are a real ally who will stand up for what people need■ are interested, non-judgemental, respectful, empowering and empathetic■ value freedom of choice, independence and taking risks■ act with honesty for the person they are supporting■ speak to the point■ are caring■ value me and my family's experiences■ are proactive■ are passionate about getting things right for me.	<ul style="list-style-type: none">■ don't practice what they preach■ are too controlling, e.g. speaking for me■ think they know a lot about autism■ are opinionated and don't realise they are biased and making wrong assumptions■ start by considering budgets and resource constraints before my needs and hopes■ disbelieve my circumstances, difficulties, diagnosis or sensory differences■ are judgemental, blaming or criticising me and my family for my difficulties■ are bullies■ think in institutionalised ways, wherever they are working■ let their personal life affect their professional life.



Knowledge

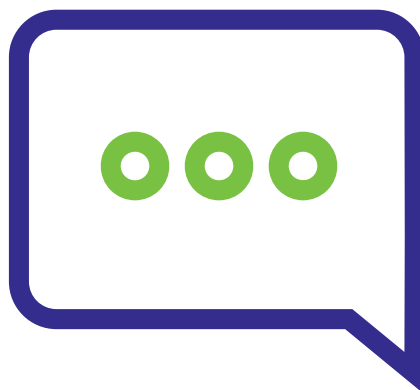
The best workers...



Know that autism can affect someone differently in different situations and environments.



The best workers...	The worst workers...
<ul style="list-style-type: none">■ understand about autism■ understand that autism can be very different for different individuals■ understand the individual and what's important to them■ respect my lifestyle and home■ understand my specific needs, e.g. memory■ understand that somebody with autism can be very skilled in some aspects of their life but desperately struggling in others – and may feel ashamed of this■ know about a range of tools and resources that might help e.g. tools to help with communication and ways to help sensory differences■ if they don't know, ask, or go and find out!	<ul style="list-style-type: none">■ think they know a lot about autism and make assumptions about how it affects me■ don't know anything about autism■ think IQ or verbal skills equals life skills and competence■ don't understanding the real pain and distress that sensory issues cause■ record literal answers to questions in a superficial way■ think they are experts in what they do just because they have been working with other autistic people for a long time■ treat me like a child.



Actions

The best workers...



Do exactly what they say they are going to do! (or honestly explain any differences)



The best workers...	The worst workers...
<ul style="list-style-type: none">■ listen attentively■ build a rapport to create a trusting relationship■ help to find information■ make reasonable adjustment for my needs, especially communication■ accept the individual's language■ don't leave me waiting■ agree time scales■ be patient■ go at my pace■ give me time to regulate sensory problems■ believe me■ get other people involved when needed (with my permission involve my family)■ look for solutions, addressing access and communication needs■ have a holistic approach■ are person-centred and help me plan for the future■ explain everything■ are available and responsive■ work flexibly■ accept and admit mistakes■ accept the person's presentation■ are friendly and approachable■ find out what makes me angry and upset.	<ul style="list-style-type: none">■ disrespect my style or home (different for each person)■ hand pick people who are easy to work with, avoiding people with complex needs■ let their personal life affect the way they behave at work■ shy away from dealing with anything to do with sexual health and sexual relationships■ lie■ are vague about what I can expect■ leave me hanging, unsure what to do next■ tell me I lack empathy or imagination■ joke and tease■ tell me to ignore sensory issues■ are rude or dehumanising using language to describe traits or diagnostic criteria that is hurtful■ keep information from me■ make things over-complicated.

How this guide was developed

In June and July 2015 a group of people worked together with Skills for Care and Skills for Health to think about what really makes a great personal assistant for someone with autism.

The group included:

- people with autism
- carers and family
- advocates
- personal assistants
- direct employers
- health and social care professionals with a specific interest in autism.

Useful links and references

The autism skills and knowledge list, Skills for Care/Skills for Health, 2011.

www.skillsforcare.org.uk/autism

The National Autistic Society has detailed guides, training and resources for a range of professionals. www.autism.org.uk

Acknowledgements

Autism guides development group (which included individuals and groups representing people with autism, family carers and professionals working in social care, health and the police)

Autism guides wider consultation group

Leeds Asperger Adults - www.leedsaspergerblog.wordpress.com

Leeds Autism AIM - www.autismleeds.org.uk

The National Autistic Society - www.autism.org.uk

Insight Autism Consultancy - www.insightautism.co.uk

Department of Health - www.gov.uk/government/organisations/department-of-health

Skills for Care - www.skillsforcare.org.uk

Skills for Health - www.skillsforhealth.org.uk

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