A dark blue hand is shown from the right, placing a white puzzle piece onto a larger white puzzle piece. The background is a solid light blue. The puzzle piece being placed has a blue outline and contains the text 'Autism: A Guide for Adults Following Diagnosis' in blue. The larger puzzle piece it is being placed on also has a blue outline and contains the same text.

Autism:
A Guide for
Adults Following
Diagnosis

Autism: A Guide for Adults Following Diagnosis

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How to use this guide

Hello, my name is Johanna Manikiza and I am proud to have been an author of *Autism: A Guide For Adults Following Diagnosis*. I hope you find this book useful.

We have developed this guide at the request of adults who found accessing information at the time of receiving a diagnosis of ASD confusing. The development of this guide was funded by the Welsh Government as part of the implementation of the ASD Strategic Action Plan for Wales.

The aim of this guide is to provide advice and tips for everyday life to adults who have been diagnosed with an autistic spectrum disorder.

This guide was developed by professionals and people with an autistic spectrum disorder.

In this guide the term autistic spectrum disorder (ASD) is used to encompass all conditions associated with the autism spectrum including autism, autistic spectrum condition, Asperger syndrome and high functioning autism.

In this guide we refer to people without an ASD as neurotypical, this standard term was chosen to be used by the adults with ASD who have contributed to this book.

Not all of the sections may be relevant to you. You can choose to read the whole guide or the sections that are relevant to you.

The advice and tips in this book have been suggested by people with an ASD and professionals. They may not all be relevant to you. We hope that some are, and that you will find some ideas and explanations useful, but don't worry if they are not.

You do not have to follow all or any of the advice in this guide. You may choose not to follow any advice or to try one or a few of the suggestions or to try many of the suggestions.

This guide contains explanations, advice and tips, personal stories, photographs and lists of resources for further reading. These are denoted by coloured icons as follows:



Explanations: these are marked with a diamond and offer information about the topic.



Advice and tips: these are marked with a triangle and offer some ideas that you might like to try.



Personal stories: these are marked with a circle. Personal stories have been written by people with an ASD who wanted to share their experiences with you. You can read these if you would like to know about other people's experiences.



Photographs and pictures: these are marked with a square. These have been added to the guide for decorative purposes only, you do not need to consider the meaning of them.



Further reading: these sections are marked with hexagon and list resources and websites that provide further information if you wish to read more.

I hope that you find this book useful, for an electronic version of this guide or further information about ASD developments in Wales please visit www.ASDinfoWales.co.uk

A handwritten signature in black ink that reads 'Johanna Manikiza'.

Johanna Manikiza
ASD National Strategic Coordinator



Foreword

I am pleased to present to you *Autism: A Guide for Adults Following Diagnosis*.

The creation of this guide has been a lengthy project which was funded by the Welsh Government and hosted by Aneurin Bevan Health Board. The project has been developed by professionals from Aneurin Bevan Health Board in conjunction with professionals from other organisations and Adults with Autistic Spectrum Disorders.

Contributors with Autistic Spectrum Disorders have provided content and constructive comments at each stage of the preparation of this guide. They have been wholeheartedly involved using their experiences to inform the content of *Autism: A Guide for Adults Following Diagnosis*

It is hoped this guide will provide guidance and support for Adults with Asperger syndrome and High functioning Autism following their diagnosis.

During the initial stages of development of this guide, we consulted widely with individuals with Autistic Spectrum Disorder, their families and carers. There was consistent feedback expressing the need for information and practical suggestions for everyday events. We were told that receiving a diagnosis was often helpful, but that knowledge and support was not always readily available. They expressed a need for a single resource which would be easily accessible, provide information, suggest solutions to everyday issues and signpost to further resources.

We believe that *Autism: A Guide for Adults Following Diagnosis* meets the identified need and will provide a much needed

information resource which can be used as a starting point to supporting individuals with Autistic Spectrum Disorders following diagnosis.

We are extremely grateful to all the individuals who have contributed to this guide, especially those with an Autistic Spectrum Disorder. Their contribution has ensured we remained focussed on a development that truly meets the needs of the people it is intended for.



Dr Andrew Goodall
Chief Executive
Aneurin Bevan Health Board





Acknowledgements

We would like to thank everyone who has contributed to the development of this book.

In particular we would like to recognise the contribution made by the following adults with ASD who have been instrumental in informing and providing content for the guide:

Tom Mellor
Rubin Irvine
Ian Walker
Karen Thompson
Alex Lowery

We would also like to thank the professionals who have assisted in the reviewing of this guide:

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RUBIN'S ASD STORY

I didn't get diagnosed until I asked, at 46, to be tested. I function, in my own quirky way, in society and do not need any more help than your average person. There are many people on the autistic spectrum who remain undiagnosed throughout their lives or whose diagnosis becomes irrelevant after they leave full-time education. These people are a positive side of autism, a side, of which, most 'normal' people are unaware.

[Rubin Irvin]



IAN'S ASD STORY

My name is Ian, and I am now 73. I have been married to Judy for 47 years, and we have two children, now grown-up and moved away. Five years ago I retired from a very satisfying career as a college lecturer, for 30 years full-time and then 15 years gradually diminishing part-time, with maths as my main subject (please don't stop reading at this point!!)

We have both known for some time that I had mood swings and erratic behavioural problems. It was only seven years ago, however, as a "spin-off" from a colleague's lecture on "Autistic Savants", that we wondered whether there might be another cause. So we asked my GP whether I could be referred to a specialist for a diagnosis, since we felt that, if confirmed, knowing I had Asperger syndrome would answer a lot of questions about my unpredictable behavioural traits – which has indeed been the case. So he agreed, and nine months and two 90-minute interviews later the letter arrived, confirming that I did indeed have Asperger syndrome.

[Ian Walker]





KAREN'S ASD STORY

When I received my diagnosis on 10th May 2005 aged 38, I was so pleased to have the explanation for all the difficulties I had experienced up to this point. I had found the reason for the things I struggled with and it made sense of my life, as well as changing how I saw myself, so I was able to be more confident in my position as a person with Asperger syndrome. I was no longer someone who was awkward or stubborn.

When I attended appointments where the people treated me badly, the diagnosis helped with managing these difficult situations.

I found freedom in knowing that this is who I really am and that I can make the best of my life, as I learn and grow accustomed to this view of myself.

The diagnosis was not just the end of not knowing about Asperger syndrome, it was the beginning of a long journey of discovery and learning about my life, and how to relate to the world around me in a new way, whilst remembering that as a person I had not changed, because I was born this way and I quite like myself anyway.

[Karen Thompson]



RUBIN'S ASD STORY

I am proud of my autistic nature, my honesty, self-belief and autonomy. When I was told I had a disorder I felt insulted. I am not out of order, I am not wrong I am just different from. You and me are different in a similar way and one of the benefits of diagnosis is finding out that you are like other people. That said, diagnosis is a useful tool, helping you to understand yourself and others and for them to understand you better. Understanding people is vital to getting the best out of them.

[Rubin Irvine]



ALEX'S ASD STORY

Despite having difficulties; I still don't altogether see autism as a bad thing. There are a lot of good things about it.

It gives me a unique way of looking at things, so I'll often think of things in an unusual way. I'll tend to think a lot deeper about certain things that other people do. I also feel proud all the things people with autism have achieved. A lot of the most famous people are thought to be on the autistic spectrum. Who do you think would be studying all the inventions and having big fixations on the stuff they're interested in? They likely wouldn't be the really sociable people would they? They would likely be the more withdrawn people. It's actually common in autism to have obsessions, and a lot of these famous people were really fixated on the stuff they were interested in.

Truth be told, I don't really want to be normal. True: I want my difficulties to improve as much as they can, but I still like being a bit different from other people. I like having something, which makes me unique.

[Alex Lowery]



A brief overview of ASDs

Every person is different, whether they have an ASD or not. Individuals with an ASD have impairments in social interaction and social communication together with impairments in social imagination and a narrow repetitive pattern of activities and interests.

Individuals without an ASD may have difficulties in some of these areas but not all, or they may have mild difficulties in all of these areas but these difficulties are not significant enough to affect them in everyday life.

The way in which your ASD impacts you may be different to another person with ASD, and may vary during your life time

Many people with an ASD have happy fulfilling lives.

There is speculation that many famous people in history, who have influenced our world significantly, had an ASD, these include:

Isaac Newton

Albert Einstein

Hans Christian Andersen

Charles Darwin

Michelangelo

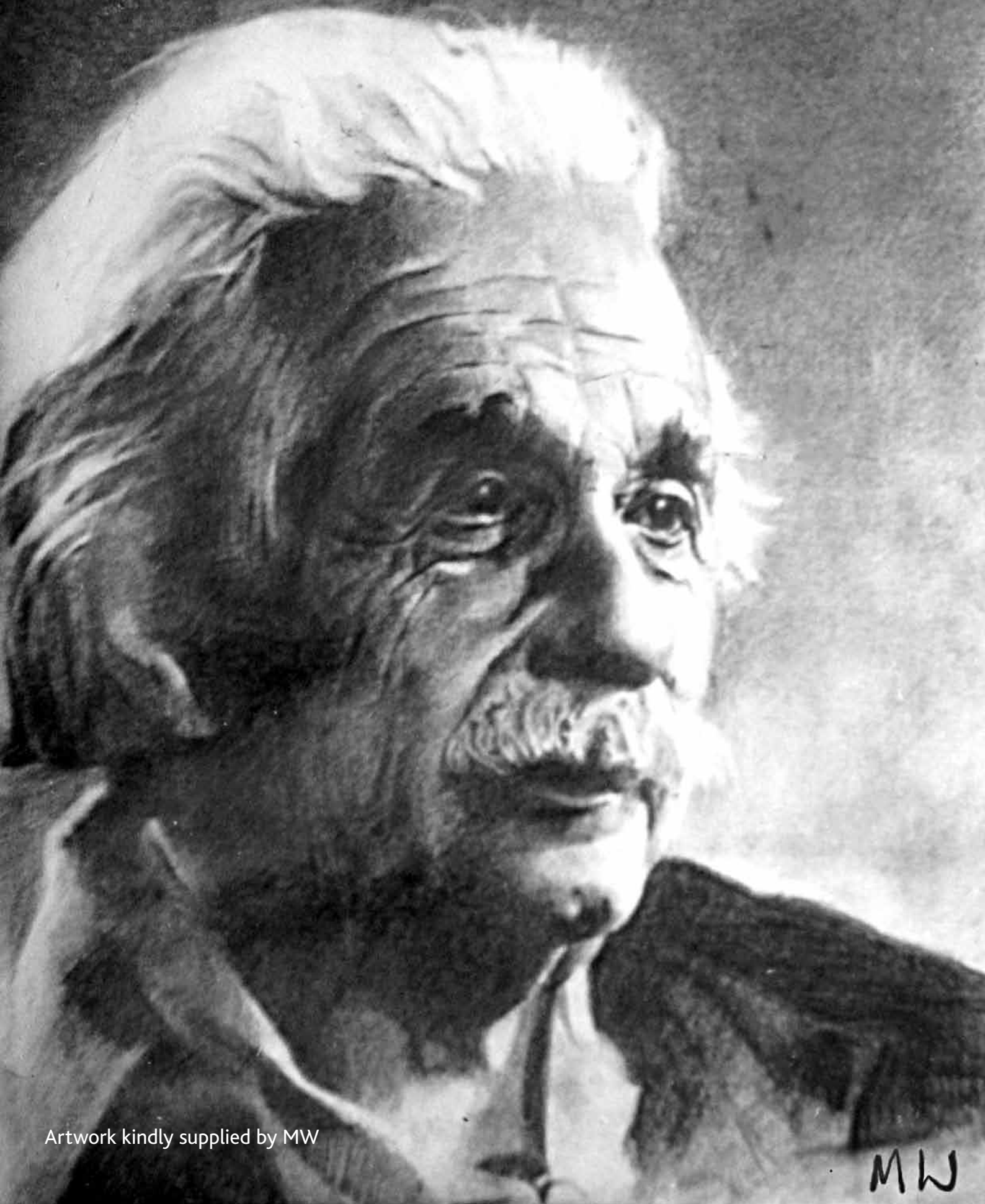
Thomas Jefferson

Wolfgang Amadeus Mozart

George Orwell

Andy Warhol

And there may be many others...



Artwork kindly supplied by MW

MW



The Complete Guide to Asperger Syndrome

Tony Attwood

Jessica Kingsley Publishers

What People with Asperger Syndrome Really Really Want

Sarah Hendrickx

Jessica Kingsley Publishers

Concepts of Normality—The Autistic and Typical Spectrum

Wendy Lawson

Jessica Kingsley Publishers

Born on a blue day

Daniel Tammet

Hodder & Stoughton Ltd

Look Me in the Eye – My Life with Asperger’s

John Elder Robison

Ebury Press

Thinking in Pictures

Temple Grandin

Bloomsbury Publishing Inc.

Autism All stars. How we use our Autism and Asperger traits to shine in life

Jessica Kingsley Publishers (15 Dec 2011)

A History of Autism: Conversations with the Pioneers

Adam Feinstein

Wiley-Blackwell (18 Jun 2010)





Neurotypical communication

Neurotypical individuals generally use a range of methods to communicate. These include:

- Language
- Facial Expressions
- Eye Contact
- Gesture
- Body Language

At times they may use these modes of communication in isolation, but more often use a few of them at the same time.



It's raining cats and dogs: An Autism spectrum guide to the confusing world of idioms, metaphor and everyday expressions

Michael Barton

Jessica Kingsley Publishers

An Asperger Dictionary of Everyday Expressions

Ian Stuart- Hamilton

Jessica Kingsley Publishers (2nd Revised edition)





Language

Often neurotypical people use words and phrases that they don't really mean. Often this is not because they are deliberately trying to deceive or trick people, but because of the way in which they use language.

They will often use specific phrases but the meaning of them is more general than the phrase suggests. For example *"I'll do it in a minute"* and *"I'll do it now"* usually means *"I'll do it soon"*,

Neurotypical individuals may say things they don't intend to do, with the intention of emphasising the point or joking. For example *"I'm going to kill you"* can mean *"I'm really annoyed with you"* or *"that really embarrassed me"* but rarely means that the person intends to commit murder.

People use idioms to describe people, objects and actions. Idioms are not meant to be taken literally and therefore can be very confusing if you have an ASD. Examples of idioms are *"pull your socks up"*, meaning *"improve the way you are doing that"*; *"it's raining cats and dogs"* meaning *"it's raining very heavily"*.

Metaphors are also frequently used to emphasise what people mean. Examples of metaphors are *"you are the light of my life"* meaning *"you are important to me"*, *"I'm feeling blue"* meaning *"I'm feeling sad"* or *"my head is spinning"* meaning *"I'm feeling confused"*.

Idioms and metaphors vary in different cultures and countries.





Facial expressions

Most neurotypical people use facial expressions to convey a range of emotions. Facial expressions occur spontaneously in neurotypical people, they do not have to make a conscious effort to use them.

Neurotypical people observe and interpret others' facial expressions and use these to guess how they are feeling. When others are smiling, they assume they are happy; when they are not smiling they assume they are not happy.

If you have difficulty with using facial expressions, a neurotypical person may make an incorrect assumption about how you are feeling.

If a neurotypical person does not understand something or is not happy with something they may try to convey this to you using facial expressions instead of words.

If someone changes their facial expression and you cannot interpret it, ask what they mean.

When someone is being sarcastic, their facial expression often contradicts the phrases they are using. For example if a neurotypical individual says "*I am so happy*", but displays a frown on their face this usually means they are being sarcastic and actually mean that they are not happy.



This can be very confusing, if you are struggling to understand the true meaning it's OK to ask.

- Practise using facial expressions to convey happiness, sadness and anger. Ask someone to help you.





Eye contact

Neurotypical individuals use eye contact in a variety of ways, including flirting and scolding.

When they are talking to someone neurotypical people look directly at their eyes ('make eye contact') for a few seconds, look away, and then make eye contact for a few seconds again. They also do this when people are talking to them.

Because this is the way that neurotypical use eye contact every day, they assume that if a person is looking at them it means they are listening to them, and are showing they are interested in what they are saying. If you do not look at a neurotypical person when you are talking to them, they may not realise you are talking to them. If you do not have eye contact when they are talking to you, they may assume you are not listening or that you are being rude.



Try and look at others when you are talking with them. If you can't make eye contact try looking at the bridge of their nose.







Gesture

Neurotypical people use different types of gesture during conversation.

Some people use gestures more than others.

Gestures can be used to emphasise a word or phrase during speech, to demonstrate or describe something, to direct attention to something, to show emotion or to pace the flow of conversation.

Sometimes gestures can be ignored as they are just being used to pace or emphasise part of the conversation.

If gestures are being used to describe or direct they may be important to the conversation.



It is OK to ask the person using gesture to explain what they mean in a different way.







Body language

Neurotypical people use body language to convey how they are feeling to other people. Body language involves movements of the whole body and is often used in conjunction with facial expression and gesture.

Communicative body language occurs spontaneously in neurotypical people, they do not have to make a conscious effort to use body language and they interpret body language in others spontaneously also.

Body language is used to indicate emotional state or to signal to someone else what they expect them to do.

Neurotypical people interpret body language of others by using the way that they use body language as a guide. For example when a neurotypical person is not happy with someone or does not want to engage with them they may sit with their legs and arms folded in front of their body. Therefore if they see someone sitting with their arms and legs folded across their body they assume that the person does not want to engage with them.

This can cause difficulties for people with ASD, if you are not able to 'read' body language you may not be able to guess what others are trying to tell you.

Also a neurotypical person may misinterpret your body language and assume you are feeling something different to what you really are.



There are many books available that explore and explain body language; you could try reading one to help your understanding in this area.

Some things that may help:

- Join a social group for people with an ASD.
- It is OK to ask the person to explain what they mean in a clearer way, or to check if your interpretation is correct.
- Tell friends and family about your ASD. Ask them to take time to learn about ASD, and to help with the things you struggle with.
- Undertake social skills training.
- There are many websites that explain the meaning of metaphors and idioms. You could take a look at one of these if you would like to learn the meanings of idioms and metaphors.
- Take note of peoples facial expressions and body language when watching TV programmes.
- Read an illustrated book about body language.
- If you don't understand, ask.

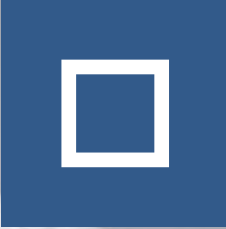


ALEX'S BODY LANGUAGE STORY

I have a hard time understanding people's body language, facial expressions and tone of voice, unlike other people who seem to automatically notice people's body language (which I completely miss). I also have a hard time knowing whether people are upset, or angry or whatever. Or I might say something that's unintentionally annoying and people might be getting more and more annoyed without me realizing and then they become really cross and I'm like, "Why? I didn't see that coming!"

[Alex Lowery]







Social behaviour

The way in which people behave in social situations can be very important to neurotypical individuals. Neurotypical individuals adapt their behaviours depending on the social situation they are in, who they are talking to and their environment.

They expect others to behave in a way that they consider to be appropriate also. This is because neurotypical people generally like to conform to social expectations, this makes them feel comfortable.

When neurotypical people see someone behaving in a way which they feel is inappropriate to the situation, they assume they are being rude or 'strange'.

In general, neurotypical people become offended if you say something that they interpret as being derogatory to them. Comments on physical appearance that are not positive often cause offence; these include comments about people being overweight, facial features or choice of clothes. This can even apply if they have asked you to be honest; when it comes to personal issues they often do not really want you to be honest, and will not necessarily be honest with you.

Most neurotypical people enjoy being praised or receiving compliments. They usually dislike criticism.

When neurotypical people have a conversation, they expect to take turns with each person taking an equal part overall in the conversation.

When they ask a question, they usually expect an answer and some additional information or another question in response.

If you do not allow the other person to speak in a conversation, or just answer a question and add nothing more a neurotypical individual may think you are being rude even though that is not your intention.

Try and ask a question following an answer, or add a little bit more information than you were asked for.

For example "how was your day?"

"it was good, how was yours?"

Or "it was good; I went for a lovely walk"

Neurotypical people prefer to maintain an empty space around them when interacting with others, especially those they do not know well.

If you have difficulty with maintaining personal space, it is a good idea to try and leave a space that is equivalent to the length of your arm between you and the person you are interacting with. Of course, this is a suggestion not a rule, as if you are sitting around a table or on a bench or bus seat this is not always possible.

When neurotypical people are in public environments such as the supermarket, park or health centre they change their behaviour to behave in a way that they feel others expect of them.

They also expect others to behave in a similar way.

For this reason speaking loudly, singing, rocking, spinning or talking to oneself in public areas may appear as odd or strange to neurotypical people.



Survival Strategies for People on the Autism Spectrum

Marc Fleisher

Jessica Kingsley Publishers

Social Skills for Teenagers and Adults with Asperger Syndrome: A practical Guide to Day to Day Life

Nancy Patrick

Jessica Kingsley Publishers



RUBIN'S SOCIAL BEHAVIOUR STORY

Neurotypical people are obsessed by social status and behaviour. Our society is dominated by that social behaviour. It is very difficult to thrive in the middle of this social maelstrom but there are many opportunities on the margins where our special skills can be advantageous.

Be gentle with neurotypicals; they can, like us, be easily offended and because of our differences what offends us doesn't offend them and vice versa. It is vital to learn how to communicate with neurotypicals, make sure they understand you as they are always looking for hidden meanings in what you say.

If you are confident enough, tell them about your autism and explain to them how your understanding of the world and how to behave in it are different from theirs. The future will be better for all of us the more understanding and, with more understanding, respect of our individual differences.

[Rubin Irvine]





Sensory issues

Some people with an ASD experience 'hyper' or 'hypo' sensitivity. You may find that you are more or less sensitive than others to stimuli such as sound, touch, taste, smells or visual stimuli such as lights or colours.

Sensory issues can also affect the senses that help with balance and body movement.



Some things that may help:

- If bright lights are an issue, try wearing sunglasses or glasses with coloured lenses.
- If noise causes you issues in certain places try wearing ear plugs or listening to music through headphones.
- Try using fabric conditioner to soften clothes.
- Tell others about your sensory issues and ask them to make environmental adjustments such as turning off fluorescent lighting or clearing messy areas.
- Seek the help of an occupational therapist, who can offer assessments, support and advice regarding sensory issues.





Coping with changes

Many people with an ASD prefer familiar environments and routines. Changes or new experiences can cause worry and upset.

Of course, the more you limit your activity the less things you are familiar with.

You may find it difficult to imagine how new things will work out or to imagine how to act in new situations.



Some things that may help you to cope with changes:

- Use timetables, calendars or planners to prepare yourself for something new
- Use staged approaches, visit places at quiet times at first, look at buildings from the outside, travel the route you will be taking
- Consider similar situations you may have experienced in the past.
- Use the internet. With such a wide range of information available you can often read about others experiences or view videos or pictures of activities
- Ask others to give you notice. Tell people who know you that you need more notice to prepare for a change or new activity.





Planning

You may find planning ahead difficult because of your ASD. You may find it difficult to remember things or hard to stay focussed.

By trying to organise and plan ahead you will feel more able to cope with daily routines and prepare for irregular activities. This may mean that you experience less anxiety and feel less confused.



Some tips and tricks to help with planning and organising:

- Keep all your materials together, use the same notebook or diary, invest in a personal organiser and keep all your information in it or at least make sure that you store everything in the same drawer or shelf.
- Utilise technology. Use a laptop, mobile phone or tablet to plan and record things. There are many apps that can help to organise and plan your week, try the ASD Planner app.
- Write lists and keep them for future reference. Make sure your lists have headings so that you can use them over. These lists can be useful for directions or instructions for frequent activities such as paying a bill.

Tips are continued on the next page.



- Use a to do list. Write down things you have to do as soon as you are made aware of them. Check your list frequently and cross out things that have been completed.
- Use a calendar or diary. Make an effort to write things down straight away. Put regular things in too, such as work, social groups, family visits etc. Check your diary regularly.
- Set alarms as reminders. Use alarms on clocks, mobile phones, computers or watches to remind you to do things.
- Ask for help. Ask a friend, family member or support worker to help you to write lists or instructions then use them and keep them for future reference.



KAREN'S PLANNING STORY

Long before any diagnosis of Asperger syndrome, my family found out that lists helped me remember to do things, so there were lists for everything.

Notes from Mum about what she is doing in the day, such as when she goes shopping without me.

Cooking, chores for the day, to do list, phone numbers,

Timetables listing when I have to be somewhere, worked out the night before.

(and the list could go on).

Lists are good if they help you organise your life. I love lists and they really help me. They may help you.

[Karen Thompson]



What is a friend?

A friend is someone whose company you enjoy, who makes you laugh, who you can trust, who won't deliberately hurt you, who won't judge you and is there to listen and to support you.

It can sometimes be difficult to find, form and sustain friendships, especially if you have an ASD.

Forming new friendships often becomes more difficult as we get older.



You do not have to try to form new friendships if you do not want to. However if you would like to here are some ideas that may help you:

Finding friends:

- Friendships are often based on commonalities; friends usually have something in common

You may find friendships with people who have had common experiences such as:

- People you went to school with
- Work colleagues
- Autism support groups

Friendships can also be formed between people who have common interests. Joining activities or groups that relate to your interests will help you to meet people. Some ideas are:

- Chess clubs
- Book clubs
- Sporting activities
- Online gaming
- Blog



Some people form friendships through common beliefs. Some places where these friendships are formed are:

- Political groups
- Charity work
- Campaigning groups
- Religious activities

Common goals may also help friendships to develop, some activities where people with common goals meet are:

- Professional groups
- College courses
- Writers clubs
- Work



IAN'S FRIENDSHIP STORY

Following up the links to the activities of the local NAS groups has proved to be of enormous benefit. At the first local "drop-in" session that I went to, they heard my story and immediately volunteered me (in the nicest possible way!) for a Q and A session with the support group for parents of ASD children. This group have wanted me to continue coming to their meetings – and as a result I have made many good friends there. Similarly, continuing at the drop-in has also led to good friendships, as well as the support of a very understanding counsellor; I have also had good support from our sympathetic vicar.

[Ian Walker]



Friendships require work for anybody. Friendships involve both giving and taking. Some tips that might help to start and maintain friendships are:

- Use social networking sites to begin with if you are not confident about meeting people in person
- Join groups or activities around things you enjoy, this will help you to meet people with common interests, experiences or goals.
- Take turns in talking about your interests; be careful not to talk about things that interest you and not the other person all the time.
- Show an interest in what your friend is doing or experiencing, ask how their week has been, what they have been doing since you last saw them, what their other interests are.
- When others are talking, show you are listening by nodding, looking at them, not fidgeting and asking questions about what they have said.
- Keep in touch. This means texting, ringing or emailing. Be careful not to overdo it or to neglect it.
- Join a social group for people with an ASD, other people in the group will understand and these groups are often supported by a professional
- You may want to tell people about your ASD, this may help others to understand you but is your choice.





Family and friends

Having a diagnosis of an ASD can help your family, friends and partner to understand you and to help.

However, they may feel upset about you receiving a diagnosis or may worry about what it means. They may need time to come to terms with it just as you do.

Many people do not understand what an ASD is, or may have an incorrect understanding they have developed from watching TV or reading the media.



Some things that can help:

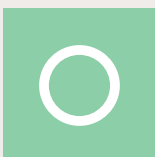
- Give family, friends and partners information about ASD
- Ask any professionals you are involved with to explain things to your partner
- Seek to introduce them to family / friends / partners of other people with an ASD
- Be clear about what you would like them to do.
- Talk to them, tell them what you know about your condition and how they might help you.
- You may want to tell people about your ASD, this may help others to understand you but is your choice.



IAN'S FAMILY AND FRIENDS STORY

The realisation that there is an underlying neurological reason has been an enormous relief for my wife, Judy. The realisation that marriage of an Aspie and a neurotypical will encounter considerable difficulties has been of great help in enabling us to work at tackling the problems.

[Ian Walker]



KAREN'S FAMILY AND FRIENDS STORY

Having the diagnosis changed relationships with family, especially with my Mum and continues to do so every day. We still have misunderstandings from time to time and we are still learning about how each other sees the world, in these things we are no different from a lot of other people.

I see the world quite differently than my Mum does and this is alright, but life is a lot, lot better knowing that I have Asperger syndrome because we now know the truth and life can move along as we learn together.

[Karen Thompson]





The Partner's Guide to Asperger Syndrome
Susan J. Moreno, Marci Wheeler and
Kealah Parkinson

Jessica Kingsley Publishers

Social Skills for Teenagers and Adults with
Asperger Syndrome: A practical Guide to Day to
Day Life

Nancy Patrick

Jessica Kingsley Publishers

Connecting With Your Asperger Partner
Negotiating
the Maze of Intimacy

Louise Weston

Jessica Kingsley Publishers

22 Things a Woman Must Know If She Loves a Man
with Asperger Syndrome

Rudy Simone

Jessica Kingsley Publishers

The Asperger Couple's Workbook — Practical
Advice and Activities for Couples and Counsellors

Maxine Aston

Jessica Kingsley Publishers

Making Sense of Sex — A Forthright Guide to
Puberty, Sex and Relationships for People with
Asperger Syndrome

Sarah Attwood — Illustrated by Jonathon Powell

Jessica Kingsley Publishers

Trouble Shooting Relationships on the
Autism Spectrum

Ashley Stanford

Jessica Kingsley Publishers

What Men with Asperger Syndrome Want to Know
About Women, Dating and Relationships

Maxine Aston

Jessica Kingsley Publishers





Shopping

Some people find shopping a difficult activity to embark on because of the busy environments and the planning required.



If you find this difficulty or anxiety provoking, try some of these tips to see if they help you:

- Shop online, this means that you can avoid busy supermarkets
- Use the same supermarket; you will be more familiar with the layout.
- Visit the supermarket when you do not need shopping. Take time to familiarise yourself with the shop and where items are kept without the added pressure of having to make purchases.
- Use smaller local shops that are less confusing; but beware! these are often more expensive.
- Visit the supermarket at quieter times so they are less busy. Quieter times of day are usually mornings or later in the evening, and supermarkets tend to be less busy Monday – Thursday than Friday – Monday.
- Make a list before you leave. Write down all the items you need and take the list and a pen with you. Cross items off the list as you add them to your trolley.
- Check you have money before you leave the house. If you want more assurance about this ask someone to help you estimate the costs or check costs online before you go.
- Sensory issues may cause difficulties Wearing sunglasses can help with the fluorescent lighting in the supermarket, ear plugs or MP3 players can help to filter the noise.
- Ask for help. If you are having difficulty finding something or with your shopping, ask a staff member to help. Visit the customer service desk, many large supermarkets have staff that can help you with your shopping.





Employment

Finding and maintaining employment can at times be difficult for people with an ASD.

Many people with an ASD have skills, knowledge and personal attributes that make them excellent employees. Many have areas of strength that people without an ASD do not have.

Steps to employment

Work experience, training, knowledge, expertise and qualifications are all factors that employers take into consideration when choosing employees.

If you have never had employment or have been out of employment for a while volunteering or work experience placements will help you to gain work experience and help with future employability. Training courses and study may also help to secure employment.

Looking for work

It is important to choose a job that suits you. Consider your strengths along with your interests when applying for a position. Most jobs are accompanied by a person specification and job description when they are advertised. Read these and consider whether you meet the personal attributes that the employer is seeking.

Supported employment: supported employment agencies can help you to find and sustain employment

Jobcentres: all jobcentres have disability employment advisors who may be able to support and advise you. Job centres also hold details of job vacancies, and are able to advise on work related benefits.

Websites: there are many websites that advertise job vacancies. On many sites you can upload your CV or specify the type of work you are looking for.

Employment agencies: joining an employment agency may help you to find work in a specific area.

Newspapers: newspapers often have a 'jobs section' which advertise jobs on certain days of the week.

Applying for work



- Seek support, agencies such as Careers Wales or Jobcentre often offer support with job applications or CV writing.
- Look online. Examples of CVs and templates can be easily accessed via the internet.
- Visit the library. There are a myriad of books to help with CV writing, job applications and interview techniques available.

Job Interviews

You may decide to inform your potential employer about your ASD. If you do you can ask for reasonable adjustments to your interview, such as requesting that interview questions do not include complex language.

Sustaining employment

Your employer has a legal duty to make reasonable adjustments to your workplace in order for you to maintain your employment.



- If you are struggling with any aspect of your work, speak to your line manager or HR department about this.
- Advise your line manager or HR department of what would help. You may prefer it if your line manager allocated your tasks in writing rather than verbally, or make like to change desks to sit in a quieter area of the office. These are reasonable adjustments that your employer can make.
- Organise your work. Use planners, diaries and lists to help you to manage your workload. Colour code tasks according to priority to help you to meet deadlines.
- Talk to your manager about workload sharing with a colleague. There may be aspects of your role that you struggle with that a colleague may excel at and vice versa.

Social Rules in the Workplace

There are a range of social rules that neurotypical people follow and expect others to follow in the workplace.



- Undertaking social skills training, or learning about social skills from others or from publications can help you in the work place.





IAN'S EMPLOYMENT STORY

When I was applying for jobs, in the early 60s, the job market was very different to its present state; all the same, I think I was very fortunate to get a job as a college maths lecturer, first on the outskirts of London for three years, and since then in Gwent. I have also been privileged to work with many very supportive and encouraging colleagues, and (mostly!) responsive students, especially in recent years. I have also been fortunate that almost none of my meltdowns while at work have occurred in the publicity of the lecture room, and the rest I have tried to keep from my colleagues as far as possible.

[Ian Walker]



The Complete Guide to Getting a Job for People with Asperger's Syndrome: Find the Right Career and Get Hired

Barbara Bissonette

Jessica Kingsley Publishers

Asperger's Syndrome Workplace Survival Guide: A Neurotypical's Secrets for Success, on how to succeed in the workplace

Barbara Bissonette

Jessica Kingsley Publishers

Asperger's on the Job: Must-have Advice for People with Asperger's or High Functioning Autism and Their Coworkers, Educators, and Advocates

Temple Grandin, Rudy Simone

Future Horizons Inc

22 Things a Woman Must Know If She Loves a Man with Asperger Syndrome

Rudy Simone

Jessica Kingsley Publishers

Asperger Syndrome Employment Workbook

Tony Attwood, Roger N Meye

Jessica Kingsley Publishers



Anxiety

You may find that you experience anxiety; anxiety is more common in people with an ASD.

Anxiety is the feeling you get when you are worrying about something and can be referred to as worried, nervous, and anxious. Sometimes people refer to anxiety as 'bad nerves'. Anxiety can be acute or chronic. Acute anxiety is short lived and usually can be explained by something such as having to attend an appointment you are worried about or having to do something you are not used to. Chronic anxiety is longer lasting, and the cause cannot always be explained.

If you are experiencing long term or severe anxiety you should visit your doctor to ask for help.

Symptoms of anxiety

Anxiety causes physical symptoms in your body which can sometimes be frightening and will make you feel uncomfortable.

The symptoms include:

- clenching hands
- fidgeting
- tense muscles, especially neck and shoulders
- sweating
- shaking
- pale skin
- feeling clammy
- increased heart rate
- increased breathing rate
- stomach churning
- needing to go to the toilet
- feeling nauseous

Anxiety can be distressing and many people start to avoid activities that make them anxious in order to avoid the anxiety. This is not the best approach to take and this can often make people more anxious in the longer term.

Rather than avoiding activities that make you anxious, it is better to try and manage the anxiety.



You can select some of these tips that may help:

- Plan and organise. Use a calendar or diary to record events that are happening so that you have time to prepare for them
- Practise. Role-play interactions with friends or family so that you feel more comfortable in problem situations.
- Distract yourself: read a book or make something. Distracting yourself by doing something you enjoy can be very relaxing.
- Eat well; a good diet will help physical and psychological health.
- Drink plenty of water. Caffeine (found in tea, coffee and cola), nicotine and alcohol can make anxiety worse.
- Sleep. Everybody needs to sleep for body and mind to recuperate, make sure you are getting enough sleep.
- Relax. Relaxation exercises can help with the symptoms of anxiety or you could try another relaxing activity such as reading a book or taking a bath.
- Exercise. Regular exercise can help to prevent anxiety, and can reduce the symptoms when they occur. Even a walk or doing some gardening can help.
- Increase your self esteem (feeling positive about yourself). People with low self esteem are more likely to experience anxiety. Write down all the things you are good at, the things you have achieved, the things people like about you and look at this list often to remind yourself how great you are!



- Talk. Talking about your worries can help. If you find it difficult to talk about it, write things down and ask a friend or family member to look through them for you.
- Seek help. There are therapies and interventions that may help with anxiety, seek the advice of a professional to embark on these.



IAN'S ANXIETY STORY

For many years, ornithology has been one of my main interests. Contrary to popular belief, no great skill is needed to enjoy this activity – the enjoyment of what you see and hear is the key factor. It is an activity that has some positive spin-offs: it is best done on foot – the combination of fresh air and exercise can be very therapeutic; it can be done anywhere – even town centres, rubbish tips and supermarkets are bird habitats, sometimes with quite unexpected results (for instance, the seven Waxwings that spent some days at the entrance to a Newport supermarket, feeding on the berries on the bushes on the roundabout). I have also found that simply watching garden visitors (enticed, of course, with feeders filled with suitable goodies!) has proved to be a great source of enjoyment and relaxation. I have, too, made many good friends through the Gwent Ornithological Society, in which I have been active for many years.

[Ian Walker]



ALEX'S ANXIETY STORY

I get anxiety. When I make some kind of mistake, I'll usually get really worried about what people will think and worry they think I look stupid.

[Alex Lowery]



Basic Pathfinder Mind/Body Techniques for Asperger Syndrome

Ron Rubio

Jessica Kingsley Publishers

Emotional Mastery for Adults with Asperger's – Practical Techniques to Work Through Anger, Anxiety and Depression

Leslie Burby, Mark Blakey

Create Space Independent Publishing

Asperger Syndrome and Anxiety: A Guide to Successful Stress Management

Nick Dubin

Jessica Kingsley Publishers (12 Mar 2009)

ISBN-10: 184310895X

Exposure Anxiety – Invisible cage

Donna Williams

Jessica Kingsley Publishers (20 Nov 2008)

ISBN-10: 1843100517





Depression

Being isolated, not talking about how you are feeling and feeling stressed are all factors that can contribute to depression. Therefore, those with an ASD are at risk of experiencing depression.

People experiencing depression experience many of the following symptoms:

- Tearfulness
- Feeling sad
- Negative thoughts
- Difficulty concentrating
- Lack of motivation
- Changes in appetite
- Sleep problems

Depression is a medical condition, and treatment for depression may involve counselling, cognitive behavioural therapy or medication.



- If you think you may be experiencing depression you should visit your GP. Your GP will be able to offer treatment or refer you to another clinician who can.





Some things that may also help:

- Eat regularly
- Eat a healthy diet, avoid alcohol and caffeine
- Take some exercise, even a short walk can help you to feel better
- Try and get some sleep, undertake relaxing activities prior to bed
- Try and undertake some activities, plan to do at least 2 things a day
- Get out, visit friends and family if possible



KAREN'S DEPRESSION STORY

I have found paper craft e.g. making gifts from paper, making greeting cards – birthday cards, a good way of distracting myself and recovering from stressful days.

It is an ongoing hobby/pastime, which I really enjoy and provides me with a way to interact with family, friends and acquaintances.

I also write poetry and have one ring folder full. This helps me to understand my world and how I see things personally but I also find it useful just to clear my mind of worry and stress.

[Karen Thompson]



**Emotional Mastery for Adults with Asperger's
– Practical Techniques to Work Through Anger,
Anxiety and Depression**
Leslie Burby, Mark Blakey
Create Space Independent Publishing



Anger Problems

Anger is an emotion that every person experiences. Feeling angry sometimes leads to aggression.

Physical signs of anger

- Tense muscles
- Facial grimacing
- Increased heart rate
- Increased breathing rate
- Feeling hot
- Red colouration to skin
- Clenched fists
- Sweating

Aggressive behaviours

- Shouting
- Swearing
- Hitting
- Kicking
- Saying horrible things to others
- Slamming / banging doors and objects

Professionals often refer to 'managing anger' or 'anger management'. This means avoiding behaving in an aggressive way when you feel angry.

There are many negative consequences of aggressive behaviour, including becoming involved with the criminal justice system, hurting others and damaging property. Even verbal aggression can have consequences such as causing you to lose your job or making other people avoid you.



If you have difficulty controlling your anger there are some things that may help:

- Seek professional help: counselling or therapeutic interventions can help you to control your anger
- Recognise the triggers, try to recognise what makes you angry so that you can be prepared
- Recognise when you are starting to feel angry, use the list of physical signs to identify anger before it escalates
- Walk away from situations that cause you distress
- Take some time, count to 10 or practice some deep breathing
- Distract yourself – tidy up, go for a walk or listen to music.
- Try to remember that often neurotypical people aren't trying to confuse you on purpose



**Emotional Mastery for Adults with Asperger's
– Practical Techniques to Work Through Anger,
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Leslie Burby, Mark Blakey
Create Space Independent Publishing





Useful websites

ASD Info Wales

This website is specific to Wales and includes information and advice for families and professionals about ASD. The site also includes a search facility which allows you to look for specific services available in your local area.

Website www.asdinfowales.co.uk

Autism Connect

An online resource providing information about autism, news and events from around the world and access to discussion forums and other web sites about autism.

Website www.autismconnect.org

Autism Cymru

Welsh national charity which aims to influence major policy change via collaborative practice, education and training, research and awareness raising.

Website www.awares.org

Email adam@autismcymru.org

Autism Networks

A charitable body run by a group of like-minded parents, carers, professionals and people with autism. One of their aims is to make links with anyone concerned with autism.

Website www.autismnetworks.org.uk

Autism UK

An active UK-based list which provides a forum for wide-ranging discussion on many issues related to autistic spectrum disorders.

Website <http://lists.autismisanotherworld.com/mailman/listinfo/autism-uk/>

Autistica

Autistica is a UK charity raising funds for medical research that will improve diagnosis, advance new treatments and discover the causes of autism.

Telephone [01491 412311](tel:01491412311)

Website www.autistica.org.uk

Email info@autistic.org.uk

Address **Autistica**
Rotherfield House
7 Fairmile
Henley-on-Thames
RG9 2JR

Autistichat

A place for people with autism and related disorders to chat online. The channel is also open to the parents, friends and family of individuals with autism.

Website www.autistichat.net

Carers Wales

Carers Wales is part of Carers UK which is a policy, campaigning and information organisation. They provide information and advice to carers about their rights and how to get support.

Telephone [02920 811575](tel:02920811575)

Website www.carerswales.org

Email info@carerswales.org

Address **Carers Wales**
River House
Ynysbridge Court
Gwaelod y Garth
Cardiff
CF15 9SS

Careers Wales

Careers Wales provides free careers information and advice for young people, adults, parents, employers and professionals in Wales. There are six Careers Wales companies covering the Welsh regions and each company has its own Chief Executive and board of directors.

The Careers Wales companies work in partnership together and with a wide range of other organisations at local and national level. The Careers Wales Association has been set up to provide the Careers Wales companies with national, centralised support facilitating joint initiatives and partner liaison.

Cardiff and Vale	0800 100 900
Gwent	0800 028 9212
Mid Glamorgan & Powys	0800 183 0283
Careers Wales Association	02920 854880
Learning and Careers Advice	0800 100 900 – from a land line 02920 906801 – from a mobile
Email	lca@careerswales.com

Crossroads Care

Crossroads Care provides support to carers and the people they care for.

Telephone [0845 450 0350](tel:08454500350)

Website www.crossroads.org.uk

Disability Alliance

Disability Alliance is a national registered charity which works to relieve the poverty and improve the living standards of disabled people. They provide information on benefits, tax credits and social care to disabled people, their families, carers and professional advisers. They also have a range of publications for download including the Disability Rights Handbook.

Website www.disabilityalliance.org

Early Support Wales

Early Support Wales offers free training for parents and have a useful free booklet on autistic spectrum disorder.

Telephone [02920 342 434](tel:02920342434)

Website www.earlysupportwales.org.uk

Address **Early Support**
c / o Children in Wales
25 Windsor Place
Cardiff
CF10 3BZ

Epilepsy Wales

Epilepsy Wales is a charity which supports people with epilepsy in Wales, their family and carers by providing help, advice and information.

Telephone [0800 228 9016](tel:08002289016) (Mon – Fri, 9am – 5pm)

Website www.epilepsy-wales.org.uk

Email weabradbury@btconnect.com

Address **Epilepsy Wales**
PO Box 4168
Cardiff
CF14 0WZ

The Family Planning Association

The Family Planning Association has information about sexual health, sex and relationships and has published three books which may be of use when talking to your child.

Website www.fpa.org.uk

Gov.uk

The UK government's digital service for people in England and Wales. It delivers information and practical advice about public services, bringing them all together in one place.

Benefits Enquiry Line [0800 882 200](tel:0800882200)

Website www.gov.uk

Email BEL-Customer-Services@dwp.gsi.gov.uk

Gwent Association of Voluntary Organisations (GAVO)

Gwent Association of Voluntary Organisations is a Community Voluntary Council which is committed to strengthening the effectiveness of the Voluntary and Community Sector across Blaenau Gwent, Caerphilly, Monmouthshire and Newport. GAVO works with individuals and community groups as well as the public and private sector.

Telephone [01633 241550](tel:01633241550)

Website www.gavowales.org.uk

Email chris.thomas@gavowales.org.uk

Address Ty Derwen
Church Road
Newport
NP19 7EJ

Interlink

Interlink is the County Voluntary Council (CVC) for Rhondda Cynon Taff, supporting individuals and organisations to work together to make a positive impact on the life of people who live and work in RCT.

Telephone [01443 846200](tel:01443846200)

Website www.interlinkrct.org.uk

Address 6 Melin Corrwg
Cardiff Road
Upper Boat
Pontypridd
CF37 5BE

Jobcentre Plus

Jobcentre Plus can help you with:

- What type of work you'd be suited to
- Schemes and resources to help you find work
- Retraining programmes
- Help if you are disabled or are a single parent
- Help with self-employment issues
- How to complete application forms and prepare for an interview
- Financial schemes / help while you look for work
- What vacancies there are at the Jobcentre Plus Jobs Centre

The following website will enable you to locate your local Jobcentre Plus.

Website www.jobcentreplusadvisor.co.uk/wales

National Autistic Society (NAS)

The NAS is a UK charity for people with autism (including Asperger Syndrome) and their families. They provide information, support and services and campaign for a better world for people with autism.

The NAS will also be able to tell you if there is an EarlyBird or EarlyBird Plus programme running in your area.

Telephone [0845 070 4004](tel:08450704004) (Mon – Fri, 10am – 4pm)

Website www.autism.org.uk

Address **NAS Cymru**
6/7 Village Way
Greenmeadow Springs Business Park
Tongwynlais
Cardiff
CF15 7NE

Rackety's

Rackety's is a clothing company for disabled children and adults.

Telephone [01538 381430](tel:01538381430)
Fax [01538 370156](tel:01538370156)
Website www.disabled-clothing.co.uk
Email info@racketys.com
Address **Rackety's Ltd**
Unit 16
Town Yard Business Park
Station Street
Leek
Staffordshire
ST13 8BF

Torfaen Voluntary Alliance (TVA)

TVA is the voluntary council for the County Borough of Torfaen and their role is to support, promote, develop and represent voluntary and community groups in the county.

Telephone [01495 756646](tel:01495756646)
Website www.torfaenvoluntaryalliance.org.uk
Fax [01495 740097](tel:01495740097)
Address Portland Buildings
Commercial Street
Pontypool
Torfaen
NP4 6JS

Turn2Us

Turn2us is a charitable service which helps people access the money available to them through welfare benefits, grants and other help.

Telephone [0808 802 2000](tel:08088022000) (*Freephone 8am – 8pm*)
Website www.turn2us.org.uk

Vale Centre for Voluntary Services (VCVS)

VCVS helps to improve the quality of life of individuals and communities by supporting voluntary groups.

Telephone [01446 741706](tel:01446741706)

Fax [01446 421442](tel:01446421442)

Website www.valecvvs.org.uk

Email vcvs@valecvvs.org.uk

Address Barry Community Enterprise Centre
Skomer Road
Barry
CF62 9DA

Cardiff Third Sector Council

Cardiff Third Sector Council (C3SC) is the County Voluntary Council which represents and promotes the voluntary sector in Cardiff.

Telephone [02920 485722](tel:02920485722)

Website www.vacardiff.org.uk

Email enquiries@vacardiff.org.uk

Address **Cardiff Third Sector Council**
Ground Floor
Brunel House
2 Fitzalan Road
Cardiff
CF24 0EB

Voluntary Action Merthyr Tydfil (VAMT)

Voluntary Action Merthyr Tydfil (VAMT) aims to support voluntary and community activity in the County Borough of Merthyr Tydfil by helping new projects, bringing groups together in forums and networks, producing regular newsletters, providing training and practical help. VAMT offers information and advice on funding, legal matters, volunteering, marketing, ICT and how your group can work effectively.

Telephone [01685 353900](tel:01685353900)

Fax [01685 353909](tel:01685353909)

Website www.vamt.net

Email enquiries@vamt.net

Address **Voluntary Action Centre**
89 – 90 High Street
Pontymorlais
Merthyr Tydfil
CF47 8UH

Wales Autism Research Centre (WARC)

The Wales Autism Research Centre (WARC) was initiated through a unique collaboration between Autism Cymru and Autistica, the School of Psychology, Cardiff University and the Welsh Government.

WARC researches risk factors, identification, diagnosis, cognitive development and intervention. Based in the School of Psychology they engage in multi-disciplinary research collaboration across a number of areas. They study and use research evidence in services for autism and contribute to awareness-raising. A unique goal, made possible by the ASD Strategy in Wales, is to integrate scientific research findings with policy.

Website www.psych.cf.ac.uk/warc

Email warc@cardiff.ac.uk

Address **Wales Autism Research Centre (WARC)**
School of Psychology
Cardiff University
Tower Building
Park Place
Cardiff
CF10 3AT
