

**Action for Carers Surrey –  
Surrey Young Carers  
INFORMATION PACK:**

*Autism*

June 2020



## Contents

1. All about Autism .....	1
2. What is it like caring for someone with Autism?.....	2
3. Hints tips and coping strategies.....	3
4. Where can I get more help? .....	7
5. Glossary.....	7

## 1. All about Autism

### What is Autism?

Autism is a lifelong disability, which affects how people communicate and interact with the world. There are approximately 700,000 Autistic adults and children in the UK. (*National Autistic Society website, May 2020*)

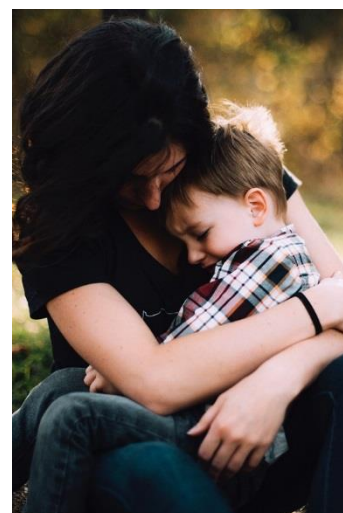
It is a spectrum condition, which means that it can affect people in different ways, and people can have different combinations of strengths and difficulties.

To gain an Autism diagnosis, you need to have difficulties in social communication e.g. late talking or difficulties expressing their feelings, not understanding facial expressions, jokes. Social interaction e.g. difficulties making friends, understanding others, showing empathy, difficulties with eye contact. Restricted and repetitive patterns of behaviours e.g. liking rules and routines, can have set, highly focused interests. These difficulties / behaviours affect everyday life.

Many people with Autism have sensory difficulties and can be over or under sensitive to sensory input. Children who love to bounce, swing, and jump love the sensory input they feel when they do these activities. Other things like cutting/brushing hair, noisy hand dryers can physically cause pain or distress; this is because their senses are very sensitive to these things.

### What causes Autism?

You cannot catch Autism; it is something that you are born with. No one knows exactly why some people have Autism and others do not. Many experts believe that it is down to a variety of genetic factors, but more research is needed to gain more understanding. There is no cure, but coping strategies and better understanding of Autism can lead to significant improvements in helping every person to fulfil their potential.



## 2. What is it like caring for someone with Autism?

There are many challenges but also many positives living and caring for someone with Autism. Not everyone experiences things the same, but have a look at the below chart and see if you recognise any of the positives or challenges in your family. **Tick the ones you can relate to:**

My brother has an amazing memory. <input type="checkbox"/>	My sibling has meltdowns. <input type="checkbox"/>
I love spending time with my sister. <input type="checkbox"/>	My brother destroys my things. <input type="checkbox"/>
My brother loves his iPad and watching YouTube. <input type="checkbox"/>	My sibling knows everything there is to know about trains/Minecraft/Disney. <input type="checkbox"/>
My sister keeps coming into my room <input type="checkbox"/>	My sibling does not like loud noises. <input type="checkbox"/>
My brother likes to know what is happening at all times. <input type="checkbox"/>	My brother is afraid of hand dryers. <input type="checkbox"/>
My sister doesn't stop talking and talks very loudly! <input type="checkbox"/>	My sibling doesn't like it when routine changes. <input type="checkbox"/>
My sibling doesn't talk yet. <input type="checkbox"/>	My brother can be unkind to me. <input type="checkbox"/>
My brother gives the best cuddles. <input type="checkbox"/>	My sibling doesn't like to be cuddled. <input type="checkbox"/>
My sister takes up a lot of my parents' time <input type="checkbox"/>	My brother has no awareness of danger. <input type="checkbox"/>
My sibling is very fussy with food. <input type="checkbox"/>	My sister loves water play. <input type="checkbox"/>
My brother hates brushing /cutting hair. <input type="checkbox"/>	My sister loves the trampoline or swing. <input type="checkbox"/>
My sibling is very literal. <input type="checkbox"/>	My brother is very talented. <input type="checkbox"/>

Below is a wonderful story written by a Surrey young carer, Honey (aged 10). Can you relate to it?

### JAM & BUTTER

Once upon a time there were 3 bears haha not really, this is a story about toast not porridge.

Let's start with the hero of this story my brother. Rocco is 8 years old, loves his iPad, Cadbury cream eggs and has an autism diagnosis.

Basically autism causes problems with Rocco's talking and communication, he finds it hard to have friends and play appropriately. Rocco finds it hard when we don't say his food in the right order.

Picture the scene:

Its a Monday morning, we are ready for school and I'm making Rocco's breakfast

Me: "Rocco what would you like for Breakfast?"

Rocco: "Honey I want Toast, Jam and Butter"

Me: "Rocco do you want toast butter and jam?"

Rocco: "no I don't like that!"

I mean I didn't know that toast jam and butter was so different to toast butter and jam.

To make sure my brother is happy with his favourite meal of the day I :

1. Lightly toast his bread as he doesn't like it too brown
2. Cut of the sides as he doesn't like the crusts
3. Spread the right amount of butter
4. Put a big blob of his chosen jam
5. Cut it into 4 equal squares
6. Serve immediately

Thinking about it I guess I'm the hero really as he still doesn't know that he's eating butter and jam not jam and butter. Its not a big fancy meal and it doesn't have a lot of ingredients but it is made with a humungous amount of love.

### 3. Hints tips and coping strategies

**Caring for a brother or sister with Autism may make you feel many different ways, and it is completely normal to feel like this.**



**Angry** – You may feel angry if your sibling breaks something of yours, or does something that is difficult to deal with. Try not to retaliate and if possible remove yourself from the situation. Remember to breathe, count to 10 slowly focusing on the breaths in and out, hearing and feeling each breath. You could do some exercise, mindfulness activities or do something you enjoy. You could create a calm space in your room/garden. Can you talk to someone once you are calm – a parent/friend/pet?



**Sad** – Remember you are not alone, you are very special and there are people around you that care and want to help. You could make a jar or book with all the things you are good at and things that make you smile. When you feel sad, take some moments to remember just how amazing you are. Talk or write down your feelings, maybe as a poem or story. Try to plan in time every day doing activities you like doing e.g. reading, arts and crafts, baking, playing sport.



**Jealous** – It can be hard seeing your sibling get more attention than you, try to remember it is because they need more help than you NOT because your parents don't want to spend as much time with you. Try to organise some special time even if it is when your sibling has gone to bed or early in the morning. Talk to your parents / teachers / friends/ Surrey Young Carers – We are all here to support you!



**Confused** – If there is something you don't understand, Please ask! There are lots of resources to help you. Your parents, teachers, Surrey Young Carers, libraries, doctors and the National Autistic Website can provide you with information about your sibling's disability as well as your caring role.



**Happy** – is a wonderful feeling, why not write down things that make you feel this way as a reminder to help you when you are experiencing other feelings? You could put quotes around your room, or somewhere that you can see them regularly.



**Proud** – You can feel proud of a sibling who has achieved something that they may have found difficult. You can also feel proud of yourself – proud of things you have achieved, proud of the patience, love and support you give to others, proud that even when things are difficult; your amazingness still shines through.

## Sample notes

Here are some examples of a note you could write to a parent / friend / someone you trust if you wanted to talk to them about feelings, worries, or any questions.

Dear .....

**I am feeling** .....

.....

Please can I talk to you about it?

From .....

Dear .....

**I don't understand**.....

.....

Please could you explain it to me?

From .....

Dear .....

**I am worried about**.....

.....

Please can I talk to you?

From .....



Here are some activities for you to try...

*Fun*  
**5 MINDFULNESS ACTIVITIES**  
*for children*  
by Big Life Journal

**1 "JUST ONE BREATH" BREATHING ACTIVITY**

- Find a relaxing place, sit comfortably, and set a timer for one minute.
- Breathe deeply in and out while paying attention to any sensations you notice or sounds you hear.
- Take another slow deep breath, imagine the air moving down into the lungs and back up.
- Take one more deep breath and hold for a moment, then release it.



**2 CREATE A GLITTER JAR**

- Finding a jar or plastic bottle and allow your child to decorate it however they like.
- Fill the bottle up 3/4 of the way with water. Next, add clear glue, food coloring, and glitter then shake.
- Seal the lid and you are ready to go.



**3 HEARTBEAT EXERCISE**

- Ask your child to stand up and either jump up and down or do jumping jacks for one minute.
- At the end of that minute, have them place their hand on their heart and pay attention to how their heartbeat and their breathing feels.



**4 GOING ON A SAFARI**

- Go outside on an exciting adventure, try picking up a small rock or touching a plant or flower.
- Notice the bugs or the birds. Take a moment to kneel down and touch the earth.
- Walk mindfully paying close attention to everything. Make sure you walk in silence because you want to notice all those little details.

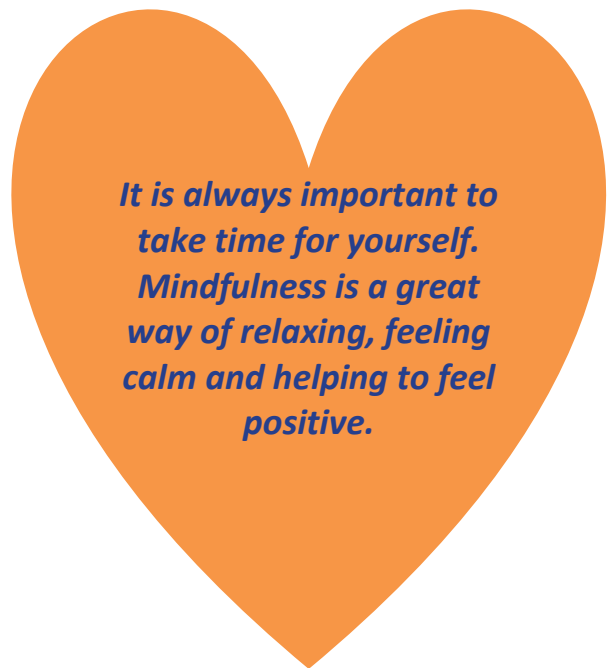


**5 TENSE AND RELEASE MUSCLE RELAXATION**

- Starting at the feet, gently squeeze the muscles in the feet by tightening them, then slowly releasing.
- Next, squeeze the large muscles in the calves for 5 seconds, then gently release. Working your way up the body, squeeze the thigh muscles for 5 seconds then gently release.
- Continue moving up the body for more relaxation.



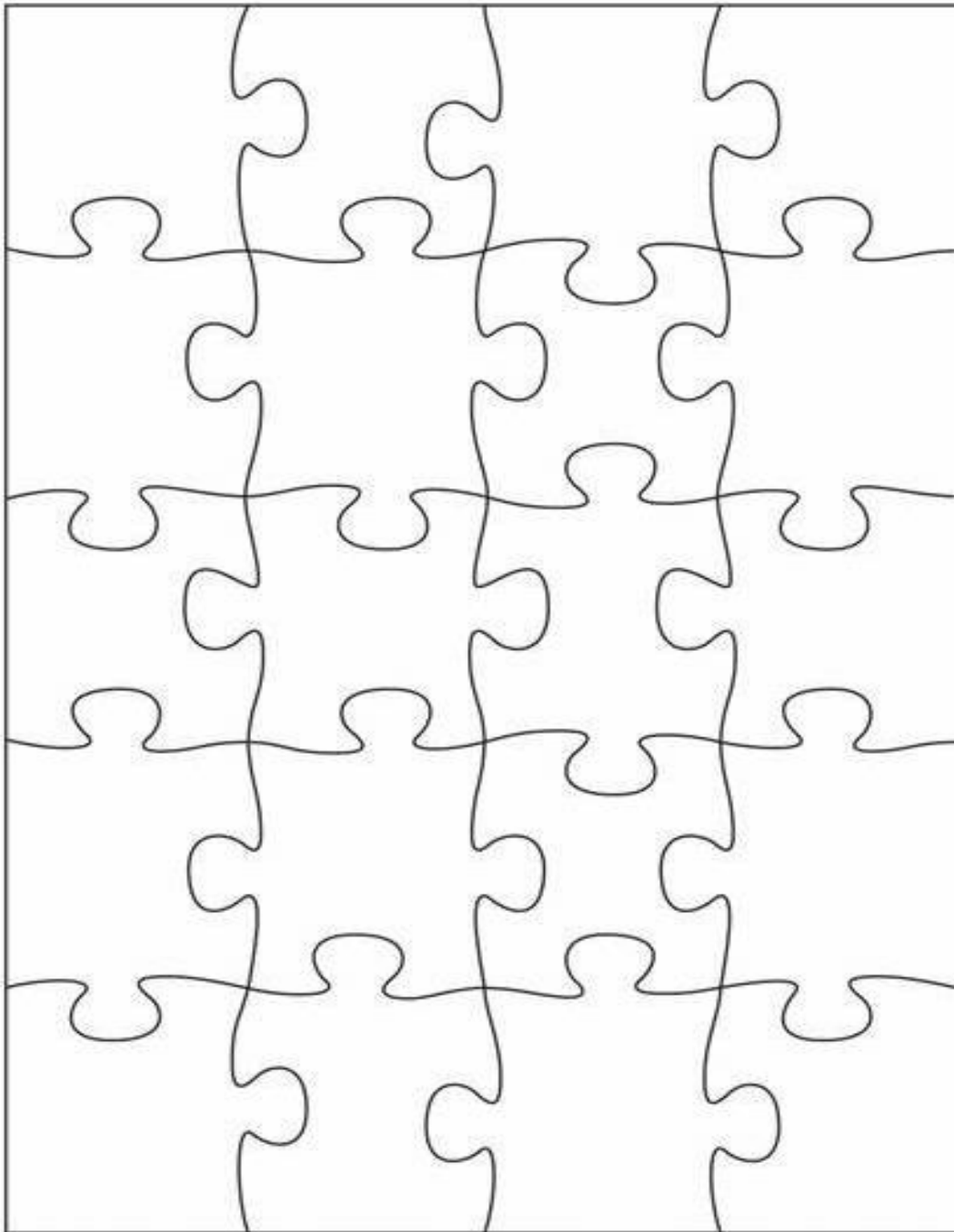
Big Life Journal - [biglifejournal.com](http://biglifejournal.com)



***Fill in the puzzle  
with things that  
are important to  
you! Colour it in!***

You can put family, friends, hobbies, things that make you smile and people that support you.

**Your puzzle will be as unique and as special as you!**



## 4. Where can I get more help?

**Surrey Young Carers** (part of Action for Carers Surrey). **We're here for you!** Call us on 01483 568269 or email [syc@actionforcarers.org.uk](mailto:syc@actionforcarers.org.uk) And read lots more on our website <https://www.actionforcarers.org.uk/who-we-help/young-carers-under-18/>

Our Education Advisors work regularly in schools in Surrey to ensure that your caring needs are supported. More here: <https://www.actionforcarers.org.uk/who-we-help/young-carers-under-18/young-carers-in-school/>

[www.actionforcarers.org.uk](http://www.actionforcarers.org.uk) – our website provides lots of information about being a young carer, different disabilities and illnesses and other support available to you and your family.

[www.autism.org.uk](http://www.autism.org.uk) – this is the national autistic society website, and gives lots of information about Autism and associated difficulties.

[www.NSPCC](http://www.NSPCC) 0800 111 111 – this helpline supports children who are in need of help and support.

[www.kooth.com](http://www.kooth.com) – an online wellbeing support network for young people.

## 5. Glossary

Here you will find some definitions of words you may have heard on your Autism caring journey.

**ADD – Attention Deficit Disorder** – a behavioural disorder that includes symptoms of inattentiveness, impulsiveness without the hyperactivity.

**ADHD – Attention Deficit Hyperactivity Disorder** - a behavioural disorder that includes symptoms of inattentiveness (concentration and focus difficulties), impulsiveness and hyperactivity.

**Aspergers** – An Autistic Spectrum Disorder, difficulties with social interaction and non-verbal communication. Generally have average or above average intelligence, have fewer difficulties with speech but may still have difficulties understanding and processing language. (Not officially used anymore but you may still hear it.)

**Meltdowns** – a complete loss of control and being totally overwhelmed.

**Occupational Therapist** – A professional that helps promote independence and functional ability to reach their potential, including supporting sensory and physical difficulties.

**PDA** – Pathological Demand Avoidance is a profile where people avoid everyday demands and expectations to an extreme extent usually driven by huge amounts of anxiety.

**Sensory Processing Disorder** – All activities in life involve processing sensory stimuli. Having difficulty processing stimuli can impact their ability to perform everyday activities. The seven main senses are: **Tactile** (touch); **Taste**; **Smell**; **Visual** (sight); **Auditory** (hearing); **Vestibular** (balance and movement); and **Proprioception** (body awareness).

**Speech & Language Therapist** – A professional that helps a person with their speaking and communicating.

**Stimming** – also called self-stimulatory behaviour, is usually harmless and used to calm or regulate the senses. Common stimming behaviours include rocking, jumping, flapping, spinning, flicking etc.

**Surrey Young Carers, part of Action for Carers Surrey**  
Call on **01483 568269** or email [syc@actionforcarers.org.uk](mailto:syc@actionforcarers.org.uk)  
[www.actionforcarers.org.uk](http://www.actionforcarers.org.uk)



**Action for Carers (Surrey)** Registered Office: Astolat, Coniers Way, Guildford GU4 7HL. A Company Limited by Guarantee. Company Number 5939327. Registered in England & Wales with Charitable Status. Charity Registration Number 1116714. ©Action for Carers Surrey. ACS0094\_06.20.