

Norfolk & Waveney Autism and ADHD Support Service November 2023 Newsletter

Welcome to our November 2023 newsletter. This month we are talking about SIBLINGS.

We speak to many parents and carers of children and young people with a diagnosis or who are waiting to be assessed for autism and/or ADHD. What has become clear is that for many of you, worry about the child with the additional needs comes hand in hand with many concerns and self-recrimination about any other children in the family. Trying to support your child or young person with neurodiversity very often takes up so much of your time, so much of your energy that you then worry about how much this is impacting on their siblings. Try to be kind to yourself. You are working hard at meeting the needs of everyone in the family. This month we are offering some ideas around supporting siblings. But remember, this is not a checklist, you do not have to tick every box!

#### This month's newsletter looks at:

- Supporting siblings
- Help and support for young carers
- Home alone!
- News from other services
  - SENDIASS clinics
  - NEW Autism Central programme
- Upcoming courses, workshops and support groups
- Family Action FamilyLine
- About our Service contact details

Just as every child is unique, every family's situation is different. We in the Norfolk and Waveney Autism/ADHD Support Service speak to many families with children of differing needs. Some of the information contained in this newsletter is anecdotal and some from respected websites. We hope you find the following interesting and helpful.

### **Supporting Siblings**



Around 2.3 million children in the UK have a brother or sister with a disability. Having a sibling with a disability can be a positive thing. They are more likely to develop strength, resilience and empathy for others as a result of living with and helping to care for their sister or brother. They are likely to be less judgemental in later life when they meet other people who look or behave a little differently. As parents, it is important to remind yourself of these positive outcomes.

But growing up with a sibling with autism and ADHD can be very confusing. Life may not feel very fair and children feel unfairness very keenly. Boundaries and rules can appear inconsistent. They may feel that their autistic brother or sister gets more attention, or doesn't get told off quite as much. They may firmly believe that they could go out and do more fun things as a family if it wasn't for the extra difficulties of their sibling with ADHD. It may appear that there isn't any time left for parents/carers to help with *their* homework or support them at *their* activities. They may be placed in stressful situations at school, where they feel pressure to advocate for their brother or sister, without having the full knowledge or skills to do so. They may feel unable to invite a friend back to the house . And they may not even fully understand what autism or ADHD means for their sibling, and need additional support with this.



All of the above can lead to a lot of emotional challenges for siblings. What might be going through their heads?

I hate you sometimes, but I love you most of the time. I resent you at times, but I then feel guilty about feeling this way. I feel embarrassed in school at times because of some of your behaviour, but I will fight anyone who says something mean about you. Maybe I should copy some of your behaviour and get my share of the attention. You cause so many problems for mum and dad that I need to be the perfect child.

This is a lot of emotional turmoil for a child or young person to handle, so, how can we support those siblings who are finding life a bit of a rollercoaster?

- Allow siblings to talk openly even if they express negative feelings. They are entitled to their feelings and need an outlet for these even if some of the things they say are difficult to hear.
- Think about whether it may be easier for them to express some of this to a grandparent, aunt, uncle or a family friend, or your GP may be able to recommend a suitable counsellor. They may not be able to be entirely honest with you due to worries about hurting your feelings.
- Give them as much information as you can about their sibling's additional needs, in language they can understand.
- Make sure that school knows some of the pressures they are dealing with at home so that
  they can make allowances but also so that they can provide opportunities for talking. More
  about this below.
- We know it is hard, but try to find some one to one time each week for a sibling even if it is just a short time.
- Make a point of attending siblings' important events such as sports days or school plays, even if you have to arrange child care for your disabled child.
- Try to find activities which the whole family can enjoy together.
- Think about how you praise your neurodiverse child for effort and not just achievement and make sure you are looking for opportunities to praise his or her siblings in the same way.

- Make sure that they get some respite and get involved in their own activities away from the home.
- Look into Young Carers support groups in your area. Some siblings find it helpful to meet other young carers to share difficult emotions in a supportive environment. They do not have to be actively caring in order to be classed as a young carer.
- Help your child with autism/ADHD to understand that the other children in the family have needs also. Social stories amongst other things can make this more accessible to your child.
- Because a sibling of a neurodiverse child can be considered a young carer, they are entitled to a carers assessment.

#### **Young Carers Assessments**

All young carers have the right to have a young carers' needs assessment. The Children and Families Act (2014) gives young carers (and parent carers of a disabled child under 18) the right to a carers assessment and the right to have their needs met where shown by an assessment.

It doesn't matter who you care for or the quantity and kind of care you provide. If caring is an having an impact on your health, education, friendships or social life, you should request an assessment. An assessment allows you to talk about the care that you are offering and how it is affecting you to identify the support that your family needs going forward.

Young carers, parents, carers and professionals can request a young carers needs assessment from Norfolk County Council by calling 0344 800 8020.

#### **Young Carers and School**

Remember to tell the school if your child has an autistic sibling, or a sibling with ADHD. Your child may be late for school if their autistic brother or sister is struggling with the morning routine. They may be tired at school becase their sibling doesn't sleep much, or disturbs their night's sleep. They may struggle with homework if they don't have a quiet space at home. They may become withdrawn or anxious at school if their sibling has meltdowns at home.

The school will need to know about your child's circumstances so that they can put in place support, and ensure that your child doesn't get into trouble for things that are beyond their control. A pupil should never be expected to care for or take responsibility for their sibling whilst at school.

#### **Useful Links**

#### General

https://senmagazine.co.uk/autism/15883/siblings-and-special-educational-needs/

https://blog.thesenexpert.co.uk/?p=125

https://siblingsupport.org/don-meyer/

#### **Explaining Neurodiversity**

https://www.socialworkerstoolbox.com/autism-sibling-colorful-workbook/

**Amazing Things Happen Video** 

What is ADHD Video

#### Guidance

https://www.autism.org.uk/advice-and-guidance/topics/family-life-and-relationships/family-life/siblings

https://contact.org.uk/help-for-families/information-advice-services/your-child-your-family/family-life/supporting-siblings/

#### Carers Assessments and the Law

https://carers.org/carers-and-the-law/the-children-and-families-act-2014

https://www.norfolk.gov.uk/care-support-and-health/get-help-with-looking-after-someone/young-carers

https://www.carersuk.org/help-and-advice/practical-support/support-for-young-carers/

https://www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/being-a-young-carer-your-rights/

# Ambitious About Autism - Tips for Siblings

#### Click to open full image





# Tips for brothers and sisters

- 1 Be proud of your brother or sister. There's no reason not to be open when you're talking to your friends about autism. If you are embarrassed by your brother or sister, your friends will sense this. It will make it awkward for them and could make it harder for you.
- Love your brother or sister for who they are. You would want them to do the same for you. Try to highlight what your sibling is good at; we all want to be recognised for our strengths.
- 3 Even though you love your brother or sister, sometimes you may feel as though you do not like them.That's okay all brothers and sisters feel like that at times.
- If you're finding it too much, make sure you tell someone. Don't bottle up your feelings. If you feel you can't talk to your parents about it, try finding someone else who will listen. There are other people you can talk to who care about you, like your teacher or other family members.

- Remember your parents may be struggling too. Try not to take it out on them. Everyone finds it difficult and everyone is trying to do their best.
- 6 You are not alone!Almost everyone has something to face in their families. Ask your friends they'll all have a story to tell. And lots of families have children with autism.
- Do things together as a family but also spend some time with your family members without your brother or sister. You need to feel important too. Speak to your family if you feel left out. They'll understand. They probably won't realise until you mention it.
- It's okay for you to want time alone.

  Having a brother or sister with autism can be tiring and frustrating. Sometimes it helps just to have a bit of space.
- Find something that you and your brother or sister enjoy doing together. You will find it rewarding to connect with them, even if it's just a simple thing like doing a jigsaw puzzle. What's boring to you might be really exciting to your brother or sister. So, just join in. They'll be so happy they can share that with you.



## Help and Support for Young Carers



#### Carers Matter Norfolk is the main service for young carers in Norfolk:

https://www.youngcarersmatternorfolk.org/

Carers Matter Norfolk provide access to a Young Carers Support App to download which gives young carers in Norfolk information and advice, self-help resources, wellbeing tips and activities, plus a catalogue of support services – all in one place.

You can get the app here:

Apple App Store - https://apps.apple.com/gb/app/young-carers-support-app/id1556955591

Google Play -

https://play.google.com/store/apps/details?id=com.expertselfcare.youngcarers&hl=en GB&gl=US&p li=1

They also offer a **parent carer** service for parents who are giving support or care to a child or young person above what would normally be expected as a parent. For example, where a child has additional needs, disabilities, long term illness, mental health or substance misuse problems.

https://www.youngcarersmatternorfolk.org/parent-carers

#### Just One Norfolk:

https://www.justonenorfolk.nhs.uk/child-development-additional-needs/supporting-development/young-carers/

#### **Norfolk County Council:**

https://www.norfolk.gov.uk/care-support-and-health/get-help-with-looking-after-someone/young-carers

**Childline - Young Carers support:** 

https://www.childline.org.uk/info-advice/home-families/family-relationships/young-carers

West Norfolk Young Carers run young carers groups in King's Lynn:

https://www.westnorfolkcarers.org.uk/ourservices

Benjamin Foundation Boom Project run carers groups in Taverham, Watton, Lakenham and North Walsham:

https://benjaminfoundation.co.uk/service/boom-young-carers/

**Holt Youth Project offer young carers support in North Norfolk:** 

https://www.holtyouthproject.org.uk/our-groups/

MTM Youth Services cover South Norfolk and Breckland:

https://mtmyouthservices.jimdo.com/young-carers/

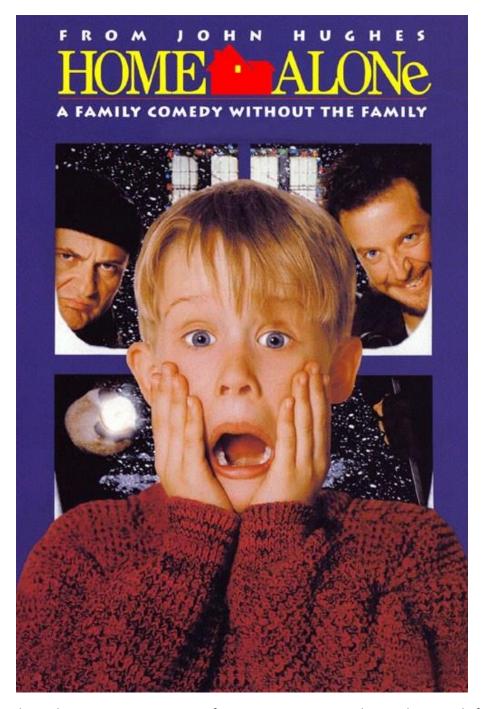
**Great Yarmouth & Gorleston Young Carers:** 

https://gygyc.co.uk/

Sibs - the only UK charity for children and adults who are growing up with or have grown up with a disabled brother or sister:

https://www.sibs.org.uk/youngsibs/info-and-advice/

#### Home Alone!



Becoming independent is an important part of growing up. Parents and carers have work, family and other commitments that mean that you may have to leave your child home alone at some point.

Where a child has additional or complex needs, it may not be appropriate to leave them home alone, or even with a sibling - adult supervision may always be required.

Every child is different and develops independence at their own pace, so it's important to create a plan and check in with your child to make sure they feel safe and are comfortable with being left home alone. So how do you know what's best for your own family?

The NSPCC have produced guidance for parents and carers to help them consider what's best for their child before leaving them alone at home.

In summary, the guidance advises that:

- You should never leave a child alone if they don't feel ready or you don't feel they are ready.
- Infants and young children aged 0-3 years old should never be left alone not even for 15 minutes.
- Generally, children under 12 years old should not be left home alone, particularly for longer periods of time.
  - Children in primary school aged 6-12 are too young to walk home from school alone, babysit or cook for themselves, or to be left alone without adult supervision. If they need to be left home alone, they will need supervision. For example, staying at a friend's house, with family or childcare.
- Secondary school age children (over the age of 12) should be consulted and involved to see how they feel about being left home alone. Just because your child is older doesn't automatically mean that they are ready or can cope with it.
- It's important to have plans and ground rules to help them stay safe at home include contact details of adults and services they can contact in case of emergency. Test these plans out with trial runs.

If your child has additional or complex needs, consider carefully whether it is appropriate to leave your child or young person alone at all. For example, consider what might happen if your child has a meltdown or shutdown, or lashes out at a sibling, with noone around to help.

The NSPCC gives some specific guidance about leaving a child with a sibling. Some considerations include:

- Do your siblings fight when you are not there?
- Don't leave an older child in charge if they are not comfortable with the situation.
- Agree rules and have an emergency or safety plan in place, include a list of emergency contact numbers.
- Carry out a trial run when you are still close by.
- Plan activities for your children to do whilst you are out.

This is just a summary of the main points - you can read the full guidance on the link below:

https://www.nspcc.org.uk/keeping-children-safe/in-the-home/home-alone/

You can take the NSPCC HOME ALONE QUIZ to get tailored advice on your own circumstances.

#### News from Other Services





A parent has recently told us about **City College and Pheonix Purple**, 'Specifically designed to support students with Autistic Spectrum Disorders into College'.

She told us what a transformation she had seen in her young person following years of struggles in mainstream education.

"XX completed the TITAN travel training over the summer and from not really wanting to leave the house much, is now happily travelling backwards and forwards on the bus to college. There are opportunities to try new subjects without the curriculum pressures. I really cannot recommend TITAN or City College more highly. Hopefully you might be able to use this information to reassure any parents/teens who might be currently struggling with GCSEs or are concerned about post 16 transitions".

We love to share examples of good practice with parents and carers so get in touch if you want to give a shout out!!!





SENDIASS SCOOP NEWSLETTER HAD INFORMATION WE WANTED TO SHARE WITH YOU ABOUT.....

#### **SENDIASS ADVICE CLINICS**

Book an hour face to face appointment with one of our SEND Advisors to discuss or review paperwork related to special educational needs in education.

The advice clinic appointments are strictly to review or discuss paperwork so please make sure to bring this with you.

For example, we can support with:

- EHC Needs Assessment paperwork
- SENDIST (First Tier Tribunal) paperwork
- Draft Education Health and Care Plan (EHCP)

**Monday 13th November - Swaffham** 

#### **BOOK NOW**



New Autism Central programme for families and carers

Autism Central is a new programme (commissioned by NHS England) aimed at helping families and carers to learn more about autism and the support available to them by signposting to useful resources and learning.

Each region has a support hub - the support hub for the East of England is based at Essex County Council.

These hubs offer guidance to families, carers and personal assistants of autistic people, including one-to-one sessions to help you find the information and support available in your area. Hubs also run group events such as workshops, drop-in sessions, coffee mornings or virtual meet-ups.

To see what support, workshops, drop-ins and meet-ups are available in the East of England region, please click on the link below.

https://www.autismcentral.org.uk/





Drop-in support groups - Come along and meet other parents/carers and share concerns...and successes.

Our Drop-In Groups are friendly and informal. No need to book. Just come along for a tea/coffee, meet other parents and members of our team.

**KING'S LYNN** 

DOBBIES, next to TESCO HARDWICK, KING'S LYNN PE30 4WQ

Come along and join us on **Tuesday 7th November -** 9.30 am - 11.00 am, FIND US IN THE COMFY, SOFA AREA.

RING 01603 972589 or EMAIL Swaffham@family-action.org.uk for more information.

#### **SWAFFHAM**

#### **UPSTAIRS IN COSTA COFFEE, MARKET PLACE, SWAFFHAM, PE37 7AB**

Come along and join us in the quiet, upstairs room in Costa Coffee on **Wednesday 8th November -** 9:30am - 11:00am.

RING 01603 972589 or EMAIL Swaffham@family-action.org.uk for more information.

#### **GORLESTON**

#### GORLESTON LIBRARY, FAMILY ACTION OFFICE, GORLESTON-ON-SEA, NR31 6SG

Come along and meet our team and other parents on **Wednesday 1st November** from 10:00am to 11:30am

RING **01493 650220** or EMAIL gorleston@family-action.org.uk for more information.

#### **LOWESTOFT**

#### AT THE RIVERSIDE FAMILY HUB, 6 CANNING ROAD, LOWESTOFT, NR33 0TQ

Come along and join us at this new venue on Thursday 2nd November from 10:00am to 11:30am

#### NOTE THIS HAS NOW BEEN CANCELLED DUE TO WEATHER WARNING

RING **01493 650220** or EMAIL <u>gorleston@family-action.org.uk</u> for more information.

# AND FOR THOSE IN THE WEST OF THE COUNTY, YOU WILL FIND FULL DETAILS IN OUR DECEMBER NEWSLETTER ABOUT A NEW DROP-IN GROUP STARTING IN EMNETH IN JANUARY 2024



WE ARE SO LOOKING FORWARD TO WELCOMING YOU TO ONE OF OUR SUPPORT SESSIONS IN THE NEAR FUTURE - Family Action's Norfolk and Waveney Autism/ADHD Support Service Team.

#### **PLAN BEE**



#### Plan Bee – Understanding and supporting your child or young person with additional needs

'Plan Bee' is a FREE 3 week course (2hrs per week) written by two Clinical Psychologists working in Norfolk and is aimed at parents or carers of children or young people with additional needs including suspected or diagnosed Autism or ADHD.

During the three week course, we will explore:

- Behaviour as communication.
- Understanding the full range of needs your child may have.
- Developing a plan to support behaviour in difficult situations which can then be shared with grandparents, schools and others.
- Strategies for creating an environment in which your child or young person can thrive.
- Sharing experiences, challenges and successes with other parents experiencing similar issues and learning from these.

NOVEMBER - The Riverside Family Hub, 6 Canning Road, Lowestoft, NR33 0TQ

Wednesdays 8th, 15th & 22nd November 10:30am - 12:30pm FULL

**DECEMBER -** Banham Primary School, 37 Crown Street, **BANHAM**, Norfolk, NR16 2EX Tuesdays 5th, 12th and 19th December 10am to 12pm **FULL** 

**DECEMBER** - St Faith's Community Hub, Gaywood, **King's Lynn**, PE30 4DZ Thursdays 30th Nov and 7th and 14th December 2023 10am to 12pm **FULL** 

# PLEASE NOTE THAT ALL OF THE ABOVE ARE ALREADY FULLY BOOKED BUT PLACES ARE STILL AVAILABLE IN JANUARY 24 AT:

#### JANUARY - ON LINE COURSE ON ZOOM

Tuesdays 9th, 16th and 23rd January 2024 10am to 12pm To book your place please ring **01603 972589** or email <a href="mailto:swaffham@family-action.org.uk">swaffham@family-action.org.uk</a>

#### JANUARY - Great Yarmouth Primary Academy

Thursdays 18th, 25th January and 1st February 10:30am to 12:30pm To book your place please ring **01493 650220** or email <a href="mailto:gorleston@family-action.org.uk">gorleston@family-action.org.uk</a>

Further courses are being arranged. Keep an eye on next month's newsletter.

You can still access the online videos of our Positive Behaviour Strategies course (now Plan Bee) on the NHS for Norfolk website, Just One Norfolk.

Just click here: <a href="https://www.justonenorfolk.nhs.uk/child-development-additional-needs/behaviour-sleep/norfolk-positive-behaviour-strategies-pbs/">https://www.justonenorfolk.nhs.uk/child-development-additional-needs/behaviour-sleep/norfolk-positive-behaviour-strategies-pbs/</a>

# **Puffins Autism Programme** - for parents/carers of children or young people with a *diagnosis* of Autism



Family Action is working with Norfolk Community Health and Care to run the Puffins ASD Programme for Parents/Carers of children or young people **with a diagnosis of Autism.** This is a free, comprehensive, four week course with sessions led by Speech and Language and Occupational Therapy professionals from within the Neurodevelopmental Service and by the Autism Specialist Educational Team.

NOVEMBER 2023 - Owen Barnes Room,, Breckland Road, New Costessey, NR5 ORW
Thursdays \*2nd, 9th, 16th and 23rd November. 9:30 to 12:30pm (\*session one only - 9:30am to 1:00pm)

THIS COURSE

NOW FULL

DECEMBER 2023 - To be delivered online on ZOOM Joining details available for participants once place is secured.

Mondays \*27th November 4th, 11th and 18th December. 9:30am to 12:30pm

JANUARY 2024 - Swaffham Community Centre, The Campingland, SWAFFHAM, PE37 7RB Mondays \*8th, 15th, 22nd and 29th January 9:30am to 12:30pm

**RING** 01603 972589 or **EMAIL** swaffham@family-action.org.uk for more information or to book your place.

#### **CYGNET-** East Norfolk version of Puffins

Please call 01493 650220 if you would like more information or want to be placed on the waiting list.

## Family Action also serves families in West Suffolk



The West Suffolk Neurodevelopmental Support Service team have been busy delivering courses and bespoke workshops, alongside our regular parent drop-in sessions at Oakes Barn in Bury St Edmunds.

To contact us for advice and support, or to book a place on one of our courses please use the details below. Our number is 01284 636655 or Email <a href="mailto:wsuffolk@family-action.org.uk">wsuffolk@family-action.org.uk</a>

Click on the link below to read the West Suffolk team's November 2023 Newsletter which this month focuses on ADHD.

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## **Family Action FamilyLine**



# **FamilyLine**

Supporting adult family members via telephone, text, email and web chat



Family life is full of special moments but it can feel difficult sometimes too. Whether you're feeling anxious or worried as a parent or carer, or need support with a problem big or small, our free FamilyLine is here to help.

<u>FamilyLine</u> is a service for adult family members that aims to:

- provide both immediate and long-term support
- help with practical information and guidance
- provide emotional and listening support
- help with understanding and accessing relevant services and information
- provide regular one-to-one befriending
- support to service users feeling isolated
- access to short term telephone counselling
- a referral into our many projects across England and Wales, where relevant.

Family members aged 18 years old and over from anywhere in England, Wales and the Isle of Man can get in touch with the service for free via telephone, text message, web chat or email, using the details below.

Opening times: Monday to Friday, 9am to 9pm

Contact details: Telephone: 0808 802 6666

Text message: 07537 404 282

Email: familyline@family-action.org.uk

Live web chat

#### **Contacting FamilyLine out of hours**

Do you need FamilyLine but it's out of our operation hours? You can either call back in our opening hours, leave a message on our voice mail for a call back in our operation hours or if you're in crisis you can contact our crisis line to get in touch with a trained professional.

#### **Text FAMILYACTION to 85258**

Our crisis messenger text service provides free, 24/7 crisis support across the UK. We know that getting the correct support at the correct time is so beneficial which is why we've introduced our crisis line. This service is delivered in partnership with <a href="Shout">Shout</a>.

#### **About our Service - Contact Details**



To contact us for advice and support, or to book a place on one of our courses or information sessions, please use the details below.

For West and Central Norfolk **01603 972589** or email <a href="mailto:swaffham@family-action.org.uk">swaffham@family-action.org.uk</a>
For East Norfolk and Waveney **01493 650220** or email <a href="mailto:gorleston@family-action.org.uk">gorleston@family-action.org.uk</a>
Unsure which area to contact? Use any of the above – we are all here to help you.

If you wish to join our closed Facebook group, go to Facebook and to the Family Action page and then search for Norfolk and Waveney Autism and ADHD Support Service.