



Welcome to the June / July issue of Surrey News

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Please note: Some of the articles in the front of the newsletter include information for young people and adults, so please do check for details.

It seems as if the whole world has moved online over recent weeks, and our Branch of the NAS is no exception.

The National Autistic Society (national charity) has updated its resources for adults with autism and parents of autistic children about coping during coronavirus, including a list of useful resources and tips for autistic people and families, benefits and employment, going out & shielding and mental health & wellbeing: <http://s.12ab.pw/1/073>

June 1st – 7th is Volunteers' Week, a chance to say thank you to all the volunteers who work to support autistic people and their families. Like many other organisations, the Branch is run entirely by volunteers who are either parents or autistic people, and we'd love to have more parents of younger children in particular to join us to share their knowledge and understanding with parents. If you can spare a bit of time (once things unlock), please get in touch.

Don't forget our moderated email forum is still very active, and lets you exchange information and ask questions of others in the group. You can join by completing this form:

<http://www.nassurreybranch.org/moderated-email-forum.html>

We hope you and your families keep safe.

Sara Truman,
Chair (volunteer)

NAS Surrey Branch

General email: NASSurreyBranch@nas.org.uk

Website: www.NASSurreyBranch.org

Twitter: @NASSurreyBranch

Facebook: @NASSurreyBranch

Donations:

www.justgiving.com/nassurreybranch

NAS Surrey Branch Contacts

Chair:

Sara Truman 07423 435413
nas@mugsy.org

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Branch Membership:

Nancy Rowell
membership@mugsy.org

Deputy Chair / Website & Newsletter:

Emma Whitfield
emma@mugsy.org

Events, Activities & Fundraising:

Please email events@nassurreybranch.org
with the name of the event in the subject line

Sarah Mead
Emma Searle
Jill Goulding
Jo Dilworth
Emma Ellis
Lisa Mangum

Parents of Girls' Group

Rachel Pearson
racheldpearson@gmail.com

Parents of Adults' Group

Hilary Dyce
hilarydyce@yahoo.co.uk

Weighted Blanket Loan

E Surrey – Penny Sims
po.sims@yahoo.co.uk

W Surrey – Emma Whitfield
emma@mugsy.org Blankets are suitable
for a child from 25kg (about 8 yrs)

POSTAL ADDRESS

NAS Surrey Branch
c/o Walton Charities,
2 Quintet, Churchfield Road,
Walton on Thames KT12 2TZ

Please note, no NAS staff or
volunteers work at this address

Unless clearly stated, organisations are not
endorsed by NAS Surrey Branch or the NAS.

NAS web site: www.autism.org.uk

NAS Helpline: Tel: 0808 800 4104 (10am –
4pm), or email autismhelpline@nas.org.uk

NAS Parent-to-Parent line 0808 800 4106

NAS national membership: 020 7903 3563
Email membership@nas.org.uk

Education Support

NAS Education Rights: 0808 800 4102

SEND Advice Surrey: 01737 737300
www.sendadvicesurrey.org.uk

SOS!SEN charity to support EHCPs etc, Tel:
020 8538 3731, Web: www.sossen.org.uk

Family Support & Representation

One Stop CAMHS / BEN Pathway family
support 0300 222 5755

Portage – support for children with SEND
under 3.5 years 0300 200 1004

Family Voice Surrey parent representation
www.familyvoicesurrey.org

Action for Carers tel: 0303 040 1234
CarerSupport@actionforcarers.org.uk

Parent Programmes

PAT-P for parents of under 5s.

Cygnets for parents of children aged 5 –
19. courses@sendteachingschool.co.uk
Tel: 020 8330 3009 ex 237

Redhill CAMHS group 01737-287002

Activities for children and young people

NAS Resource Centre, Godalming: 01483
521 744 SEResourceCentres@nas.org.uk
interAKtive, Epsom-based charity for
children with ASCs and other difficulties
07876 762178 www.interaktive.org.uk

Adult Services

Surrey Adult Social Svcs: 0300 200 1005

NAS Surrey Service Tel: 01483 861600,
email: surrey.service@nas.org.uk

Employment Support

Employability for people with disabilities
including ASCs Tel: 01483 806806, email:
employability@surreychoices.com

Benefits advice

NAS Tips page – via www.autism.org.uk

Cerebra DLA guide:

<http://w3.cerebra.org.uk/> 0800 328 1159

Other Useful Contacts

NAS Surrey Branch online meet-ups

As our normal parent support groups are unable to meet at the moment, the Branch is organising some online get-togethers for parents, using Zoom. There are two separate groups for parents of adults with autism (see adults section) and a group for parents of children meeting on Tuesday evenings. If numbers grow we may have more separate groups, such as different ones for parents of girls and parents of boys.

If you would like to join one of these online meetings, please email Sara Truman at nas@mugsy.org

Ice skating event cancelled

Sadly, we have had to make the decision to cancel our planned ice skating event at Guildford Spectrum as there is not yet enough clarity about when live events will be possible.

Thank you to everyone who took the time to express their interest on our Eventbrite page. Please do keep an eye on future issues of the newsletter and our email forum for further news.

Online resources for parents and autistic people

Here's a summary of some of the online resources, meetings and activities available for use if you have someone with autism in the family:

- **NAS coronavirus resources** – see chair's letter for details or go to <http://s.12ab.pw/l/073>
- **Special Needs Jungle** – Useful information about how EHCPs work whilst schools are closed, plus other useful information <https://www.specialneedsjungle.com/>
- **Family Voice Surrey online meet-ups and weekly Facebook Live:** <https://www.facebook.com/groups/FVSurrey/>
- **Surrey Local Offer** Coronavirus resources, information and FAQs <http://s.12ab.pw/l/b19>
- **Surrey Partnership Board for adults with special needs - easyread guides:** <http://s.12ab.pw/l/6150>
- **Linkable online activities** including sensory and messy play ideas, theme of the week, songs and nursery rhymes <https://www.linkable.org.uk/pages/131-online-activities>

Remember, you can connect with around 1000 other parents, professionals and people with autism in and around Surrey via our online forum: If you are already a member but haven't participated for a while, just send an email to NASSB@groups.io from the email address you registered with.

Please see additional links and information for adults on pages 6 - 8.

Courses in managing PDA for parents and professionals from PAST

Positive Autism Support and Training (PAST) are running a range of online courses for parents, plus accredited courses for professionals. They offer insight into managing challenging aspects of autism and Pathological Demand Avoidance (PDA)

Upcoming courses include a short course for parents on anxiety management for children (£15) and a course on PDA in the classroom for professionals (£70). For details go to <https://www.positiveautismsupportandtraining.co.uk/>

Workshops by Dr Mark Brown

Mark Brown of Special Help for Special Needs is running a series of online workshops for parents – please use the relevant Eventbrite link to book, check prices or contact him with queries:

Obsessions and anxiety - 9th June or 29th June

This aim of this webinar is not to get rid of obsession, but to provide insight into their reasons and how to gain some sort of balance. Mark will explore some of the issues relating to having additional needs and anxiety, including the display of obsessive behaviour, how it can impact upon everyone involved and how to develop support and interventions to reduce the consequences of being anxious.

<https://www.eventbrite.co.uk/e/obsessions-and-anxiety-webinar-tickets-104360633464>

Managing behaviour by understanding the individual 10th June or 1st July

Supporting an individual who has felt the need to resort to behaviours; whether violent or not, can be a challenge for all involved. This workshop will explore the issues involved when someone displays behaviours that challenge, including areas of anxiety and communication, and consider potential strategies to support all involved.

<https://www.eventbrite.co.uk/e/managing-behaviour-by-understanding-the-individual-tickets-104361564248>

Sleep Problems in neurodiverse people 16th June, or 6th July

Mark will explore the difficulties associated with sleep and children with special needs, as well as some neuro-typical children, and provide some general ideas and approaches towards getting better sleep.

<https://www.eventbrite.co.uk/e/just-a-few-more-minutes-please-sleep-problems-in-neurodiverse-people-tickets-104366099814>

Puberty & Neurodiversity: Ready Or Not Here It Comes! 18th June or 8th July

Exploring the issues faced by children and teenagers with a learning disability and/or autism, when they are going through puberty, and the impact this can have on their family and wider circle. Topics covered will include:-

- Identifying the characteristics of puberty that can have a significant effect on young people
- Providing an understanding of anger management related to puberty
- Practical approaches which can be taken to address inappropriate sexualised behaviours

<https://www.eventbrite.com/e/puberty-and-neurodiversity-ready-or-not-here-it-comes-webinar-tickets-104362523116>

Online courses from The Curly Hair Project

The Curly Hair Project have also moved their busy schedule of events online. You can view details of their courses for parents and professionals which cover topics from eating, to emotions and education on their website here:

<https://thegirlwiththecurlyhair.co.uk/services/events/>

The Curly Hair Project (CHP) is an award-winning social enterprise founded by autistic author and entrepreneur Alis Rowe. Prices vary, but there are discounts for autistic people.

School nurse support line for SEN children who can't attend school

Children and Family Health Surrey have launched a special school nurse support and advice line for parents and carers whose child is not attending their special school due to partial closure or self-isolating. The advice line can be contacted on 07817 092205 and is open Monday to Friday between 9am and 12pm.

Family Voice Surrey online meet-ups

Family Voice Surrey is hosting weekly Zoom catchups for parents of children with special needs and disabilities in all Surrey boroughs.

They also have a regular Friday afternoon Facebook Live Chat with Benedicte Symcox, FVS Operational Lead who can raise parents' issue with Surrey County Council. See their Facebook page for details: <https://www.facebook.com/pg/FamilyVoiceSurrey/events/>

NAS Sleep Survey

The National Autistic Society is conducting a survey in association with Happy Beds to explore autistic people's experiences with sleep, what causes difficulties and what helps. Feedback from the survey will be collated by the NAS and used to inform Happy Beds' communication channels and specifically a blog about autism and sleep. They are looking for autistic people age 16 and over or parents/family members of autistic children/people of any age who know them well enough to support them to answer or answer the questions on their behalf.

Please respond to the survey based on your experiences prior to the pandemic. There is opportunity to discuss sleep differences during COVID-19 in one specific question should you wish to share this experience. It takes about 15-20 minutes to complete.

<http://s.12ab.pw/l/bf2>

PDA free virtual summit

There is a virtual summit focusing on Pathological Demand Avoidance from 3rd to 6th July which will be available online for you to watch in your time. It is bringing together professionals and experts within the PDA community to deliver keynote talks, promote awareness, provide strategies, share real life experience and signpost to resources to help understand and manage PDA. It's designed to enhance understanding of PDA, whether you are just learning about it for the first time, or an ASD professional. The event is free, but you can buy videos and resources. <http://positivepda.com/> The organisers will make a donation to the PDA Society from profits raised.

Giving carers a voice consultation

Action for Carers is consulting with carers to find out about their experiences, so they can work towards changes to improve the lives of all carers. To book your place, please complete the 'I am interested in this event' form on their website – but please note that the places are limited: <https://www.actionforcarers.org.uk/event/carers-consultation/> This is a video event using Zoom, you will be sent the access code ahead of the session.

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8th – 14th June is Carers' Week - highlighting the role of unpaid carers in the UK. You can share information about your caring role and help get your voice heard:

<https://www.carersweek.org>

RESEARCH REQUESTS

Feelings of parents whose children have been diagnosed

Kelly Silk is a MSc Applied Psychology student at the University of Bedfordshire. She is working on a masters study exploring the experiences and feelings of parents whose children have been diagnosed with autism spectrum disorder, specifically their experiences of the assessment process. She is hoping to interview parents over the phone at the interviewees convenience. Email Kelly.silk@study.beds.ac.uk

Study of adults - Autism and learning environments

Katherine Macy, a postgraduate masters student at the University of York with the Department of Archaeology, is conducting research into learning environments and preferences for adults with autism, including during the current covid-19 crisis and in other potential crises. The survey can be filled out by neurotypical and neurodivergent people. You can see the survey here <http://s.12ab.pw/l/22d> or email Katharine Macy with any queries: km1190@york.ac.uk

INFORMATION FOR ADULTS AND YOUNG PEOPLE

Online get-togethers for parents of autistic adults

As our normal support groups are unable to meet at the moment, the Branch is organising some online get-togethers for parents of adults with autism, which meet monthly on Friday afternoons or Wednesday evenings. For details, contact Sara Truman nas@mugsy.org

Professionals from the NAS Surrey Service are running online meet-ups for adults with autism, in place of the Aspire groups. For information about these groups, email aspire.groups@nas.org.uk

Survey on health & social care during the pandemic

Healthwatch Surrey is supporting the NHS and social care to help them understand what is working well, and not so well, with health and social care during the coronavirus pandemic. They want to hear about all experiences, whether they are related to COVID-19 or not. You can complete the survey here:

https://www.surveymonkey.co.uk/r/Healthwatch_Surrey_Health_Social_care_during_pandemic (it can also be completed on behalf of someone else).

Alternatively, you can share your experiences via phone, text, email or online – details are at <https://www.healthwatchsurrey.co.uk/>

'Grab and Go' Form in case you have to go to hospital

There is a form you can complete if you are autistic or have a learning disability. This can be completed in advance so you have it ready to give to NHS staff if you do have to go to hospital. It doesn't replace your hospital passport, but gives the information that doctors and nurses will need if you go to hospital because of COVID-19 and, for example, are struggling to breathe. You can download it here: http://www.surreypb.org.uk/assets/c0381_nhs-covid-19-grab-and-go-lda-form-.pdf and there is an explanation of how to use it here: <http://s.12ab.pw/l/ef2>

Easyread guides

There is a range of easyread guides, videos and posters about coronavirus related topics such as:

- Coronavirus - Things you can do to help yourself and your community
- Keeping away from other people - coronavirus guidance
- Shielding - coronavirus guidance
- Looking after your feelings and body - coronavirus guidance
- Words about coronavirus and what they mean

You can download them here <http://s.12ab.pw/l/cfc>

Linkable online activities for adults

Linkable is running many of its activities online during the pandemic, including a Zumba session, craft fun, performing and cooking classes.

<https://www.linkable.org.uk/pages/135-adult-groups>

Information on coronavirus, autism and mental health

There is a blog by a young autistic woman of 19 about how the pandemic has affected her mental health, looking at areas including dealing with changes in routine, social interaction and coping with uncertainty:

<https://youngminds.org.uk/blog/coronavirus-autism-and-my-mental-health/>

Autistica also has a list of tips for coping with the situation:

<https://www.autistica.org.uk/what-is-autism/coronavirus/tips-for-managing-mental-health-coronavirus>

Supported living documentary on Channel 4

Channel 4 produced a two-part documentary last year called Home Free, about a group of young adults with learning disabilities (at least one of whom also had autism) moving into independent living. If you missed it, you can see it here: <https://www.channel4.com/programmes/home-free>

Parents may find it quite emotional to watch, as it addresses the concerns virtually all parents have about their sons and daughters with special needs leaving home.

Dramatize online activities and family quizzes

Dramatize, a theatre company for individuals with learning disabilities, is running live stream sessions, video uploads, online parties and family quizzes during lockdown.

The live streams and video uploads will run at the following times:

9am - Live stream on Facebook

10am - Video upload to the website

1pm - Live stream on Facebook

3pm - Video upload to the website

You can find the videos here: <http://www.dramatize.co.uk/online-video-activities.html> or go to their Facebook page:

<https://www.facebook.com/DramatizeTC/?ref=hl>

Surrey Coalition for Disabled People virtual activities

A reminder that Surrey Coalition for Disabled People hosts online 'virtual' meet-ups:

Virtual Walk and Talk - every weekday 2.30 pm – 3.00 pm. It's free and an opportunity for people to chat whilst doing some gentle activity in their own home and is open to anyone over 18.

Zoom: <https://zoom.us/j/3106670662>

Skype for Business: <https://zoom.us/skype/3106670662>

Phone: 0800 358 2817 United Kingdom Toll-free - meeting ID: 310 667 0662

SMS text: 07780 933 053

Surrey virtual café – available every Monday for a good catch-up!

11.00 am – 12.00 noon

Anyone over 18 can join for free, you just come along when you want to for some light-hearted discussion over a cup of tea or coffee.

Zoom: <https://zoom.us/j/3106670662>

Skype for Business: <https://zoom.us/skype/3106670662>

Phone: 0800 358 2817 United Kingdom Toll-free - Meeting ID: 310 667 0662

If you are joining by Zoom for the first time, you'll need to download the free app here beforehand: <https://zoom.us/download>

About NAS Surrey Branch

NAS Surrey Branch is a volunteer-run, support group for the parents of autistic children and adults. It's FREE to join (although a small donation is appreciated) and we have around 2,000 members. We hold regular support group meetings, organise social events and special interest groups and represent parents in meetings with health, education and social services. We host an active online forum and produce this email newsletter every two months. To join, go to www.nassurreybranch.org or email NASSurreyBranch@nas.org.uk to request a membership form. If you are a member of the National Autistic Society at national level, you can nominate us to receive part of your subscription by emailing supportercare@nas.org.uk.

The National Autistic Society works for autistic people and runs a wide range of services such as schools, clubs and adult centres. It has over 2,000 members and 100 branches and works in partnership with more than 50 local autism societies. The NAS exists **to transform lives** by being a trusted source of support and practical advice for autistic people and their families at key stages in life and **change attitudes** by working with businesses, policy-makers, autism professionals and the public to reduce isolation and open up opportunities in society as a whole.

National Autistic Society, 393 City Rd, London EC1V 1NG www.autism.org.uk. Registered charity, number 269425. Company limited by guarantee number 1205298.

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