

Welcome to the April / May 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.

The Coronavirus pandemic has had a devastating effect on this country, and the rest of the world.

For the autistic community, in addition to worries about catching the virus, they also have to cope with big changes to their daily routine which has been very hard for some. On the other hand, for many of our autistic family members, social interaction is something they prefer to avoid, and they may cope with the social distancing better than most neurotypical people.

For the Branch, the Coronavirus has meant cancelling all Branch activities in April and May, if not longer. This includes our branch conference planned for May - those who have booked should have now all had their refunds.

We were expecting to put lots of our events into this newsletter, as well as activities arranged by other organisations. However, while we can't meet in person, our **online support group** - also known as our moderated email forum - is still very active. It enables members to exchange information and ask questions of others in the group via email. If you are not already a member, you can join by completing this form: <http://www.nassurreybranch.org/membership.html>

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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Haywood Drake
bobdrake357@btinternet.com

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

Other Useful Contacts

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.sendadvice.surrey.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

Autism friendly Ice skating – Sunday 14th June?

We don't know whether group activities will be permitted again by June or whether everyone will still be required to stay at home. However, we are hoping to hold our annual private visit to the Guildford Spectrum ice skating rink on Sunday 14th June. This is an event for the whole family, autistic children or adults and their parents/carers, grandparents and siblings.

In the hope that the event will go ahead, we ask anyone interested to book their place NOW so that we can gauge interest before we confirm the booking. **You do not need to make donations towards the cost at this stage**, but if the event is confirmed we will be asking for a suggested donation of £4.00 per skater.

Please express your interest here: <https://www.eventbrite.co.uk/e/nas-surrey-branch-family-ice-skating-2020-tickets-101538404100> If the event goes ahead, we will ask you to transfer the money to NAS Surrey Branch direct.

If all proceeds, the session will be from 4.45 to 5.45, p.m., but we suggest arriving from 4.30 p.m. to collect boots and helmets. This is one of our most popular family events: we take over the whole rink, and get flashing lights and loud music turned off to make it accessible for those with sensory issues. If you wish, you can bring your family in via a back door directly into the rink to avoid the hubbub of the main reception.

This event is as much about siblings, grandparents and other family members getting to spend time together in a non-judgmental atmosphere as it is about skating. For children who are new to skating, there are push along penguins and snowmen to help gain confidence on the ice.

Please note: Parents will remain responsible for their children throughout. All children must be accompanied on the ice by a responsible adult.

THANK YOU John Muggleton!

This year the branch celebrates its 25th birthday, and having been a branch volunteer for most of that time, John Muggleton is finally retiring.

John set up the branch's original website in 1997 – before many of us knew what a website was - and it quickly grew into a massive source of information for families of people with autism or learning disabilities.

The "mugsy.org" website became famous in the autism community across the country for the range of information and interesting articles it contained, at a time when it was very difficult to find information about autism anywhere. At the same time John also set up the NASSB email forum to enable members to talk in a group via email (seven years before Facebook was invented!) and he has been the lead administrator and moderator from then until last month.

John has also represented the branch at various meetings with managers from health, education and social care for many years, and was a committee member until June 2015.

We cannot thank John enough for everything he has done for the Branch over virtually all of its 25-year history.

Coronavirus Resources

- **Action for Carers** – see article overleaf.
- **National Autistic Society** (national charity) - helpful tips for adults with autism and parents of autistic children about coping during Coronavirus, including a list of useful resources for families & free downloadable book for children called 100 Things To Do Indoors <https://www.autism.org.uk/services/helplines/coronavirus/resources.aspx>
- YouTube video on **Supporting Neurodiverse Children In Challenging Times Such As During Self-Isolation** by NHS Clinical psychologist Dr Louise Acker and Occupational Therapist Vicky King (If the link doesn't work, search YouTube) <http://s.12ab.pw/l/551>
- **Special Needs Jungle** – Useful information about how EHCPs work whilst schools are closed, but much more useful information <https://www.specialneedsjungle.com/>
- **WeShine** – local parent-run community group on Facebook: <http://s.12ab.pw/l/944>
- **ANT** (Additional Needs Together) Surrey Facebook group: <http://s.12ab.pw/l/81a>
- **Family Voice Surrey on Facebook**: <https://www.facebook.com/groups/FVSurrey/>
- **Surrey Local Offer** Coronavirus page <https://bit.ly/2Ulk9OB>

And don't forget that 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.

Surrey Autism Strategy – Upcoming Consultation

Professionals from Surrey County Council, the NHS Clinical Commissioning Groups (CCGs) in Surrey and other organisations will be producing a new Autism Strategy during 2020, which will replace the Surrey Learning Disability and Autism Commissioning Strategy 2016-2020. People with autism and parent carers are also involved in drawing up this new strategy. The current strategy was just about services for adults, but the new Autism Strategy will include services for children too.

A consultation is being prepared so that people with autism and families can say what they think the new strategy should include. Details of the consultation have been delayed because of the Coronavirus, but as soon as we know them, we will announce these on our branch forum and Facebook page, as well as in the newsletter. You can see the current strategy here: <http://www.surreypb.org.uk/our-strategy.html>

Carer's leave Consultation

The Department for Business, Energy and Industrial Strategy is seeking views on giving unpaid carers a week of unpaid leave each year to provide care. Your responses will help them understand:

- how carers use existing employment rights
- who should be eligible to take the leave
- what the leave can be taken for
- how the leave would be available to take and the process for taking the leave
- the costs and benefits to employers and employees

They are seeking responses from all stakeholders, including employers, individual carers, trade unions, representative organisations, charities, professional bodies, medical or social care providers, researchers and academics

In light of COVID-19, they are extending the consultation period to 3rd August 2020 <https://bit.ly/3bLTAh7>

Why It's Worth Joining Action for Carers Surrey

Anyone who cares for someone with a disability can register as a carer with Action for Carers. Benefits of registering include:

- Getting an official letter that says you are a carer for use in places such as supermarkets during special Coronavirus opening times
- Roundup of supermarkets with special times during the current situation for elderly, vulnerable people and carers <https://bit.ly/2ymkrlP>
- Advice for Young Carers: <https://bit.ly/2yjLE8B>
- Helpline if you need to find someone to help with shopping or fetching medication
- Online support forum

They usually hold speaker meetings for parents/carers of autistic adults or children, although live events and meetings are not running at present. Contact details:

Helpline: Tel: 03030 040 1234

Email: CarerSupport@actionforcarers.org.uk

Website: www.actionforcarers.org.uk

Facebook: @ActionforCarersSurrey

Surrey Carers' Strategy

Surrey County Council and the NHS Clinical Commissioning Groups, along with partner organisations, are also updating the Surrey Carers Commissioning and Development Strategy this year. This is the plan for how unpaid family carers of people with any kind of illness or disability get support to help them in their caring role. The kind of thing it covers includes Carers Support workers (who can advise on things such as carers rights to benefits and support from social services), carers breaks and respite care, and support for young carers (which includes siblings of children with autism). For instance, you might want to ask for individual advice from an autism expert.

It is really important that parents/carers of people with autism complete the consultation survey so your views are heard. You can complete it only at:

<https://fs4.formsite.com/surreygp/xrfrpujnow/index.html?1579518343918>

This is your chance to say what would help you in supporting your family member with autism. The survey closes on April 30th.

Free SEND Resources for Parents and Schools

ChatterPack is a voluntary organisation creating free resources for schools, parents and young people with special educational needs and disabilities. They have created 3 lists of free online resources to use during the Coronavirus outbreak.

- Speech, Language, communication and SEND resources for schools and parent/carers including free SLT, OT resources, entertainment, movement and exercise, anxiety, behaviour and emotional support
at: <https://chatterpack.net/blogs/blog/list-of-free-speech-language-communication-and-send-resources-for-schools-and-parent-carers>
- Boredom-busting online resources for anyone staying at home including arts & culture, learning, well-being, music, entertainment, literature
at: <https://chatterpack.net/blogs/blog/list-of-online-resources-for-anyone-who-is-isolated-at-home>
- Home learning list for schools and families
at: <https://chatterpack.net/blogs/blog/resources-list-for-home-learning>

Do share your feedback on the resources on our online forum.

Podcast on Helping Children with Autism

The Association for Child and Adolescent Mental Health (ACAHM) has produced a free 30-minute podcast with Dr. Ann Ozsivadjian and Dr. Marianna Murin 'Coronavirus and Helping Children with Autism'. They discuss issues that may arise for autistic children including the disruption of closing schools, anxiety and obsessive behaviours. They focus on practical tips like how to manage anxiety, maintain structure and support and explain the situation to young people. Additionally, tips on how to keep well as a parent and reliable sources for coronavirus updates.

The podcast is sponsored so there is a short reference to the sponsor at the very beginning. It can be found at: <http://s.12ab.pw/l/635>

Thank you to Laura Pearce

Our thanks go to member Laura Pearce and all the staff and customers at The Bell Inn in Shepperton for once again for collecting money for the National Autistic Society Surrey Branch amounting to an amazing £136.

This is the second generous donation the pub has made: our thanks to Landlord Gerry McKenna and staff. We hope that you will be able to open your doors again soon.

New Date For Kidz to Adultz Expo in Farnborough

Kidz to Adultz South which was previously scheduled for May 2020 will now take place on **Wednesday 30th September 2020**, from 9.30am – 4.30pm, at the same venue, Farnborough International Exhibition & Conference Centre.

Kidz to Adultz events are for carers and health professionals involved in the care of vulnerable children and young adults. Organisers Disabled Living will be sending out regular newsletters and mailings and posting regular updates on their website and social media sites, including lots of useful tips and ways to keep fit and entertained during this period of isolation. For more information go to <https://bit.ly/2JnNDeh>

'Singing Hands' Virtual Events with Makaton

Singing Hands is run by two mums, Suzanne and Tracey, who work with schools, nurseries and young adults to help develop children's communication potential through music, songs, games and activities using Makaton and music. They also offer classes, resources, educational concerts and training for professionals.

They focus on learning language in a way that is motivating, engaging and fun and their website has signed stories and resources. During the lockdown they are offering virtual events over Zoom videoconferencing:

PreSchool - Tuesday 7th & 14th April 10.30am

Nursery rhymes and action songs. Grab some props such as toy animals, colourful scarves or ribbons, a shaker and a drum (or a saucepan and wooden spoon) to replicate the sensory elements that they can't provide through a screen. Each week will follow the same structure but feature a different combination of songs.

Early Years & Primary Thursday 9th & 16th April 10.30am

Makaton signed rhymes & action songs with a few pop songs for older children. It costs £2.50 to register. Go to <https://singinghands.co.uk/what-we-do/forthcoming-events/>

Congratulations to Special Needs Jungle

The parent-run blog Special Needs Jungle has been chosen as 'Volunteer of the Year 2020' by the Your UK Parliament. The award recognises the work of people who have volunteered their time to help others get involved with democracy.

Special Needs Jungle is an excellent resource for information about your rights as a family that includes someone with special needs:

<https://www.specialneedsjungle.com/>

They are currently running a series of answers to questions about legal issues around school attendance and exclusions in the current situation.

Don't Forget easyfundraising if You're Shopping Online

Whilst the shops are shut, many of us are ordering goods online. If you sign up to easyfundraising and chose NAS Surrey Branch as your charity, we get a small amount every time you shop.

It's easy and completely free to sign up and 4,000 shops and sites will donate to us when you use easyfundraising to do your everyday online shopping - at no extra cost to you! Every donation you raise makes a difference to us, so please sign up today

https://www.easyfundraising.org.uk/causes/nassurrey/?invite=2T1QLV%26referral-campaign=c2s%26utm_campaign=admin-trigger%26utm_content=srt

RESEARCH REQUESTS

Many people would like to help with research requests but often don't have the time. If you are now at home and have a bit more capacity than usual, please consider supporting one of these research projects if appropriate.

How Parents and Professionals View the Benefits and Risks of Fidget Toys in Children with Autism

UCL and Kingston University are conducting a study into How Parents and Professionals view the Benefits and Risks of Fidget Toys in Children with Autism and Typically Developing Children

The study is investigating both parents and professionals' views on the use of fidget toys in children between the ages of 3 and 16 within the UK who have a diagnosis of autism, or who are typically developing. There are separate questionnaires for parents and professionals but many of the questions are similar. The questionnaire for parents will take approximately 20 minutes to complete.

Please contact a researcher (below) with any questions you may have about the study:

Sekayi Rodney K1511454@kingston.ac.uk
Latifa Mahdi K1713009@kingston.ac.uk
Emma Flower K1608505@kingston.ac.uk

Nigel Ortega K1715168@kingston.ac.uk
Victoria Learmond
K1708464@kingston.ac.uk

For parents: http://kingston.eu.qualtrics.com/jfe/form/SV_ezJGTGRJLMGUqhl

For professionals: http://kingston.eu.qualtrics.com/jfe/form/SV_411o8Mag625gma1

Stress & Coping Among Fathers of Young People with Autism

The information below has come from Florence Ruston-Griffiths, an MSc psychology student at the University of Derby. If you are interested in taking part, or just want to find out more, please email her at f.rutsongriffiths1@unimail.derby.ac.uk

Are you a father of a child (or children) with autism? If so, you are invited to take part in a research study that will explore experiences of stress and coping amongst fathers of children with autism.

Whilst there has been much research into stress and coping amongst parents of children with autism, much of this has focused on mothers. This study aims to address this by shining a light on the unique experiences of fathers of children with autism.

In order to take part in the study, you must

- be a father of at least one child / young person (aged 0-25) who has been diagnosed with autism and lives with you
- be at least 18 years old
- live in the UK
- be able to speak and understand English
- have access to a telephone and be available for a telephone interview lasting approximately one hour.

You are not able to take part in the study if you have been diagnosed with any mental health condition that may impact upon your stress and coping.

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Barnardos Moving Forward Story Time Videos

If your child likes stories, you may be interested in the videos of stories being made available on the Barnardos 'Moving Forward' Facebook page @BarnardosMF.

INFORMATION FOR ADULTS AND YOUNG PEOPLE

COVID-19 Health Action Plan for Autistic People

There is a free to download Health Action Plan for adults with autism about the Covid-19 coronavirus. It is a clear document that helps people assess if they have symptoms and whether they are in a priority group and includes information about how you like to communicate and important information if you were to become ill or needed to be taken to hospital.

You can download the document from here: <http://s.12ab.pw/l/b62>

Seminar on Strategies for Living with Autism in Covid-19 Times

The Curly Hair Project is running one-hour webinars on April 8th and 14th on Strategies for Living with Autism in Covid-19 Times. It is being given by Sam Ramsay, a mum of an 18 year-old autistic girl who is trained as a teacher.

To book go to: <https://www.eventbrite.co.uk/e/strategies-for-living-with-autism-in-covid-19-times-1-hour-webinar-tickets-10070335447>

Surrey Coalition for Disabled People Virtual Activities

Surrey Coalition for Disabled People is hosting online 'virtual' meet-ups:

Virtual Walk and Talk - every weekday 2.30 pm – 3.00 pm from Monday 30 March 2020 onwards! 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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