

Welcome to the December '23 – January '24 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.

We are very pleased to be taking on the role of Co-Chairs after Sara Truman recently stepped down as Acting Chair. We want to express our thanks to Sara for all she has done in her most recent role and throughout her time with the branch. Sara has kindly agreed to remain on the committee for the time being.

The NAS Surrey Branch is an organisation run entirely by volunteers, most of whom have work and/or caring commitments in addition to their branch roles. It is also an organisation which has doubled in size over the past few years. It has therefore become increasingly difficult for one person to manage all the Chair's responsibilities. Figuring out how the Co-Chairs' respective roles will work is a challenge, but so far so good!

We are very conscious that this is your organisation and are constantly reviewing what we do to meet members' changing needs.

The results of our recent branch survey are published on page 8 and we will be taking them into account in our future planning. We are always looking for volunteers and ideas, so please do get involved and let us know what you would like us to be doing in the future.

Christine Malik and Jason Malschuk
Joint Chairs, NAS Surrey Branch

Email: surrey.branch@nas.org.uk

Website: <https://NASSurreyBranch.org>

Tel: 07423 435413

Facebook: @NASSurreyBranch

Donations:

www.justgiving.com/nassurreybranch

NAS Surrey Branch Contacts

General Information

Branch Mobile: 07423 435413

surrey.branch@nas.org.uk

Joint Chairs:

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Jason Malschuk

Treasurer:

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Sara Truman
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Rachel Boyce-Davis
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Website & Newsletter:

Emma Whitfield
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Parents of Girls' Group

Sally Roberts
sallyaroberts@hotmail.co.uk

Parents of Adults' Group

Hilary Dyce
hilarydyce@yahoo.co.uk

Parents of Children with PDA Group

Emma Ellis
Emma.ellis@nas-volunteers.org.uk

Other Activities:

Jill Goulding
Rachel Boyce-Davies
Stella Smith
Victoria Nunn

POSTAL ADDRESS

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

NB: No NAS staff / volunteers work here.

Other Useful Contacts

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

NAS website: <https://www.autism.org.uk/>

NAS membership: <https://bit.ly/3l84tBW>

Education Support

NAS Education Rights: <https://bit.ly/3BTfux6>

SEND Advice Surrey: 01737 737300

www.sendadvice.surrey.org.uk

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

Family Support & Representation

Family Support Service

Mindworks www.mindworks-surrey.org

Portage – support for children with SEND under 3.5 years <https://bit.ly/3zLW635>

Family Voice Surrey parent representation www.familyvoicesurrey.org

Action for Carers tel: 0303 040 1234 <https://www.actionforcarers.org.uk/>

Parent Programmes

NAS Stepping Up For Autism course

Email: Surrey.FamilySupport@nas.org.uk

Activities for children and young people

NAS Resource Centre, Godalming: 01483

521743 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

<https://bit.ly/3f8WXTu>

AS Mentoring specialist mentoring and employment support for autistic people <https://asmentoring.co.uk/>

Benefits advice

For children: <https://bit.ly/3xblygN>

For adults: <https://bit.ly/3ydoXNq>

Cerebra Downloadable DLA guide: <https://bit.ly/3lpEoyh>

Save the Date - Cinema Outing in Reigate February

In conjunction with the professionals at the NAS Family Support Service, we have secured exclusive use of Everyman Cinema Reigate for members in the morning of Monday 12th February, during half term.

The film to be shown is still to be decided, but it will be a relaxed performance of a family-friendly film. The session will be free for NAS Surrey Branch members and families registered with the NAS Surrey Service.

Please put the date in your diary and look out for an email after Christmas with details of the film and instructions on how to book. Ticket allocation will be on a strictly first come, first served basis.

Climbing Event in Walton-on-Thames in January

We are hosting two, one-hour indoor climbing taster sessions for children on the spectrum and their siblings aged 7 – 17 on the afternoon of Saturday 20th January at 4.30 and 5.30pm.

It will be at the climbing wall at Xcel Leisure Centre, Walton-on-Thames. We are subsidising the cost, and asking for a suggested donation of £8 per child. To book please email Emma Whitfield emmawhitfieldnassurrey@gmail.com with 'Climbing' in the subject line. Please include:

- How many places you'd like
- Which session time, 4.30 or 5.30pm you'd prefer (or no preference)
- The names and ages of the child / children and which one(s) are autistic

We will then send you details of how to confirm your place(s). Please note: Parents remain responsible for their children throughout this event.

Autism Learns PDA Online Webinars

Autism Learns is running a series of webinars exploring Pathological Demand Avoidance (PDA). The Speakers will look at how to meet specific needs of young people with a PDA profile at home and in education. Learnings include:

- Recognising and understanding the features of a PDA profile
- Why it's important to identify and describe PDA in a young person
- Is PDA masking different to autistic masking?
- How to support pre-verbal children with a PDA profile
- Strategies for supporting children and young people with PDA at school
- Stop saying "no" – strategies for supporting your young PDA-er at home
- Why sleep is sometimes difficult for PDA people
- Understanding anxiety for people with PDA and what you can do to help

The two-day series costs £49.99 for parents and family carers, and £74.99 for professionals. Content is CPD certified for professionals.

The price includes 30 day access to recordings of all webinars in the series.

<https://www.autismlearns.co.uk/understanding-pathological-demand-avoidance-pda-3/>

If you have problems clicking on any links, you may need to paste them into your browser

Workshop on Completing DLA and PIP Forms in Farnham

Action for Carers is hosting a session on completing DLA and PIP application forms on Friday, 15th December from 10:30am - 12:00pm at it Farnham Hub at The Maltings, Bridge Square, Farnham , Waverley, GU9 7QR.

The session will be led by Lesley Palmer who was a Tribunal Judge in the 1st Tier Social Entitlement Chamber for 20 years and has been in practice dealing with Wills, LPA and EPA and Court of Protection work (now retired).

Booking is essential. Go to <https://www.actionforcarers.org.uk/event/tips-on-completing-dla-and-pip-forms-farnham/> for more details and to book.

Relaxed Christmas Performance in Farnham

Farnham Maltings and The Bucket Club are holding a relaxed performance of it children's play, The Christmas Lobster, on Monday 18th December. This performance has been designed to cater for the requirements of people with further access needs including autism.

To find out more or to book, go to <https://farnhammaltings.com/events/the-christmas-lobster>

Group Coaching Group for Parents in Surrey Heath

Surrey Heath Primary Care Network is starting a Coaching Group for parents of autistic children and young people up to 25 from 9th January 2024. The sessions are designed to support parents and their wellbeing and they will not be discussing autism or care needs for autistic children and young people. The sessions will cover:

- Relationships and Connections
- Boosting Wellbeing
- Stress and Resilience
- Eating for Wellbeing
- Movement and Exercise

Sessions will be held in person in the Theta Building, Lyon Way, Frimley, Camberley GU16 7ER and consist of six fortnightly one hour coaching meetings. Sessions will start at 5:00 p.m. Each meeting will be followed by a one hour session on peer support and external services. You do not need to have a child with a formal diagnosis to join this group.

Participants are asked to commit to each of the six sessions on the following dates:

Session 1 – 09th January 2024 - 5pm-7pm

Session 2 – 23rd January 2024 - 5pm-7pm

Session 3 – 06th February 2024 - 5pm-7pm

Session 4 – 20th February 2024 - 5pm-7pm

Session 5 – 05th March 2024 - 5pm-7pm

Session 6 – 19th March 2024 - 5pm-7pm

Space is limited in each group, so they will be running multiple groups throughout the year. These sessions are for those who are registered at a Surrey Heath GP practice only. To sign up go to <https://forms.gle/VqhdAnbByCSueCiQA> For more details call 0333 332 0013 or email: shcp.healthandwellbeingservices@nhs.net

If you have problems clicking on any links, you may need to paste them into your browser

SEND Support Group For Parents and Carers in Woking

Woking Family Centre's SEND group for parents / carers runs free sensory play and learning sessions for children (0-5 years) with Special Educational Needs and Disabilities (SEND), pre and post diagnosis. Siblings are welcome.

Sessions are all year round and provide:

- Interactive and specialist play opportunities
- Access to professional advice from Woking Family Centres, HomeStart and partners
- Signposting to further Woking Family Centres Services
- Safe space to meet other parents and carers of SEND children.

Priority is given to families living in Woking

They also offer course for parents / carers covering topics like:

- EHCPs
- Boundaries and useful parenting tools
- Accessing useful websites and other support networks
- Support on applying for DLA and other funding options.

For further information, go to www.woking.gov.uk/familysupport. To register your interest, email familycentres@woking.gov.uk or call 01483 743 812

Open Letter from Liz Mills about EHCPs

Director of Education and Lifelong Learning, Surrey County Council Liz Mills has published an open letter on the Surrey Local Offer website to update families about what is being done to improve the delays in EHCPs and ensuring annual reviews are up to date.

The letter says, "Using the EHCP Multi-agency Recovery Plan we have in place, we are seeing green shoots in relation to progress in the three aims: reducing long waiting times, providing better support during waiting times and securing a long-term sustainable model of assessments.

"We are completing assessments for our most vulnerable children on time, clearing assessments that are overdue and enhancing our support offer for children at SEN support.

"Progress has also been externally reviewed as part of a recent visit by Ofsted and the Care Quality Commission to inspect Surrey's Additional Needs and Disabilities partnership arrangements for supporting children and young people with additional needs. The inspection took place between 11 and 29 September 2023 and the report is due to be published in November."

The letter also acknowledges that communication with parents is in need of improvement.

To read the letter in full, including an update on waiting times, go to the Surrey Local Offer website: <https://www.surreylocaloffer.org.uk/news/november-update>

If you have problems clicking on any links, you may need to paste them into your browser

NAS SURREY BRANCH CALENDAR December '23 – February '24

NAS Surrey Branch support groups enable parents or other family members of autistic children or adults to meet up with others and share their knowledge and experiences. If there isn't a group in your area, why not start one yourself? For more information, email surrey.branch@nas.org.uk

Please note, all dates are provisional and could change due to unexpected events. Please contact the host if you are planning to attend a meeting so that they know numbers and to confirm that the meeting is going ahead.

ZOOM SUPPORT GROUP FOR PARENTS/CARERS OF AUTISTIC CHILDREN IN SURREY

Meets monthly during term-time. Your child does not need a diagnosis for you to attend. For Zoom links for these meetings, email support@nassurreybranch.org

Wednesday 13th December 10.00 am

Monday 22nd January 8.00 pm

Wednesday 21st February 10.00 am

LOCAL IN-PERSON SUPPORT GROUPS

In-person support groups run by parent-volunteers for parents/carers of autistic children in Surrey. Your child does not need a diagnosis for you to attend.

Ashtead

For venue contact: Tarah Basu tarahbasu@googlemail.com

Tuesday December 12th 10am.

January and February dates to be confirmed.

Frensham

For venue contact: Christine Malik christinemalik@btinternet.com or
[Bonnie Noyce JBNoyce@yahoo.com](mailto:BonnieNoyce@yahoocom)

Monday 4th December 9.30 – 11.00 am

Monday 8th January 9.30 - 11.00 am

Monday 5th February 9.30 - 11.00 am

Guildford

For venues contact Sara Truman strumansurrey@gmail.com

Thursday 7th December 10.00 am – 12.00 noon (Note different day)

Monday 15th January 7.30pm – 9.00pm

Friday 23rd February 10.00am – 12.00 noon

Reigate

For venue contact: Victoria Nunn: victoria.nunn@nas-volunteers.org.uk

Friday 1st December 10.00 am – 12.00 noon

Friday 5th January 10.00am - 12.00 noon

Friday 2nd February 10.00am - 12.00 noon

Woking

For venues contact Paula Gerrard: paulagerrard@live.co.uk

Wednesday 6th December 10.00 am – 12.00 noon

Tuesday 9th January 8.00 – 9.30pm

Wednesday 7th February 10.00am – 12.00 noon

If you have problems clicking on any links, you may need to paste them into your browser

SPECIAL INTEREST GROUPS

Parents of Adults Group

Face-to-face meetings in West and East Surrey alternate with Zoom meetings.
Contact hosts for venues/links.

Tues 5th Dec 2.30pm **Zoom** Contact Hilary Dyce hilarydyce@yahoo.co.uk

Thurs 14th Dec 7.30pm **Zoom** Contact Sara Truman strumansurrey@gmail.com

Weds 3rd Jan 10.00am **Guildford** Contact Sara Truman strumansurrey@gmail.com

Friday 19th Jan 10.00am **Redhill** Contact Sara Truman strumansurrey@gmail.com

Thurs 8th February 2.30pm **Zoom** Contact Hilary Dyce hilarydyce@yahoo.co.uk

Thurs 22nd February 7.30pm **Zoom** Contact Sara Truman strumansurrey@gmail.com

Parents of Girls Group – Woking and Guildford

A group for parents of girls. Meets about once a month during term-time.

For venue contact Sally Roberts sallyroberts@hotmail.co.uk

Thursday 14th December 10.00 – 12.00 noon - **Guildford**

Thursday 18th January 10.00 – 12.00 noon - **Woking**

Tuesday 13th February 10.00 – 12.00 noon - **Guildford**

Spouses and Partners Group, Guildford

Meetings for the partners of autistic people (no diagnosis necessary).

For venue contact: Janet Moore janet.moore195713@gmail.com

Wednesday 13th December 8.00pm – 9.30pm

January and February dates to be confirmed.

Parents of children and young people with Pathological Demand Avoidance

This group meets over Zoom. To receive the Zoom link contact Emma Ellis at emma.ellis@nas-volunteers.org.uk

Thursday 25th January 8.00 pm

Thursday 29th February 8.00 pm

Don't forget our **email support group** – the NASSB online forum.

To join go to: <https://nassurreybranch.org/moderated-email-forum/>

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Little Diamonds SEND Group in Spelthorne

Stanwell Family Centre runs Little Diamonds, a group for children with additional needs and the parents and carers who care for them. The sessions offer fun activities, sensory resources; a chance to have a chat with other families and share ideas and experiences. Forthcoming dates are:

- Tuesday, 12 December with Family Voice Surrey
- Thursday, 25 January 2024 with Community Health, Speech and Language & SEND Advisor
- Thursday, 29 February 2024 with Community Health Early Support & Action for Carers
- Thursday, 21 March 2024 with Community Health Early Support, National Autistic Society & SEND Advisor

For details go to <https://www.stanwellfamilycentre.org.uk/support-additional-needs>

If you have problems clicking on any links, you may need to paste them into your browser

NAS Surrey Branch Survey Autumn 2023 - Summary of Results

Since we last ran a member survey in 2017, the Branch has changed hugely: we have grown from around 1,000 to 4,500 members and as you will have seen, have just appointed joint Chairs for the first time in our history.

Despite our membership having quadrupled, we only had 82 responses this time. Our thanks go to those who were able to find the time and to people who shared comments that give us a good insight into families' experiences.

Here's a brief summary of our findings:

RESPONDENTS

- 66% parent carers of under 18s
- 29% parent carer of over 18s
- 14% adults
- 5% other relatives
- 4% professionals

FAMILIES AND CHILDREN

- 73% have 1 autistic child.
- 25% have two and 3% have three.
- From 60 responses, 67 children have a diagnosis.
- 10 children awaiting diagnosis

- 42 children are 11 - 17
- 28 are 5 - 11
- 5 are 4 or under

EDUCATION

- 34 are in mainstream with no EHCP
- 11 are in mainstream with an EHCP
- 14 in specialist provision
- 1 home-schooled by choice
- 3 in education other than school or college.
- 6 out of school, on roll, 3 out of school off-roll.
- 1 in a PRU

4 children did not fit into any of these categories.

These comments were typical:

The EHCP has been the most stressful thing to date Surrey council have done everything possible to put up barriers for us to obtain the needed EHCP. To date we have had 4 case workers - they just keep changing.

We are battling to get an EHCP which is exhausting.

ADULTS

34 responses

- 79% have 1 adult in the household, 21% have two.
- 31 have a diagnosis and 2 are awaiting diagnosis or assessment.

Ages: 15 are aged 18 - 25 years old, 11 are 26 - 40, 13 are 41 - 60 and 3 are over 60.

If you have problems clicking on any links, you may need to paste them into your browser

ACCOMMODATION

- 16 live in own accommodation, 2 supported by family
- 18 with parents / relatives
- 3 in supported living.
- 4 in residential care

EMPLOYMENT AND TRAINING

- 20 in paid employment without support
- 3 in voluntary employment
- 6 in education or training
- 14 not in any employment or training

Comments included:

Son is out of work and/or in between jobs every few weeks or months.

Not able to attend employment or education, essentially housebound due to complex mental health needs.

MEMBERSHIP DEMOGRAPHICS

Respondents live all over Surrey, with the largest cohort (22%) in Guildford, followed by Woking and Epsom (8.5% each)

It was very good to hear that 94% would recommend joining the Branch to others. 43.2% are also a member of the NAS nationally.

93% found the newsletter fairly or very helpful / enjoyable and 95% found the online forum fairly or very helpful / enjoyable.

ACTIVITIES & EVENTS

Most people found our Zoom and in-person meetings with speakers and local parent / carer support groups fairly or very helpful / enjoyable.

We had a very low response rate to questions about family events such as ice skating, climbing, crazy golf etc, so will get feedback on individual events going forwards to decide which ones to continue.

FUTURE TOPICS & ACTIVITIES

The Branch is run by volunteers who are predominantly parents of autistic children and young adults so it's essential that the work we do is useful for as many people as possible. Topics suggested for future talks ranged from helping under-5s to information for late-diagnosed adults. Ideas for activities included miniature railway visits, games, art-based activities and trampolining.

We have already added a swimming event and Dungeons & Dragons this year.

If you know of people who would be willing to speak to our group on relevant topics, please ask them to email surrey.branch@nas.org.uk with an outline of their talk.

If you are able to help with organising events and activities, please also let us know using the same email address.

Thanks to everyone for their suggestions and kind comments.

If you have problems clicking on any links, you may need to paste them into your browser

Surrey Local Area SEND Inspection Report Publication

Our local parent participation organisation, Family Voice Surrey (FVS), was involved with contributing to the recent Ofsted and Care Quality Commission (CQC) Local Area SEND Inspection Report of Surrey Local Area Partnership. They have published a useful summary of the report.

The inspection found that local arrangements lead to inconsistent experiences and outcomes for children and young people with SEND and has said that the local area partnership must work jointly to make improvements.

FVS are now encouraging parents to digest the Inspection Report and to share their views on the outcomes by emailing inspection@familyvoicesurrey.org

They are hosting dedicated sessions for parent carers to attend – both in person and virtually – so they can review the outcomes together, hear your feedback and discuss how FVS can best continue to support members in line with any recommendations outlined in the report.

Dates will be emailed to FVS members and posted on the Family Voice Surrey Facebook page as soon as they are confirmed.

Surrey Carers Cards

Crossroads Care Surrey is encouraging all carers to become Surrey Carers Card holders, to highlight their caring status and allow them to access a host of discounts and offers.

There are two types of card, both of which highlight your caring role if you are suddenly unavailable:

The Surrey Carer's Card contains the contact details of your substitute carer and is a good option if you already have a trusted second person who can step in to provide care. It includes a card and key-fob with your emergency contact's phone number, so they can be contacted to step in and provide care if you are unavailable.

The Carers Emergency Card comes with a unique reference number, which enables a personalised Emergency Care Plan to kick into action, 24/7, and comes with up to 48 hours of emergency support. It includes

- Card and key fob.
- Crossroads phone number and your unique reference number printed on the card/fob.
- Access to a fully-funded Emergency Care Planning Service enabling someone you know or trained Crossroads staff members to step in and provide short-term care in an emergency situation.

Both cards include access to a range of perks and benefits for unpaid carers. Find out more on the <https://crossroadscaresurrey.org.uk/surrey-carers-card/>, call 01372 869970 or email enquiries@ccsurrey.org.uk.

INFORMATION FOR ADULTS, YOUNG PEOPLE AND THEIR FAMILIES

Mentoring for Neurodivergent Students Going to University

Marina King, a Specialist Mentor supporting neurodivergent students at university and beyond, is offering flexibly delivered and personalised courses intended for students planning to go to university.

The first course will start in January (dates TBC) and is designed to support individuals with issues such as:

- Managing anxiety
- Creating structure
- Support networks
- Living independently or in halls

Each course is six weeks long, with an hour of virtual 1:1 sessions each week. In order to provide accessibility to this resource for as many people as possible, fees are on a sliding scale of £40 / £60 / £80 per hour. Payment plans are available.

For more details email hello@ndmentoring.org or go to <https://ndmentoring.org/home/>

Research Request – Autistic Adults Who've Had Head Injuries

King's College London scientists are investigating how head injuries affect autistic adults. Head injury can lead to unpleasant symptoms, mental health challenges, communication difficulties, or sometimes no issues at all. They're also interested in hearing from someone close to the affected person (optional).

Who can join?

Group 1:

- Autistic Adults (18 or older) who have experienced a head injury resulting in passing out or feeling dazed/confused.

Group 2 (optional):

- An adult chosen by, and well-known to, the autistic person who is willing to discuss the impact of the head injury.

Participants will be asked to complete two questionnaires and have a conversation about the head injury (online or in person). Topics will include mental and physical health, sensory sensitivity, and social/healthcare experiences. Suggesting another person for their views is optional. The session takes about 1 hour

Compensation: a £20 Love2Shop voucher. Any travel expenses will be compensated

To take part, you can express interest using the sign-up link:

<https://forms.gle/C8KQmVcPVKVKcEYQ8> or contact: Richard Cole, richard.1.cole@kcl.ac.uk

Boccia Club in Staines

The Spelthorne Boccia Club is aimed at people aged 16+ with disabilities (young people aged 14+ may join with an adult carer present). Booking is not necessary.

Venue: Spelthorne Leisure Centre, Knowle Green, Staines

Date: Every Thursday

Time: 6pm to 6.55pm

Cost: £3 per week

For more details, go to <https://www.spelthorne.gov.uk/boccia>

For up to date news and information about our events, and those organised by other local organisations, do sign up to the NAS Surrey Branch email forum <https://nassurreybranch.org/moderated-email-forum/>

About NAS Surrey Branch

NAS Surrey Branch is a volunteer-run, support group for the parents of autistic children and adults, and the partners of people with autism. We have over 4,500 members in and around Surrey.



It's FREE to join but a small donation via our JustGiving page is appreciated as we receive no external funding: <https://www.justgiving.com/fundraising/nassurreybranch>

If you're a member of NAS at national level, you can nominate us to receive part of your subscription by

We run an active email forum and produce an email newsletter every two months. We also host talks, parent and partner support groups online and across Surrey and family events. To join for free, go to nassurreybranch.org or email surrey.branch@nas.org.uk to request a membership form.

We are part of the National Autistic Society which works for autistic people and runs services such as schools, clubs and adult centres. It has over 20,000 members, over 100 local branches and works in partnership with more than 50 local autism societies.

**National Autistic Society, 393 City Rd, London EC1V 1NG www.autism.org.uk.
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