



# Newsletter

For parents and carers of children and young people with disabilities and/or special educational needs in Sheffield

Published by the Sheffield Parent Carer Forum

Written by parents, for parents!

Spring 2020 - Issue 21 - FREE!



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# About us

We are an independent group of over 1,900 parents and carers of children and young people with disabilities and/or special educational needs in Sheffield.

Our aim is to make sure the needs of our children are met. We understand the challenges you face on a day-to-day basis, because we are parents and carers too. We organise regular events where parents can meet each other. We can tell you about the most up-to-date sources of information for your children.

We are here to give parent carers a voice. By joining the Parent Carer Forum, we can work together to improve services for our children.

## Membership is free, join us today!

Fill in the membership form at the back of this newsletter, or go to [www.sheffieldparentcarerforum.org.uk/become-a-member](http://www.sheffieldparentcarerforum.org.uk/become-a-member)

## Get in touch

### By Post:

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Bramall Lane, Sheffield S2 4QZ

**By phone:** 0300 321 4721

### By email:

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### Website:

[www.sheffieldparentcarerforum.org.uk](http://www.sheffieldparentcarerforum.org.uk)

### Drop-in:

Currently by appointment only; please contact us to arrange a time.



Find us on Facebook!



Follow us on Twitter!  
[@ShefParentForum](https://twitter.com/ShefParentForum)

St Mary's Community Centre



Produced with funding from the Big Lottery Fund



National Network of Parent Carer Forums  
'Our Strength is our Shared Experience'  
[www.nnpkf.org.uk](http://www.nnpkf.org.uk)

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Our rates are:

- Full page £150
- 1/2 page £75
- 1/4 page £37.50

Charity discounts available. Please call us on **0300 321 4721** to discuss your requirements.

If you wish to unsubscribe from this newsletter, please contact us on **0300 3214721** or email [enquiries@sheffieldparentcarerforum.org.uk](mailto:enquiries@sheffieldparentcarerforum.org.uk)

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## A very warm welcome to this “coronavirus edition” of our newsletter

I do hope that you are all coping as well as possible in such extremely difficult times. I recognise that it will be slightly easier for some than others. We have heard such a wide range of feedback about the support that families are receiving; some schools contacting families weekly, others just dumping an enormous amount of work online; some social workers making weekly calls to families to ensure they are safe and well, other services making very little contact. There has been an urgency for schools to distribute home learning resources and for services to put emergency support in place. Some, it seems, have managed this better than others. I hope that we will soon see more streamlined information for all.

Since we have entered the world of home education (which is certainly not my forte!), along with most respite and short break provision ceasing, we have been in frequent contact with the local authority, including a weekly call with the Executive Director. We feed back your queries and concerns and then publish the responses on Facebook and on our website, to ensure families are kept up to date with new information. Although some of our normal services have had to stop temporarily, I want to make it clear that we are still here to help as much as we can. Please do contact us by email, via our website or



through Facebook if you need information or signposting to support, or simply to tell us how things are going. We can also ring you back if you leave us a number.

Over the next few weeks, as we face the uncertainty of when schools will reopen and “normal” service will resume, we will be changing the way we work with families and services. We will be asking you, our members, what are the best ways we can give support.

Finally, I would just like to say that you are all wonderful! We are not teachers, we are not social workers. Our children’s health and welfare are our top priority and your best is absolutely good enough! Stay safe everyone, and I will see you on the other side. We will plan some fantastic events for us to look forward to!

Best wishes,

*Katie Monette*  
Chair

# Coronavirus updates and information

At the time of going to print, the UK is in lockdown. Schools are closed to most children, and families are adjusting to the social distancing measures.

Many people are worried - about vulnerable friends and family members catching the virus, about losing their jobs, and about the long-term impact on the economy and public services. The situation is difficult for everyone, but it is especially hard for families with disabled children.

There is a wealth of information available online, from making visual timetables to looking after your own mental health.

We have collated the most useful links here: [www.sheffieldparentcarerforum.org.uk/news/coronavirus-useful-links/](http://www.sheffieldparentcarerforum.org.uk/news/coronavirus-useful-links/)

We have also been working with Sheffield City Council and health services to put relevant information onto the Local Offer website: <https://tinyurl.com/w3r82rr>

If you are on Facebook, please follow us on [www.facebook.com/SheffieldParentCarerForum](https://www.facebook.com/SheffieldParentCarerForum) to get alerts when new information becomes available.

**Please continue to send us your questions and feedback.**

We are in regular contact with John Macilwraith, the new Executive Director of People Services at Sheffield City Council, and will flag up any issues raised by our members.

## Changes to our services

**Due to the coronavirus outbreak, all of our events and meetings have been cancelled until further notice, and our staff are working from home.**

We are unable to answer the office phone, but you can still contact us by email ([enquiries@sheffieldparentcarerforum.org.uk](mailto:enquiries@sheffieldparentcarerforum.org.uk)) and through Facebook ([www.facebook.com/](https://www.facebook.com/SheffieldParentCarerForum)

[SheffieldParentCarerForum](https://www.facebook.com/SheffieldParentCarerForum)). Please provide a phone number if you would like us to call you back. We aim to respond to messages within two working days.



## Practical support around coronavirus

Voluntary Action Sheffield have published an interactive map ([www.vas.org.uk/sheffield-covid-support-map](http://www.vas.org.uk/sheffield-covid-support-map)), which shows support offered by community aid groups in Sheffield. You can zoom into your neighbourhood to see where you can get information or support; or to offer to volunteer.

If your child has a social worker or a case worker via MAST, SNIPS or the Looked-After Children Team and you would like support with meeting your child's ongoing care needs, please contact the Children with Disabilities Team on **0114 273 5368**. They will be able to help you with concerns regarding prescriptions, groceries, etc.

If you or the person you care for has a medical condition that makes them extremely vulnerable to coronavirus, you should have received a letter from the NHS or your doctor advising you to "shield" for 12 weeks. If you don't have family members or friends who

can support you during this time, go to [www.gov.uk/coronavirus-extremely-vulnerable](http://www.gov.uk/coronavirus-extremely-vulnerable) to register for support. This includes help with food, shopping deliveries and additional care you might need.

Disability Sheffield have created a new **Covid-19 PA register** (go to [www.disabilitysheffield.org.uk/blog/new-covid-19-pa-register-2020-03-26](http://www.disabilitysheffield.org.uk/blog/new-covid-19-pa-register-2020-03-26) or call **0114 2536750**). This holds details of Personal Assistants (PAs) and other support workers (e.g. from day services) who are available for work, and can match people who need support with a potential PA. Please note, the PA register is not able to support people who are looking to recruit PAs for the first time.

Sheffield City Council have set up a coronavirus helpline. You can call **0114 273 4567** between 8.45am and 4.45pm, Monday to Friday, to get advice, signposting and referrals.

## School closures

The government has said that all children who can safely be cared for at home, should stay at home, to limit the spread of the virus.

However, children whose parents are key workers and those classed as "vulnerable" may be eligible to attend school, nursery or college. Vulnerable children include those who have a social worker, and those with Education, Health and Care (EHC) plans. Children who fall into these categories should only attend a setting if this is absolutely necessary.

Settings have carried out risk assessments of all children and young people with EHC plans. If a risk assessment has shown that a child cannot safely be cared for at home,

they should have been offered a place.

This does not have to be at the setting they normally attend, and is for childcare rather than education. Parents are under no obligation to take up this offer, and they won't be fined for non-attendance if they don't.

For children who do not have an EHC plan, settings have discretion to undertake a risk assessment and offer support if that is needed.

If you feel that you need further support or that your child needs to return to school, please contact your child's school who will be able to review their risk assessment with you.

You can also apply for emergency childcare here: [www.sheffield.gov.uk/form/schools-childcare/apply-for-emergency-childcare](http://www.sheffield.gov.uk/form/schools-childcare/apply-for-emergency-childcare).

## Shopping vouchers for children on free school meals

The government has launched a national voucher scheme for children who are eligible for benefits-related free school meals.

Eligible families can receive a £15 shopping voucher per child per week to spend at supermarkets while schools are closed due to coronavirus. Vouchers will be distributed by schools and can be sent electronically as a code, or physically as a gift card. At the time of going to print, some schools in Sheffield were having problems getting hold of the vouchers.

Schools also have the option of continuing to provide meals for collection or delivery themselves.

## Charging policy for SNIPS clubs postponed

Due to the coronavirus crisis, Sheffield City Council has decided to postpone the introduction of a new charging policy for clubs accessed through SNIPS (Special Needs Inclusion Playcare Service).

SNIPS helps disabled children aged 5 to 18 years to take part in out-of-school activities and clubs to give their parents a break from caring. All SNIPS clubs are currently closed.

The charging policy will now take effect from 1 April 2021.

## Benefit reviews and reassessments suspended

On 24 March, the government announced that there would be no new reviews or reassessments across all benefits for three months. This includes Universal Credit, Employment and Support Allowance (ESA), Personal Independence Payment (PIP) and Disability Living Allowance (DLA). If your

benefit was due to expire, then the end date will be extended and the benefit will continue to be paid at the current rate.

Face-to-face assessments for all sickness and disability benefits have also been suspended for three months, including for any new claims.

## Coronavirus Act becomes law

The Coronavirus Act is emergency legislation that went through Parliament very quickly and came into force on 31 March 2020. It gives the government wide-ranging powers to respond to the coronavirus crisis. These emergency powers are time-limited - for two years - and will be reviewed by MPs every six months.

Some of the provisions in the Act relate to children and young people with Education Health and Care (EHC) plans, and to adult social care.

However, it is important to be aware that until these provisions are formally implemented, the duties on local authorities remain unchanged. We will keep you updated through our website, Facebook page and email bulletins.

## Honouring an unsung community hero

Shelley Eggleston, who helps to run the parent support group Ray of Hope in the north of Sheffield, was the first winner of our David Woodhouse Community Award.

Funding for the award comes from donations made in memory of David Woodhouse, who sadly died last year. David was husband to Deborah, one of our founding members.

Presenting the award, Forum trustee Jayne Woodward said: "David Woodhouse was a remarkable man – when he saw something that needed doing, he just did it. He worked tirelessly, without seeking recognition or reward, to improve the outcomes and life chances of vulnerable children and young people. We are so touched that Deborah thought of us when she had just lost David and was going through the worst time of her life."

Deborah Woodhouse explained what the award means to her: "Although I am no longer a trustee of the Forum, I still feel part of it. I am proud to have been there from the beginning and helped to set it up. I think the Forum is a fantastic example of women coming

together to do things for themselves and their community. It makes me so proud of David, and I can't think of

a better person than Shelley to receive this award. Shelley is incredibly kind and selfless. She cares passionately, not just about her own family, but about others who are in similar difficult situations."

Shelley said: "It is lovely to be recognised, but that's not why I do the work I do. I do it because I have been there myself; I remember how overwhelmed and confused I felt when my daughter had just been diagnosed. The help I got from other parents was invaluable, and my daughter wouldn't be the person she is today without their advice and support. Now I just want to pass it on."

Shelley received a trophy, a cheque for £250 and vouchers for a spa experience and a meal.

The award will be presented annually, and the next round of nominations will open in October 2020.



## Facebook chat group now private

Last year, we set up a Facebook group called "SPCF Chat". The purpose of the group is to enable parent carers in Sheffield to support each other and share information.

In response to feedback from users, we have changed the status of the group from "public" to "private" (closed).

This means that only members of the group can see who is in it

and what they post. Your posts to the group will not appear in your friends' newsfeeds.

You can request to join the chat group here: [www.facebook.com/groups/SPCFChat/](https://www.facebook.com/groups/SPCFChat/)

In addition to the chat group, we also have a public Facebook page. This is an excellent way for us to get information out quickly, particularly during the current crisis. Please follow us at [www.facebook.com/SheffieldParentCarerForum](https://www.facebook.com/SheffieldParentCarerForum).



## Wellbeing activities for parents set to continue after lockdown

Last year, we received a grant from the National Lottery Community Fund, which allowed us to produce two issues of this newsletter and run 30 information and wellbeing sessions for parent carers.

Activities included taster sessions for pottery, fused glass art, yoga and singing. We also ran information sessions on a wide range of topics, from applying for an EHC plan to learning Makaton.

We are pleased to announce that we have just received another grant, this time from the People's Health Trust, for a similar project.

This time, the funding is for two years, and will enable us to produce four issues of our newsletter and continue to run information and wellbeing activities for parent carers. We will start arranging sessions as soon as the social distancing measures have been lifted.

*It was really informative. It empowered me and enabled me to reach out for help with requesting an EHC plan for my son.*



*Pottery was a fantastic opportunity to try something new and relaxing. The atmosphere was really calm. Lovely!*

## Autism Education Support Service takes on extra staff

The Autism Education Support Service has recruited six additional members of staff. The extra capacity will allow the team to provide more support for children under the age of 5 and for post-16 students. They will also be able to offer increased support at key transition points, such as nursery to primary school, primary to secondary school, and secondary school to further education.

The Autism Education Support Service provides training, coaching and advice to

mainstream schools, nurseries and colleges to help them meet the needs of learners with autism and related conditions.

The team also supports parents through drop-ins in schools, a specialist parenting course called Cygnet, and a telephone advice line.

During the coronavirus crisis, you can contact the team by emailing **autism.educationteam@sheffield.gov.uk**. Please include your child's name and date of birth, a contact phone number and your question or details of what you need advice on. If you don't have access to email, you can leave a message with the same details on **0114 2506800** and someone will call you back.



## New sensory service to be rolled out

Many children with a Neurodisability (such as autism or ADHD) also have sensory processing difficulties. For example, they may be oversensitive to certain noises, smells or lights, or they may be undersensitive and seek sensations through behaviours like chewing on things, staring at lights or spinning objects, or listening to the same sound or song on repeat.

Sheffield Clinical Commissioning Group (CCG) has commissioned the rollout of a sensory service across Sheffield. This service will provide training for school staff on how to adapt the school environment to make it more sensory friendly, and on carrying out sensory profiling to better understand the needs of individual children.

There will also be more workshops for parents on understanding their child's sensory needs.



Initially, these will only be offered to parents whose children have been seen by a clinician at the Ryegate Children's Centre. The aim is to clear the waiting list, so that parents will then be able to book in straight away when their child has been seen in clinic. Once this has been achieved, the CCG will look at opening up those workshops to a wider group of parents.

There will also be a new workshop for teenagers to help them understand and manage their own sensory needs.

Initially, the plan was to have additional workshops in place by the school summer holidays, and for the training work in schools to start in September. We do not yet know how the coronavirus crisis will affect this timetable.

## Could you be our next Treasurer?

Our wonderful Treasurer John Vear, who has been keeping us on the straight and narrow for over ten years, is hoping to retire "properly" in the near future. We are therefore looking for a dependable individual to gradually take over from John.

The ideal candidate would have some experience of charity finance and book-keeping, and would be able to commit to a minimum term of two years.

Duties of the Treasurer include: monitoring and reporting on the financial health of the organisation; ensuring that proper records are kept; assisting with bookkeeping activities; and overseeing the production of financial reports, budgets, accounts and audits.

This is an unpaid role, but expenses (including childcare costs) will be reimbursed. The time commitment is approximately three hours per week, which includes attending two committee meetings per month (currently on Friday mornings and Wednesday afternoons).

For more information, please see [www.sheffieldparentcarerforum.org.uk/support-us/volunteering-opportunities](http://www.sheffieldparentcarerforum.org.uk/support-us/volunteering-opportunities)

If you are interested in this role, please email [enquiries@sheffieldparentcarerforum.org.uk](mailto:enquiries@sheffieldparentcarerforum.org.uk).



## More special school and IR places

Demand for specialist school places continues to grow year on year.

Over the past two years, Sheffield City Council has been increasing the capacity of our special schools by adding three extra classes at Mossbrook, two extra classes at Bents Green and extra places at Kenwood.

Since the current Year 6 is an unusually large year group, more capacity is needed in our secondary special schools from September 2020. To achieve this, Talbot and Seven Hills will move some of their post-16 provision into the Learn Sheffield building on the Talbot site, and Bents Green is also working to create extra space.

In addition, a new special school for children aged 8 to 16 years with complex needs (linked to autism and social, emotional and mental health difficulties) is being built on the former Norfolk Park special school site. The 80-place school will be run Nexus Multi-Academy Trust and is due to open in September 2021.

A second new special school, also with 80 places, is scheduled to open in September 2022. An academy sponsor for this school is yet to be announced.

The council also wants to create more Integrated Resources (IRs) across the city. IRs are specialist units in mainstream schools for children with complex needs. In the first instance, they are focusing on creating more places in the north of the city, as this area has a high level of need and only one primary IR (Fox Hill) and no secondary IRs.

To improve long-term planning, the council is working with head teachers of special schools and IRs to develop a sufficiency plan for 2020-2024. This will assess what the city needs in the coming years, both in terms of special school and IR places, and in terms of support for children with complex needs in mainstream schools.

## Autism toolkit for parents of young children

Ambitious about Autism have created a practical toolkit for parents who think their child may have autism, or whose child has just been diagnosed.

From the autism assessment process to the first day of school, the toolkit is packed with practical tips and checklists to support parents during the earliest years of their child's life. It also provides signposts to sources of support or additional information.

You can download it here:

[www.ambitiousaboutautism.org.uk/  
right-from-the-start](http://www.ambitiousaboutautism.org.uk/right-from-the-start)



## Staying safe when out and about

Once the coronavirus measures have been lifted, your young person might want to start venturing out into the community. The schemes listed below could be helpful:

**Alert cards for emergency services:** South Yorkshire Police have launched a scheme that will help police officers and other emergency service workers communicate better with people on the autism spectrum and people with learning disabilities.

Joining the scheme is free. Applicants are asked to supply information (e.g. about their communication needs, situations they find difficult, things that help them, emergency contacts), which is then stored in a central database. People registered on the scheme receive a credit-card-sized card, which they can show to emergency service workers if they find themselves in a crisis or stressful situation. Workers will then be able to retrieve information about the individual from their call handling system and adapt their communication and actions accordingly.

To request the card, please email [Autism\\_Alert\\_Card@southyorks.pnn.police.uk](mailto:Autism_Alert_Card@southyorks.pnn.police.uk)

**Alert cards for bus drivers:** Sheffield's two main bus companies provide cards with messages like "Please be patient, I have difficulty speaking", or "Please tell me when we reach [name of stop]". Passengers can hold these cards up to the driver so they know what their needs are. For more information, please visit [www.stagecoachbus.com/journeyassistance](http://www.stagecoachbus.com/journeyassistance) (Stagecoach) or [www.firstgroup.com/help-and-support/extra-help-travel](http://www.firstgroup.com/help-and-support/extra-help-travel) (First Bus).

**Safe Places network:** Over 50 places in Sheffield - shops, libraries, medical centres, cafes etc. - are designated as "Safe Places". They aim to support vulnerable people to feel safe when they are out and about in Sheffield. If someone needs help, for example if they are lost, ill or frightened, then they can enter the nearest safe place to get help. The staff or volunteers in safe places will assist anyone who goes to them for help. For more information please visit [www.sheffieldsafeplaces.co.uk](http://www.sheffieldsafeplaces.co.uk)

## Preparing your child for a hospital appointment

Sheffield Children's Hospital have produced a series of videos that explain to children what happens when they come to an outpatient's appointment at the hospital - including having their height and weight measured, and blood and urine tests. All of these videos include Makaton signing. You can watch them at <https://tinyurl.com/wgz77we>.

The hospital has also created a new virtual reality app called "**Little Journey**", which is

free to download from **Google Play** or the **App Store**. It allows children awaiting surgery to explore Sheffield Children's Hospital and get prepared for their visit from the comfort of their own home. Animated doctors, nurses and anaesthetists show children around the hospital and explain what happens when they come to the hospital for surgery.



# Two very different experiences of blood tests

*By Adel Taylor*

My daughter Rosie (13 years old with Down Syndrome) is something of a veteran at the Sheffield Children's Hospital, and usually the staff are great, and very experienced at making procedures bearable for her.

It all went horribly wrong one evening though, when we had been booked in for a blood test at the emergency assessment unit. It had been agreed between Leeds General Infirmary (heart unit), and Sheffield Children's Hospital that we needed to arrive at 8pm for the blood test (the old school type – needle in the vein, as finger prick wasn't suitable).

It must have been a hectic evening at the unit. We waited until about 10pm before

being taken to a clinic room. Once there, things went horribly wrong – the doctor and nurse optimistically thought Rosie might sit quietly while they put a needle in her hand. Rosie wasn't having any of it and quickly became hysterical – trying to escape, kicking out etc. Rosie is very strong, and it was impossible for me and the nurse to pin her down. She ended up lying on the floor, terrified and sobbing. I was also in tears, the poor nurse was doing her best not to cry, and the doctor was standing well back, just looking scared. They beat a hasty retreat, and found somebody else to help with holding Rosie down on the floor for the blood test. This was just an awful experience, and I think everybody, staff included, felt upset by it.

Contrast this to the previous evening - same arrangements, same time, same blood test – but a team of three staff ready and waiting. The “distraction” nurse had her box of interesting things for Rosie to look at, the doctor quickly explained the process, while the other nurse and I held Rosie's hand tightly. And that was it – blood test done in a few minutes, and Rosie left with her dignity intact.

I think these two very different experiences just go to show how important it is that all staff are trained on how to adjust their usual approach when they are treating a child with additional needs.





## Response from Sheffield Children's Hospital:

We are really sorry that Rosie and mum had this experience with us. We do have distraction boxes and our play specialist has sent a reminder out to all staff so that they are aware of them and use them when appropriate. There is a box in the blood treatment room in Acute Assessment Unit where Rosie would have been seen.

We are currently undertaking a Trust-wide piece of work on reasonable adjustments and communication for all our children, especially those with complex needs and sensory issues. We know we have areas of excellent practice and are undertaking work to ensure it is shared across the Trust. We are introducing training and support for staff

to help make the adjustments necessary for a more positive outcome for all. We would welcome suggestions on how we can get it right for all our young people. Please contact PALS with your thoughts and ideas on how to make it better.

### Contact details

PALS:  
**0114 271 7594** or  
**scn-tr.pals@nhs.net**

Outpatient Play Team:  
**07920 765788**



### Coping with blood tests

Rosie's story is not unique. When we asked parents on Facebook to tell us about their children's experiences, we received a lot of negative feedback, as well as some positive stories.

Using this feedback, we have worked with Julie Mather, who manages the Patient Advice and Liaison Service (PALS) at the Sheffield Children's Hospital, to compile a list of tips for parents:

**Book a quiet room to wait in.** Do this as soon as you have a date for the blood test, by contacting PALS or the Outpatient Play Team (see contact details on previous page).

**Ask in advance whether it is possible to have a thumb prick test,** if you think your child would cope better with this. It may not be – not all blood tests can be done in this way – but if it is, you could practise at home by putting Vaseline on your child's thumb and squeezing it to get them used to the sensation.

**Ask whether the procedure could be done in Medical Day Care.** Medical Day Care can provide sedation (e.g. gas and air), and their staff are good at distracting and reassuring. Children can only be referred to Medical Day Care by a consultant, or by staff working in Outpatients if it proves difficult to get bloods there. GPs cannot refer to Medical Day Care.

**Explain to your child what will happen,** and answer their questions honestly. You could watch a video about blood tests together ([www.sheffieldchildrens.nhs](http://www.sheffieldchildrens.nhs)).

**uk/patients-and-parents/outpatients/blood-tests)** or ask PALS or the Outpatient Play Team to post a booklet about blood tests out to you. The play specialists also have some magnetic boards with pictorial images that can be adapted and used on the day.

**Give your child a big drink an hour or so before the blood test,** as the blood will be less thick and flow better. Get them to move around if it's an early morning test, as the movement helps to pump the blood around the body more efficiently.

**Ask staff about numbing options as soon as you arrive.** Emla numbing cream can take up to 45 minutes to work. Staff can also use a numbing spray, which takes a little less time to work.

**Stay calm, don't rush your child, and offer them a big treat after the procedure.**

**Consider asking for psychology input if your child has a needle phobia.** If your child is under a consultant at the hospital, the consultant or your GP can refer them to the Paediatric Psychology Department at the Sheffield Children's Hospital. Your child would first be seen in an assessment clinic to agree a way forward. Psychological support could include counselling sessions or attendance at a procedural anxiety group. There is currently a six-month wait for psychology appointments.

# SUPPORT GROUP FOCUS

## Sheffield Deaf Children's Society



We provide support and impartial advice to families with deaf and hearing-impaired children in Sheffield, Rotherham, Barnsley, Doncaster, Chesterfield and the surrounding areas.

Throughout the year we host events to give children the opportunity to try different activities and meet new people. In the past our events have included climbing, swimming, skating and bowling, and we also have our annual trip to the seaside. We advertise these events on our website, Facebook page and via email.

We also run a baby and toddler group called "Little Ears" and a youth club for school-aged children and their siblings or a friend. Our youth club volunteers are the parents of deaf children or work in Hearing Services. They are able to speak of their own experiences and give advice to parents.

The youth club runs fortnightly on a Friday, 6.30-8pm (term time only), at The Spires Centre, East Bank Road, Sheffield S2 2AN.

We offer a range of different activities at our youth club. Most recently we have hosted



a TV game show night, a talent show and a disco, which have all been great family fun. We have tea and coffee making facilities and also a tuck shop. We do require parents to stay and supervise their children.

We offer a taxi service for families who need help with transport to and from youth club. To get more details about this or to book a taxi, please contact the SDCS Mobile on **0749 7261426**.

### Contact details

Email:

[sheffielddeafchildrenssociety@gmail.com](mailto:sheffielddeafchildrenssociety@gmail.com)

Mobile:

**07497 261426**

Facebook:

[www.facebook.com/SheffDCS](http://www.facebook.com/SheffDCS)

Website:

[www.sheffielddeafchildrenssociety.co.uk](http://www.sheffielddeafchildrenssociety.co.uk)

# Learning to swim

Alongside the obvious safety benefit of helping to prevent drowning, learning to swim can have physical and emotional benefits for children with additional needs.



Swimming is a great activity for children with low muscle tone or balance and co-ordination difficulties. Many children enjoy the sensory experience of water and swimming can be calming and reduce anxieties. Michael Phelps, who won 23 Olympic gold swimming medals, was diagnosed with ADHD at the age of 9. He couldn't sit through lessons without fidgeting, but he could swim for hours after school. He has said that "being in the pool slowed down my mind. In the water I felt, for the first time, in control."

Whatever your reason for encouraging your child to swim, the starting point is water confidence. Before you think about formal swimming lessons, introduce your child to playing in water (bath or swimming pool) as early as possible. What you are aiming for at this stage is that they should be happy to be in the water, experience the fun of splashing and not be afraid to get their face wet.

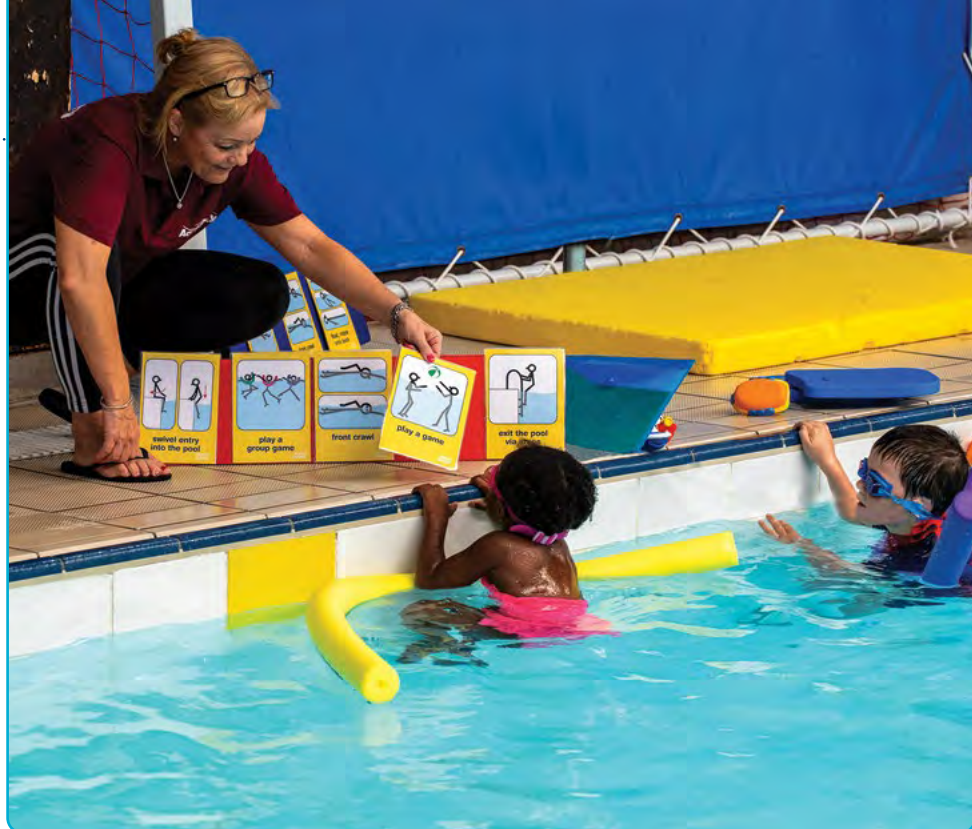
As their confidence grows, you can introduce games that encourage them to put their face in and under the water, such as blowing bubbles, picking up toys from the bottom of a shallow pool, jumping into deeper water, or shaking hands on the bottom of the pool. Adapting familiar songs and nursery rhymes for the pool can help. For example, sing "Twinkle Twinkle Little Star" to encourage your child to float on their back and look up at the

stars (swimming pool lights).

Let them experience the freedom of the water. If they are wearing a buoyancy aid (such as armbands), then you can support them lightly by holding a hand – don't cling together. To be successful at teaching water confidence, you need to be positive and encouraging, and you must overcome or hide your own fears and anxieties. If your child accidentally swallows water or is splashed unexpectedly, don't panic! Smile and make a joke of it and they will be reassured.

When you think they are ready, ask at your local pool about swimming lessons. All swimming teachers should be able to include children with additional needs and adapt their lessons accordingly, using swimming schemes that reward smaller steps in progress. If you think your child will find mainstream lessons too difficult, speak to the swimming co-ordinator about specific lessons for children with disabilities and/or 1:1 lessons. NB not all pools offer disability swimming lessons, and those that do may have a waiting list.

All children should access swimming lessons through school because swimming and water safety are part of the national curriculum. Lessons usually take place during primary school. Contact your child's school and work with them to plan for a successful outcome:



- Ask them about the swimming teacher's experience of working with children with disabilities.
- Make sure they have established links with the local authority to access any special provision.
- Push for one-to-one support in the water for your child, if needed.
- Don't take no for an answer. Your child is learning a life skill just like every other child.

Ask your child's swimming teacher if they use visual aids to help children with additional needs to follow instructions, for example SwimPix cards:

[www.swimming.org/swimengland/swimpix/](http://www.swimming.org/swimengland/swimpix/)

## More information

Find your local swimming pool here:  
[www.swimming.org/poolfinder/](http://www.swimming.org/poolfinder/)

**Swim England's** free 'My Learn to Swim' app allows children to gain extra rewards and unlock new features as they develop their swimming skills and water confidence:

[www.swimming.org/learntoswim/my-learn-to-swim-app/](http://www.swimming.org/learntoswim/my-learn-to-swim-app/)

Always supervise your children near water to prevent drowning.

## FORUM STARS

In this section, we celebrate your children's successes – from the small steps that perhaps only you noticed, to the big milestones everyone can see. So, get snapping, get writing, and tell us what your wonderful children have been up to...

**For this issue we have TWO stars!**

[illegible]

Logan has autism, ADHD, dyslexia and obsessive-compulsive disorder (OCD). He is ten years old.

His mum Fern reports: “Logan has been doing Cub Scouts with the 33rd Sheffield Scout Group in Chapeltown for the last three years. He has worked so hard and done things he would never have done if it wasn't for Cubs. He has just received his Chief Scout's Silver Award, which is the highest award a cub can receive. I can't thank all the leaders enough for their support. It just goes to show that, with the right support and encouragement, anything is possible!”

[illegible]





Rio has Asperger's Syndrome, global sensory processing disorder and ADHD. He is eight years old and attends Heritage Park special school.

His mum Jennifer reports: "Rio has never coped well in a group setting, but he recently went for a trial at a gymnastics club and was able to cope with the 45-minute session. He listened well and was able to be around children and adults that he had never met before and concentrate. This took a lot of effort on his part, but he really enjoyed the gym activities and has joined up as a member."

Jennifer is full of praise for the gym that Rio attends: "The team at Attercliffe Gymnastics Academy have been amazing. They are doing everything at his rate and supporting him to be able to be part of the club, which is so lovely and refreshing."

"It won't sound much to many people, but if you know Rio, you know he usually has headphones on, eyes on his iPad, closes off in public rather than have to cope with other people. He has suffered greatly with anxiety and difficulties regulating his emotions over the years. Rio has had to overcome so much in order to get to this point, and he's surprised us all. I am just so proud of him!"



Star of this issue:  
**Rio Dunstan**



# When it's not just fussy eating

Many children go through phases of being picky about food and this is normal. A fussy eater may not like trying new foods and may adamantly refuse certain foods, but they will still eat a reasonable range and grow as we expect them to.

A child with a restricted diet, on the other hand, will only eat a very limited number of foods, may not eat foods from each food group and can seem quite stressed and anxious around new foods.

A child with a very restricted diet could be considered to have a list of “safe foods”, which may include specific brands or foods prepared and presented in a certain way. Without their “safe foods”, a child with a restricted diet would be likely to just go hungry. A child with an extremely restricted diet may be reliant on supplements or tube feeding to support their nutrition and growth.

Children with extremely restricted diets may be diagnosed with a little-known condition called ARFID (Avoidant / Restrictive Food Intake Disorder). This is a relatively new diagnosis. It is different from other eating disorders like anorexia or bulimia, as it is not driven by issues around body image. ARFID can be difficult to diagnose as there are often co-existing disorders, and a consensus between several health professionals is needed to give a diagnosis.

## Why do some children restrict their diets?

First of all, it is unlikely to be because of something you did or didn't do as a parent! Having a restricted diet is more common if your child has a history of another medical condition, if they were born prematurely, or if they are on the autism spectrum. We know that children with ARFID may appear to have a lack of appetite or interest in food, or they may find the sensory characteristics of food and eating difficult to manage. These difficulties are often present from a very young age. Some children with ARFID have a fear of the consequences of eating, such as vomiting or choking, and these children tend to experience a more sudden onset of a restricted diet as a result of this fear.

## What can parents do?

There is lots of mixed advice out there for fussy eaters, and much of it does not apply to children with restricted diets. So, what does work for this group of children?

The most important thing is to stay calm. Having a child with a restricted diet can understandably cause a lot of stress and anxiety for parents and the wider family. But trying to reduce stress and anxiety at mealtimes is really important. Whatever works for you and your family to make mealtimes calm and fun, do it! Finding a support network of other parents facing similar issues can also be very helpful.



Offer your child's preferred foods. Offering non-preferred food with no other options usually results in a child with a restricted diet eating nothing at all and becoming very anxious.

When offering new foods, try to find foods that are similar in one or more ways to your child's preferred foods. Think about introducing new foods that your child could possibly tolerate, rather than a food that triggers complete disgust. You could also offer foods that your child had previously accepted and then refused.

Avoid forcing a child to eat, and don't hide or disguise foods. If you hide foods in other foods, a child with a restricted diet is likely to discover this. That can mean that they stop eating their safe food, even when it isn't "contaminated" anymore. Forcing children

to eat tends to trigger anxiety and disgust, which are the enemies of a calm, relaxed food experience.

**Reduce your child's anxiety around food and mealtimes by:**

- Establishing routine, as this is calming for most children
- Using distraction - some children need distraction to cope with the sensory experience of eating
- Increasing the fun
- Having positive conversations about food and positive interactions with food
- Cueing food/mealtimes in with songs and symbols

- Giving your child a sense of control by creating a visual list of your child's accepted foods, and letting your child select from a choice of two items
- Managing the sensory environment. Eliminate any smells, noises, textures etc. that your child finds difficult
- Being careful about using reward systems. Non-food reward systems can work, but consider what you're asking your child to do for a reward - is it achievable, or will it just end in distress?

Support school staff and other professionals working with your child to understand that restricted diets are more than just fussy eating. Work with the SENCO to ensure that all staff are properly briefed and understand the support a child with a restricted diet needs, including having preferred foods available. If your child finds the noises and smells of the

dining hall overwhelming, alternative eating settings may need to be considered.

### When will it change?

Supporting a child with a restricted diet can be a long journey and we can expect setbacks and bumps in the road, with general anxiety and sensory issues changing over time.

Change tends to occur when the child wants the change, and their motivation to tackle their eating behaviour can increase as they get older. This is often driven by a social motivation to fit in with peers. However, this may not be a motivating factor for some young people.

So, how can you support your child to change their eating behaviour?

Start wherever your child is. Rethink your definition of success and have realistic expectations and realistic timescales. Your goals will depend on your child. You might



need to focus on increasing your child's calorie intake to help them grow, or you might be able to work on expanding your child's range of preferred foods. Your end goal might not always be for your child to eat the food, but merely to tolerate other people eating it next to them, as that may increase their participation in social activities. Remember that every new food your child starts to eat is a win, regardless of its nutritional value! It shows that they felt relaxed enough to push their boundaries.

Break things down into little steps. We don't just jump into new experiences that terrify us, we get used to them gradually. Exposure to non-preferred foods can be just that, exposure –not always eating. Photos of food, supermarkets, being near non-preferred foods – all of that is exposure and can be really tricky for some children with restricted diets. Touching non-preferred foods can be challenging, as can smelling them. Involve your child in food preparation or messy play with food, if they can tolerate it –it takes the pressure off eating, but allows for exposure. Do "science experiments", and become

curious about the sound, texture or look of foods in a playful way. Don't give up if there appears to be no immediate impact on your child's eating habits. Tolerances can change over time. Keep exposing your child to different foods in a fun and relaxed way, and it will be much easier for them to make the step to eating them when they are ready.

Make minor changes to preferred foods. By cutting the toast slightly differently or serving the cheese in a different shape, you can help your child to not get bored of their preferred foods, so that they won't drop them from their diet. But make the change explicit and don't change too many things at once!

Every child with a restricted diet is different and working out what works for your child and your family is key. If you think your child may have ARFID, or you want more support for your child's restricted diet, talk to your child's paediatrician or your GP.

This article was written in collaboration with Ailish Harrison, Speech and Language Therapist, and Jennifer Simpson, Dietitian.

## More information

Beat Eating Disorders:

**[www.beateatingdisorders.org.uk/types/arfid](http://www.beateatingdisorders.org.uk/types/arfid)**

National Eating Disorders Association:

**[www.nationaleatingdisorders.org/learn/by-eating-disorder/arfid](http://www.nationaleatingdisorders.org/learn/by-eating-disorder/arfid)**

Facebook support group for parents:

**[www.facebook.com/groups/1188680687816813/](https://www.facebook.com/groups/1188680687816813/)**





# Useful Contacts

<b>0-5 SEND Service</b> (formerly Early Years Inclusion Service)* Works with young children (0-5+) with additional needs both in their homes and in settings	0114 273 6411 <a href="mailto:elizabeth.hodkin@sheffield.gov.uk">elizabeth.hodkin@sheffield.gov.uk</a>
<b>ADHD Support Service</b> Run by Family Action, this service provides information, support and training for families with a child with ADHD	07587 633179 <a href="mailto:adhd.sheffield@family-action.org.uk">adhd.sheffield@family-action.org.uk</a>
<b>Autism Education Service*</b> Supports mainstream schools to meet the needs of pupils with autism and related conditions	0114 273 6567 (helpline, 1-4pm) 0114 250 6800 (office) <a href="mailto:moira.bolan@sheffield.gov.uk">moira.bolan@sheffield.gov.uk</a>
<b>Becton Hospital and Outreach Team*</b> (formerly Home and Hospital Education Service). Provides education for children who are unable to attend school for medical or related reasons	0114 255 7679 <a href="mailto:headteacher@becton.sheffield.sch.uk">headteacher@becton.sheffield.sch.uk</a>
<b>Child Disability Register</b> A local register of disabled children aged 0-19. Join up to receive the termly newsletter "What's Going On"	0114 271 7626 <a href="mailto:martina.capaldi@sch.nhs.uk">martina.capaldi@sch.nhs.uk</a>
<b>Children with Disabilities Team*</b> Social work team for children and young people with disabilities	0114 273 5368
<b>Contact</b> National charity which provides information and advice on any aspect of caring for a disabled child, including education and benefits	0808 808 3555 <a href="mailto:info@contact.org.uk">info@contact.org.uk</a>
<b>Direct Payments Team*</b> Provides support, advice and guidance relating to direct payments	0114 273 5985
<b>Educational Psychology Service*</b> Works with families and staff in educational settings to support the education and development of children and young people	0114 250 6800 <a href="mailto:stuart.williams1@sheffield.gov.uk">stuart.williams1@sheffield.gov.uk</a>
<b>Hearing Impaired Service*</b> Works with deaf and hearing-impaired children and their families	0114 273 6410 <a href="mailto:caroline.chettleburgh@sheffield.gov.uk">caroline.chettleburgh@sheffield.gov.uk</a>
<b>Independent Travel Training*</b> Trains young people with disabilities/learning difficulties to use public transport to get to school, college and other education providers	0114 205 3542 <a href="mailto:jill.siddall@sheffield.gov.uk">jill.siddall@sheffield.gov.uk</a> <a href="mailto:Indetravel@sheffield.gov.uk">Indetravel@sheffield.gov.uk</a>
<b>IPSEA</b> National charity providing free legally-based advice on educational issues for parents of children with SEN	Book a call-back via <a href="http://www.ipsea.org.uk">www.ipsea.org.uk</a>
<b>Local offer</b> A website with information about support and services for children and young people with special educational needs and disabilities in Sheffield	<a href="http://www.sheffielddirectory.org.uk/localoffer">www.sheffielddirectory.org.uk/localoffer</a>

<b>Paces Sheffield</b> A leading specialist centre for children with cerebral palsy and other motor disorders	0114 284 4488 <a href="mailto:info@pacesheffield.org.uk">info@pacesheffield.org.uk</a>
<b>Portage Home Visiting Service*</b> Home-visiting educational service for children under three with additional support needs and their families	0114 273 6411 <a href="mailto:debbie.marshall@sheffield.gov.uk">debbie.marshall@sheffield.gov.uk</a>
<b>Ryegate Children's Centre</b> Assessment, diagnosis and therapy for children and young people with developmental and neurological problems	0114 271 7000
<b>SENDIAS (formerly Parent Partnership Service)*</b> Provides information, advice and support to parents of children with SEN/disabilities in relation to education, health, social care, leisure, disability benefits and support groups	0114 273 6009 <a href="mailto:disabilityinformationservices@sheffield.gov.uk">disabilityinformationservices@sheffield.gov.uk</a>
<b>SEN Statutory Assessment and Review Service (SENDSARS)*</b> Deals with statutory assessments, EHC plans, annual reviews and specialist placements	0114 273 6394 <a href="mailto:sendassess&amp;review@sheffield.gov.uk">sendassess&amp;review@sheffield.gov.uk</a>
<b>Sheffield Carers Centre</b> Offers information, advice and a range of services for carers, including parents of disabled children	0114 272 8362 <a href="mailto:support@sheffieldcarers.org.uk">support@sheffieldcarers.org.uk</a>
<b>Sheffield Children's Hospital</b>	0114 271 7000 <a href="mailto:sheffield.childrenshospital@sch.nhs.uk">sheffield.childrenshospital@sch.nhs.uk</a>
<b>Sheffield Futures Learning Difficulties and Disabilities (LDD) Team</b> Supports young people with learning difficulties & disabilities to make the transition into further education and employment	0114 201 2800 <a href="mailto:enquiries@sheffieldfutures.org.uk">enquiries@sheffieldfutures.org.uk</a>
<b>Sheffield Young Carers</b> Offers support to children and young people (8-25 years) who provide care for a family member, e.g. a disabled sibling	0114 258 4595 <a href="mailto:information@sheffieldyoungcarers.org.uk">information@sheffieldyoungcarers.org.uk</a>
<b>Sibling Support Group</b> Support group for children who have a sibling with a disability	0114 233 2908 <a href="mailto:laura.westmorland@burtonstreet.org.uk">laura.westmorland@burtonstreet.org.uk</a>
<b>Special Needs Inclusion Playcare Service (SNIPS)*</b> Helps disabled children aged 5-18 years access out of school activities / clubs to give their parents a break from caring	0114 273 4017 <a href="mailto:SnipsBusinessSupport@sheffield.gov.uk">SnipsBusinessSupport@sheffield.gov.uk</a>
<b>Transport Services*</b> Provides transport services including home-to-school transport for pupils with SEN	0114 203 7570 <a href="mailto:transportservices@sheffield.gov.uk">transportservices@sheffield.gov.uk</a>
<b>Vision Support Service*</b> Supports children with a visual impairment and their families	0114 294 1201 <a href="mailto:joanne.hogg@sheffield.gov.uk">joanne.hogg@sheffield.gov.uk</a>

For changes to services during lockdown, please see: <https://tinyurl.com/w3r82rr>

\* Part of Sheffield City Council

# FEEDBACK

## Going the extra mile

We asked parents for some positive stories about support they had received during the coronavirus crisis. Here's what they told us:

*My children's primary school is delivering weekly food packages for pupils on free school meals.*

*Ryegate Psychology have been fantastic throughout this. My son's psychologist, who is always amazing anyway, has scheduled weekly phone calls for him, where he can either chat to her or play a game over the phone. She's sent us information in social stories about the virus, as he is over anxious. We can also email the team any time to arrange a phone call.*

*We've had lots of help and support from the Best Start Communities Count project run by Manor and Castle Development Trust regarding our middle daughter's new diagnosis (highly allergic to something, so having to eliminate certain foods to find out what she is allergic to). They've helped with sourcing food for her and have told us to just call if we need anything and they will help where they can.*

*Mossbrook Primary special school have been so organised and proactive. They've organised transport for children who still remain in school, and they've called numerous times to see how the families are doing and if there's anything else they could do. They've provided food vouchers on top of the ones from the government to those who qualify. They've offered to send breakfast to homes. I've literally been in tears as we've been so blessed by them and a 'thank you' doesn't feel like it's enough.*

*School has made it clear that there is no pressure to get work done (there is a lot being posted online, so it would be easy to get stressed about it). They have also reassured us that they are not expecting us to send in any work, but are happy if we can keep some examples of what our daughter has done just for reference.*

*One of my daughter's teaching assistants has posted various work sheets out to us, which are more appropriate for her than the stuff being posted online for her year group. They did this automatically, I didn't ask for it. We have a printer at home, but I suspect that many students at our school don't.*

*Burton Street have been brilliant - doing weekly calls to make sure we're okay. The Sheffield Inclusions Officer has also been ringing us weekly to see how we are getting on.*

Tear along here

# Sheffield Parent Carer Forum

## Application for Full Membership

Full membership is free and open to all parents and carers of children and young people (aged 0-25 years) with special educational needs and/or disabilities who live in Sheffield or access services in Sheffield.

### About you

First name		Surname	
Street and house number			
Town/city		Postcode	
Email address (please print)			
Home phone		Mobile	
Your ethnic group (optional)			

### About your disabled child/children

#### Child 1

Date of birth	
Main disability	
Other disabilities	
School (name)	

#### Child 2

Date of birth	
Main disability	
Other disabilities	
School (name)	

#### Child 3

Date of birth	
Main disability	
Other disabilities	
School (name)	

### Please tick as appropriate :

<input type="checkbox"/>	Please add me to your email list.		
<input type="checkbox"/>	Please add me to your text messaging list.		
<input type="checkbox"/>	Please add me to your postal mailing list.		
I am happy to take part in consultations:			
<input type="checkbox"/>	by phone	<input type="checkbox"/>	by email
<input type="checkbox"/>	by post	<input type="checkbox"/>	by SMS
<input type="checkbox"/>	I am interested in volunteering with the Parent Carer Forum.		

Signature	
Date	

Please note: By signing this form you consent to the Sheffield Parent Carer Forum storing your information. We will not pass any of your details on to any third parties. Members of our postal mailing list will receive a regular newsletter. Members of our email list and text messaging list will receive news updates and events information. You are free to opt out of this service at any time.

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Freepost RTBJ-SHTR-RRGJ  
Sheffield Parent Carer Forum  
St. Mary's Church Community Centre  
Bramall Lane  
SHEFFIELD  
S2 4QZ

Fold along here



Positive Change for our Children and Young People  
with Disabilities and Special Educational Needs